# Imagining the self

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Patient 223-6D Williams, Jane S. February 21, 2001 10:42 AM.

Patient admitted to clinic for observation of advancing degenerative symptoms. First recorded motor difficulties in April 1998, with steady progression until present time. Currently the patient's status is functional but severely reduced - complains of headaches, loss of sleep, and blunt pain in the extremities.

(Fig. 1)

In the clinical setting, the construction and maintenance of patients' medical records is of primary significance to the administrative regulation of the patient as well as the institution. Rather than simply a notation of the body, the medical dossier is the compilation of the inscribed pluralistic practices of contemporary medicine - it is the collected notations of what is seen of the body, or done to the body, through the lens and the hand of contemporary medicine. The dossier is comprised of digital and analogue texts, 3D and real time video footage, and satellite samples of the subject in terms of ovum, sperm samples, placenta, and DNA (Fig. 2). It houses appointment notations, prescriptions, hospitalization charts - test results - x-rays and CAT scans. The multi-media dossier is also multi-purpose. It is a wealthy mine of information a resource tool - a site for cross referencing and statistical analysis. It captures the quality and rate of the physical deterioration of the social (or statistical) body as succinctly and with as much intent as it documents the fluctuating health status of any individual. For the practitioner the dossier serves as a receptacle and as a site of contemplation or study - a satellite body to reflect upon in the pursuit of good medicine. In terms of hospital administration, records are seen less as individualized documents, but as data bases used to analyze and forecast admission statistics, space requirements, treatment strategies and physician performance. For laboratory and field researchers, medical records provide valuable information about trends in disease and success or failure rates of different treatment regimes (Fig. 3). But what of the patient, and his or her relationship to the compilation of medical information about their body? For the patient the dossier is an exclusive and codified document; manufactured, mobilized, and referred to by trained professionals on behalf of the individual. It is confusingly technical - and extraordinarily high tech. The dossier is the test dummy, the stand in, the administrative and administered to clinical self. It is an alter ego, a reincarnation, only this version of the self is deemed diseased and requires institutionalization. It is the concrete embodiment of the most private indiscretions of the body.

This is Jane – Jane Stacey Williams. She is twenty five years old, a student, currently no serious romantic attachments, but owns a cat named Charlie. She has recently entered the clinical sphere and requires medical as well as critical and theoretical attention. She is a fictitious character - a case study of sorts – where we can ethically access and play out the relationship that one might have with their personal documentation. However this is not to imply that her experience is not authentic or valid. She is a compilation of dozens of very real individuals – ranging from

Fig. 1.

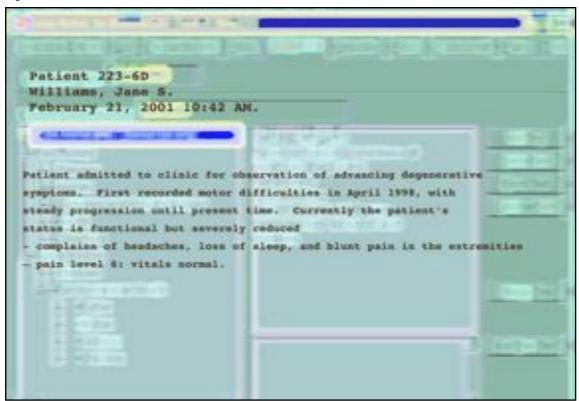
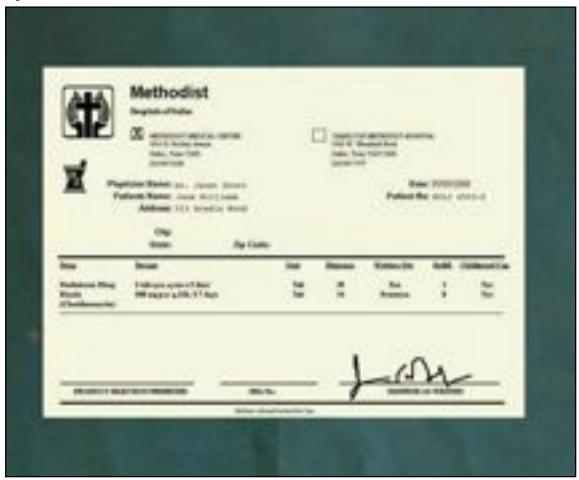


Fig. 2.



a woman who once dragged me into a public washroom to show me the stratified scar tissue covering her entire stomach – to my own mother who died five years ago of Cancer. She provides for us the possibility of focusing on the subjective experience of a single patient in a way that is so often overlooked in the medical institution. We are challenged to scrutinize the specialized language and images found within the medical dossier with the goal of uncovering the meaning that such texts hold for their correlated owners, patients – selves.



