

Daniela Crocetti

L'invisibile intersex: storie di corpi medicalizzati [The invisible intersex: histories of medicalised bodies].

Pisa: Edizioni ETS, 2013, pp. 192

Silvia Fornasini and Enrico M. Piras

FBK - Fondazione Bruno Kessler, Trento

We would like to start, if we may, with a critical note: the title of Daniela Crocetti's work does not do justice to the complexity and the richness of its content. Intersexuality and its medicalization are only a part, albeit significant, of a more extensive discourse proposed to the reader, a journey starting from the Classical antiquity and continuing to this day. *L'invisibile Intersex* examines in depth the history of hermaphroditism, intersexuality and DSD (Disorders of Sex Development), the scientific observation of the gendered body, and the social approaches towards gender and bodies. If on the one hand the author has suggested to highlight some intrinsic levels of social perception in the scientific theories of the gendered body, on the other hand she tried to gaze on the experiences related to such scientific theories.

The book is open to a wide range of interpretations. The first, as suggested by the author, is a historical approach that shows the relationships between professions, bodies of knowledge, explanations, classifications, bodies, and their changes in the course of time. If we imagine the book as a play, the first act would take place during the western ancient times, and on the stage we could spot philosophers-physicians discussing on the hermaphrodite, a body where the shape of the genitals does not match the expectations suggested by overall appearance. The second act, that brings the story until the sixteenth century, would show the Church around the hermaphrodite, interested not so much to the body but rather in searching the origin of the "monstrosity" and its moral implications. Only from the third act we could see the medicine appear: it acquires undisputed authority in the field, and uses also deeply invasive methods of inquiry. It is precisely with the arrival on the scene of medicine as an independent science from philosophy and religion that we can strictly talk about medicalization.

With the "gonadic era" (1870 – 1915) medicine, by now a discipline legitimized to discuss about the body, takes an interest in the biological construction of sex starting from hormones, genes and chromosomes, which illustrates the sexual distinction in scientific (and more and more normative) terms. During this period the definition of hermaphrodite itself appears to be disputed: it is first restricted by "pseudo hermaphroditism", and fully overcome by "intersexuality" during the twenties. As the author says, the linguistic change reveals the transition from a classificatory logic to an interventionist one. The surgical techniques allow to act on

the “different” body and bring it back to “normality”. Starting from the fifties and until 2005 the interventions aimed at modify children’s genitals become the main part of a medical procedure, resting on the assumption that a healthy psychosexual development depends on the genital’s appearance. In this third act we can find medical knowledge, or better, several exponents of a more and more specialized discipline (endocrinologists, surgeons) but also of similar disciplines (psychologists, geneticist). Not only the scene became more and more crowded, but the term “intersexuality” is modified in specific syndromes (an explosion of syndromes, as the author explains), until it is replaced by DSD. In the fourth act of our hypothetic play, we would observe the body coming alive on the stage. Patients and their relatives become vocal, show an interest in informed consent and right to information, disapproving the interventionist model and building their presence through the associations, contributing to the advent of the PCC (Patient Centred Care Model) in which patients, parents and doctors are invited to collaborate as experts. We can say that we have seen a transition from a paternalistic model (where patients have no role whatsoever), moving from a period of disagreement, and coming to a condition in which we can speak about expert patients and able to negotiate.

In addition to the historical reconstruction, the readers of “Tecnoscienza” will find in the book some familiar recurring themes, although not addressed by the author through the lenses of the STS debate. To be brief, we will simply considerate only a few.

The first theme is the production of body through the professional gaze. The body is brought into being through a multiplicity of practices: it is sliced, colored, probed, talked about, measured, counted, cut out or prevented (Mol 2002). Each professional community observe the DSD in different terms: surgeons focus on some aesthetic and functional characteristic of genitals; endocrinologists only consider hormones and genetics; gynaecologists are interested just in sexual and reproductive functions; geneticists some selectable markers; psychologists the psycho-social and gender issues; patients and their parents the informed consent and right to information; social scientists the bioethics issues related to gender medicalization.

A second theme is the ethical and political dimension of classification system which often are only partially interested in what is categorized. The book shows accurately how the body of ‘hermaphrodite’ / ‘pseudohermaphrodite’ / ‘intersex person’ / ‘DSD patient’ is an ‘object’ that does not fit a dichotomic male-female scheme. In these cases, to put it with the words of Geoffrey Bowker and Susan Leigh Star: “the individual’s trajectory— [...] — is at each moment twisted and torqued by classifications and vice versa” (Bowker and Star 1999, 324). Daniela Crocetti shows how the ‘torquing’ becomes dramatic when the classification system and surgical procedures are aligned and they allow the success of the interventionist model through which, for half a century, bodies were altered to

make them fit with the predominant classification system.

A third theme is that of the silent bodies that build their voice organizing in associations contributing to knowledge production and sharing, recalcitrant bodies that do not fit in classification schemes that build their legitimacy in the arena of medical experts. The last chapter of the book is dedicated to Italian DSD associations and to the analysis of their role as they gain respect and participate side by side with healthcare professionals. STS scholars will find significant resemblance with the body of work on patients associations and, in particular, with the notion of “evidence based activism” (Rabeharisoa et al. 2013) through which patients’ expert knowledge is transformed into credentialed knowledge.

These three themes are not just what might interest the STS community but also some topics we hope the author will develop in forthcoming publications.

Let us take the last theme as an example. The book focuses only on Italian associations but their relevance could emerge more clearly if compared more extensively with international ones. Another theme that could be further developed are the narratives of the patients which, presented in the frame of medical congresses, lose part of their relevance becoming somehow marginal. In more general terms, while we found the historical part of the work accurate, the last sections of the book does no justice to a 5-years ethnographic work. And we look forward reading more about it.

References

- Bowker, G. and Star, S. L. (2000) *Sorting things out: Classification and its consequences*, Cambridge, MA, MIT Press.
- Mol, A. (2002) *The body multiple: Ontology in medical practice*, Durham, NC, Duke University Press.
- Rabeharisoa, V.R. Moreira, T. and Akrich, M. (2014) *Evidence-based activism: Patients’, users’ and activists’ groups in knowledge society*, in “BioSocieties”, 9 (2), pp. 111–128.

* * *

Patrick Forterre, Louis d'Hendecourt, Christophe Malaterre et Marie-Christine Maurel

Da l'inerte al vivente. Une enquête scientifique et philosophique [From inert to living: a scientific and philosophical inquiry]. Paris: La ville brûle Éditions, 2013, pp. 256

Francesca Merlin *Université Paris I Panthéon-Sorbonne and CNRS*