Fig. 3.

April 10, 1998 Williams, Jane S.

#### **SOAP Notes**

S: Patient complains of slight decrease in motor functions, muscle weakness, numbness in the extremities (especially the right hand). Also frequent headaches, emotional duress, and general fatigue.

O:

B/P: 110/70 Temp: 98.6 Pulse: 88 Respiration: 16

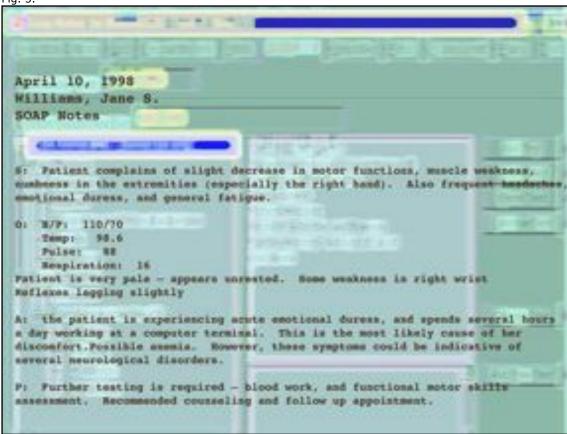
Patient is very pale appears unrested Some weakness in right wrist Reflexes lagging slightly

A: the patient is experiencing acute emotional duress, and spends several hours a day working at a computer terminal. This is the most likely cause of her discomfort. Possible anemia. However, these symptoms could be indicative of several neurological disorders.

P: Further testing is required – blood work, and functional motor skills assessment. Recommended counseling and follow up appointment. (Fig. 4)

In the medical setting, the patient's files serve as the primary source of qualifiable facts, and therefore reliable information, about the patient's condition. The medical text is the site of reference – the site of knowledge of the patient's body. Until the individual's condition and utterances are codified, categorized and written by the expert, they are unreliable in nature,

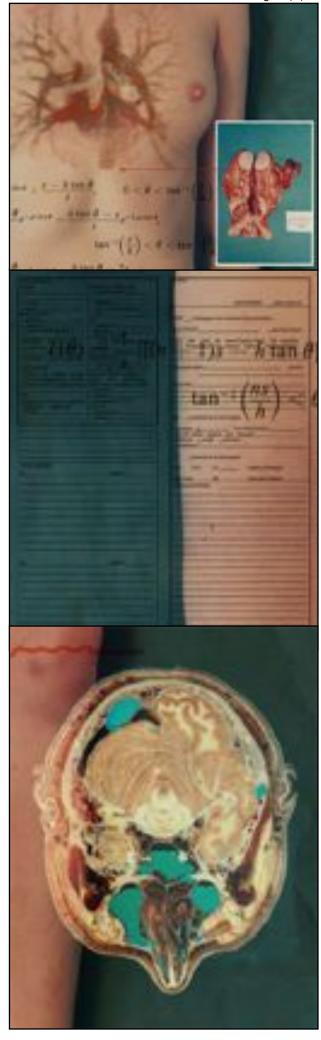
Fig. 5.

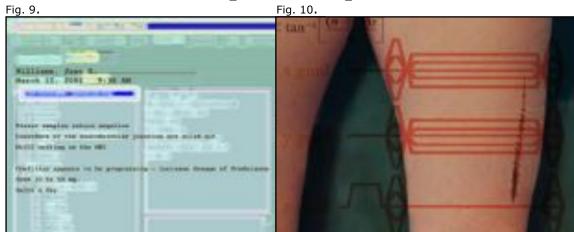


based on hearsay, and tainted by the un-objective standpoint of the subject. Once inscribed, disease and malfunction becomes a tractable, and therefore controllable phenomena which better lends itself to medical notions of successful patient management. In North America there are several different records keeping protocols used by different institutions. The most common protocol is called SOAP (Fig. 5). SOAP is a medical records mnemonic for the Problem-Oriented Medical records system. The letters S-O -A - P stand for Subjective (what the patient says), Objective (what the doctor sees), Assessment, and Plan. Here the patient's voice is recorded, but immediately re-written and either substantiated or undermined by the authority of the expert. These practices serve to standardize records entries and the doctor-patient relationship and are considered promotive of objective fact finding as well as better cross-physician and inter-institutional data accessibility. The acronym SOAP suggests that through the act of assessing and recording - through the written word and the authority of the physician - what is felt and said by the patient is processed, run through the wash cycle, and rendered somehow clean. This inversely implies that what comes before the record, the experience and concerns of the patient, is dirty or tainted in some manner and thus requires purification. From the patient's vantage point, the subjective knowledge of one's body lacks currency when traversing the site of the clinic. The language ascribed to ones body is unknowable, but impressed upon by the physician as accurate and important in finding a solution to patient's problems (Fig. 6). It is here, in the clinic, and ever so vulnerable, that the patient conceives of herself as adorning the qualities that the physician ascribes to her. Before setting foot in a hospital Jane was a student, a lover, and an avid reader. She possessed talents, dreams, and insecurities. But when the threshold was crossed, and she entered the doctors office complaining of difficulties holding utensils in her right hand - she was transformed into a specimen of medical inquiry – a patient. It is here that the dossier retains currency becoming a better source of information then the patient herself.

I've started watching The Nature of Things on television, and reading any medical or scientific material that I can get my hands on, hoping that I will pick-up on the jargon that the physicians use to discuss my case. It's like learning a new language - as if my body has a secret voice I never noticed before - it speaks in a dialect foreign to me - and the doctors are my translators, my liaisons between me and my body. I an forced to trust that what they tell me about myself is true.

In Jeanette Winterson's work Written on the Body the protagonist imagines that the touch of a lover's hand is forever imprinted on the body of the touched (Fig. 7). That a cumulative process occurs with the layers of each subsequent touch impressing on top of the one before. Here the palimpsest is made – The body is written on (Winterson 1992, p.89). Winterson is not suggesting a physical or tractable phenomena, but a psychological one – a bodily memory of instances that are absorbed by the individual and reconstituted into definitions of the self. In terms of the medical dossier, I am arguing that the same applies to language. That each entry in a patient's dossier become entries into the body into the self. The dossier is the textualization and technoloization of the patient's body, and as if in a cyclical embrace, the text informs the body as the body informs the text. With anthropomorphic likeness it grows and changes in direct accordance with the subject's body and the development and nature of its' disease. I would go so far as to suggest that within the site of the clinic the text is the body, metaphorically, inscriptionaly, and physically. In terms of the dossier, the text becomes an alternate version, an incarnation of the individual, that inhabits the clinic, and supersedes the currency of the





corporeality of the patient within that site. The dossier attains girth, history and personality. It traverses both time and space – each sheet of paper like a latitudinal slice of the specimen – compiled to make a whole (Fig. 8). Each entry into the digital data bank like a node, or chromosome, in our informatic conception of the human body. The record inscribes the body, but also physically possesses the body with minute DNA samples, preserved ovum, and placenta. The organism is transformed into a complex multi-functional text, and that text is in turn reabsorbed into the body – in to the constructed self of the patient (Fig. 9).

I had a biopsy last week. They wanted a sample of my quadricep to determine if the degeneration was occurring in the muscle tissue itself. I wonder what happened to that little piece of me – if it was tested and then disposed of – or if it was saved, and if so where is it? I often imagine endless store houses deep within the bowels of every hospital where records are kept for an eternity. It is like something out of a Peter Greenaway film – a bacchanal of bodily information – where paper meets organism – where each biopsy, tissue sample, and amputation is filed with it's correlative documentation. Rotting and infested. And there, along with pieces of everyone else is my muscle tissue contributing to the warm stench.

Williams, Jane S. 9:36 AM

March 12, 2001

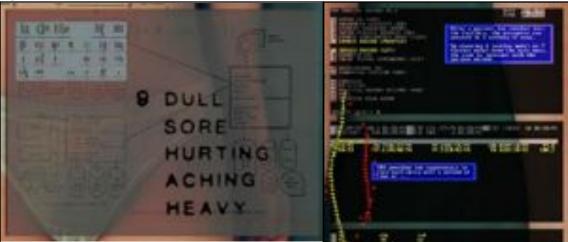
Tissue samples return negative
Disorders of the neuromuscular junction are ruled out
Still waiting on the MRI

Condition appears to be progressing – increase dosage of Prednisone from 30 to 50 mg.

Twice a day. (Fig. 10)

And so, we must ask ourselves; what is the nature of the codified document, and thus the medicalized body of the patient? Through such analysis and interpretation we can aim to not only access and understand the text, but to posses it and author it ourselves. However, as the patient is without the vocabulary and the expertise to read their dossier in the clinical manner for which it was intended, one must rely on folk knowledge of the field, cultural and linguistic assumptions, and visual signifiers by which to interpret the significance of the text for its owner. The patient's body is transformed at the moment of recognition - the instant the patient sees them self reflected in the complex and incomprehensible discourse of medicine (*Fig.* 11). Today I will elaborate on two specific incarnations of the textualized patient; including the

Fig. 11.



patient as war zone, and the patient as lexicon.

#### The Patient as War Zone

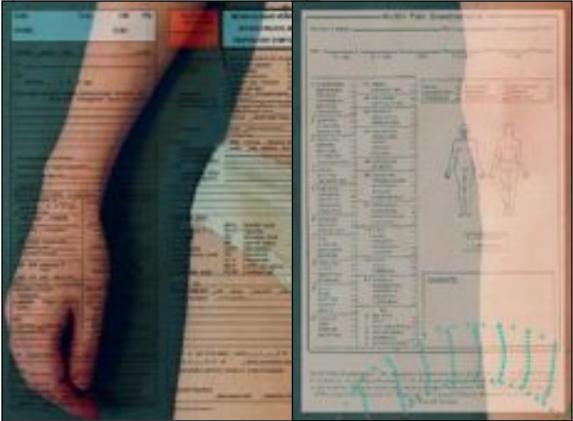
In *Illness as Metaphor*, Susan Sontag argues that cancer and its' treatments have been deeply codified by post war medical and colloquial language with harsh metaphors of the battle ground and tactical warfare. She illustrates for the reader how the language of battle is applied to the cancerous body.

..cancer cells do not simply multiply; they are "invasive." Cancer cells colonize from the original tumor to far sites in the body, first setting up tiny out-



Fig. 12.





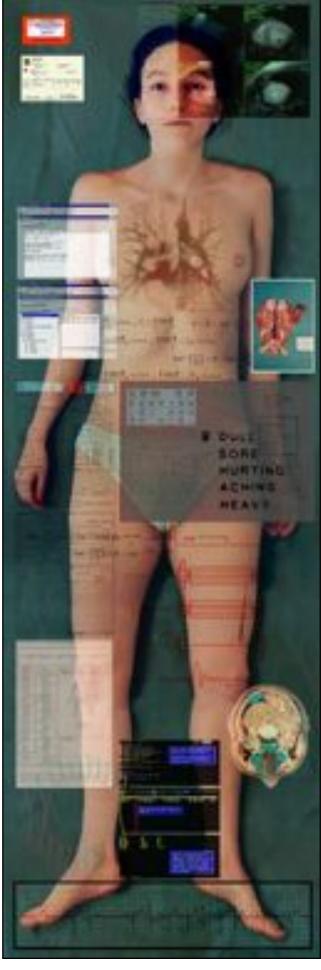
posts ("micrometastases") whose presence is assumed, though they cannot be detected. Rarely are the body's "defenses" vigorous enough to obliterate a tumor that has established its own blood supply and consists of billions of destructive cells. (Sontag 1978, p.64)

These metaphors are not restricted to oncology wards. Notions of warfare are proliferated throughout modern medicine - particularly in the area of medical imaging. Seen here, is a myocardial perfusion (similar to an MRI) where organ tissues are targeted and surveyed from aerial perspective for evidence of enemy invaders (Fig. 12). The physician utilizes these types of images to diagnose internal abnormalities, and in turn presents them to the patient as evidence to better visualize and explain the problem. However, Jane isn't versed in the language of medical imaging, and finds the results difficult to understand. Through visual associations she sees indicators of surveillance, and is reminded of the televised target footage of bunkers and bridges about to be obliterated during the Dessert Storm conflict. The non-specialist imposes notions of night vision and heat seeking missiles on the images the doctor relies on for diagnosis. The patient believes that the mandate of scientific inquiry and medical intervention presupposes objective truths, and thus how can one not come to the conclusion that their body is in fact a battle ground; that these images are not constructions, they are merely reflecting facts about the state of their interior surfaces? Under these circumstances - if the records say so, and the patient believes so, and acts so - and so it is inscribed. Technological warfare is being waged within the body of the patient (Fig. 13). The dossier in it's digitized form becomes the command center, and physician is the commander in chief. Here decisions are made, tactics strategized, and the enemy - the enemy is depersonalized to non-human status to render warfare more palatable for the offensive line. Only this is misleading, as in both cases - within the hospital and the battle field the targets are human, and both will suffer injuries and sometimes casualties resulting from the wages of war. Though the clinic has healing intentions, the patient (the target) is forced to bear excruciating witness to their own planned invasion, through the observation of specialized medical images of their body in consultation with the physician.

### The body as lexicon

Fig. 16.

And what of the endless charts and questionnaires the patient encounters during one's stay at the hospital? Dr. J.H. Mitchell, in his paper Information Flow in Hospitals presented at The Second International Symposium on Computers in Medicine (1972) - describes computerized medical records as systems of entrenched taxonomies (Fig. 14). He states "Any attempt to computerize case records themselves, for diagnostic and other reasons, immediately possess problems of standardization." (Mitchell 1972, p.34) Medical questionnaires and data entry charts, in digital form or hard copy, are developed by technicians and records specialists to encompass all possible patient histories and symptoms that may be of use to the physician. They aim to expeditate and standardize the doctor patient interview and encourage objective fact recording. They are intended to enhance communication between the subject and the scientist, and aid the individual in the difficult task of ascribing codified language to personal interpretations of the self. Although the various categories and selections offered are prolific, even encyclopedic-such standardization of patient information inevitably assumes a norm of possibility and relevance. Thus excluding anyone or any occurrence that deviates from the predetermined possibilities of the medicalized human body. Additionally, rigid design, rooted in columns, compartmentalization and branching subcategories suggest to the viewer that the body can and should be succinctly described within these terms. Here the body is described and represented as a veritable lexicon (*Fig*. 15). The textualized patient adopts the linear and dimensional qualities of a very extensive dictionary. Here, the patient is



either relieved to find their personal discomforts listed as possible within the document, and therefore substantiated – or frustrated and unsure when they are unable to locate the appropriate language to describe their pain in the encyclopedic listing of all pains known and recognized by the medical establishment. If the patient fails to be suitably categorized – diagnosis and treatment become problemitized – even impossible. The subject is thrown into a tail spin of unidentifiable, and therefore non-existent corporeal experience. In Michel Foucault's preface to *The Order of Things*, he describes the case of the aphasiac, which provides insight and understanding into the position of the uncatagorizable patient.

It appears that certain aphasiacs, when shown various skeins of wool on a table top, are consistently unable to arrange them into any coherent pattern; as though the simple rectangle were unable to serve in their case as a homogeneous and neutral space in which things could be placed so as to display at the same time the continuous order off their identities or differences as well as the semantic field of their denomination. (Michel Foucault 1971. p.Xviii)

Pattern is attempted by the aphasiac time and time again and the individual suffers "becoming more and more disturbed, and teetering finally on the brink of anxiety." (Michel Foucault 1971. p.Xviii) The body not found in the physician's diagnostic encyclopedia is essentially no body at all.

To be honest with you, I am growing more and more confused and irate. I have endured, X-rays, biopsies and blood tests. So many imaging procedures that I've lost count. I am booked for another Cat Scan tomorrow – they think that they might have missed something the first time. And still after all this – no one can explain what is happening to me. I am running out of imagination – out of energy. I am getting bogged down, clumsy in my body and clouded with bureaucracy. This person – this malfunctioned machine – infected system – invaded territory – patient 223-6D - this person isn't me. (Fig. 16)

### Literature

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#### **Industry Texts**

<u>Virginia Effective Documentation Practices</u> (2000) published by the Doctors Insurance Reciprocal Risk Management Department

### Web sites

**Duke Medical Informatics Research** 

http://dmi-www.mc.duke.edu/dukemi/research/research.html

eICD.com

http://www.eicd.com/Default.htm

**ER Records** 

http://www.erchoice.com/electronic\_medical\_records.html

Illustrated Health Encyclopedia

http://www.oso.com/shared/health/adam/ency/article/002341.html

The Johns Hopkins University School of Medicine

http://www.hopkinsmedicine.org/medicalschool/

Medical Computing Today (MC Today)

http://www.medicalcomputingtoday.com/index.html

MEDVALET/COHIS: Community Outreach Health Information System

http://www.bu.edu/COHIS/cardvasc/cvd.htm

Patricia Loofbourrow, MD, FAAFP (Doc Trish)

http://www.askdoctrish.com

Revealing Bodies at The Exploratorium 2000

http://www.exploratorium.edu/bodies/index.html

The Visible Human Project

http://www.nlm.nih.gov/research/visible/visible\_human.html