

Interview with Susan Kelly. Co-coordinator of the 1st workshop about the Sociology of Diagnosis in Brazil

Entrevista com Susan Kelly. Co-coordenadora do I Workshop sobre a Sociologia do Diagnóstico no Brasil

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Abstract *In this interview, Susan Kelly, professor and researcher at the Center for Life Sciences - Egenis, and the University of Exeter, England, discusses her academic career, involvement with the Sociology of Diagnosis and the work involved with the first activity on the Sociology of Diagnosis carried out in Brazil.*

Key words *Sociology of Diagnosis, Genetic condition, Normality.*

Resumo *Nessa entrevista, Susan Kelly, professora e pesquisador do Centro sobre as Ciências da Vida – Egenis, e da Universidade de Exeter, em Inglaterra, aborda a sua trajetória acadêmica, o envolvimento com a Sociologia do Diagnóstico e os trabalhos envolvidos com a primeira atividade sobre a Sociologia do Diagnóstico realizada no Brasil.*

Palavras-chave *Sociologia do Diagnóstico, Condição genética, Normalidade.*

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Presentation

Following we are presenting the interview with professor Susan Kelly - University of Exeter, England. Prof. Susan is a research of the Sociology, Philosophy and Anthropology department in the University of Exeter and the research center of life science (Egenis) in the same university. The technological innovations implication in the understanding of the diagnosis is one of her research interests. As an active member about the Sociology of Diagnosis (SD) studies, Prof. Susan has been promoting meetings/seminars in this new area since 2013. In 2017, at the Biomedical Institute of the Fluminense Federal University, in Niterói - Brazil, were one of the organizers of the first workshop on sociology of diagnosis in Brazil, *Sociology of Diagnosis: concepts and applications*. The workshop was a partnership between the University of Exeter and the Fluminense Federal University - UFF. Based on the multidisciplinary and the observation of the relation between the biomedical definition and the social understanding of disease, SD has a direct interface with Collective Health, characterizing itself as an important contribution to the investigation on the social determinants for the health-disease process. On this framework, SD stresses the biomedical power, synthesized at the diagnosis' time, and challenges on the consequences understanding for the "disease's diagnosis" to the person and his network. Intends, in this way, discover the reality of those who live with a certain diagnosis, their routine of suffering and the social stigma. Therefore, go beyond the discourse centered on medicalization and reaches the social needs for the development of public policies of health promotion and the families health. Surely, as the bases of the SD, we can mention those works developed by Milred Blaxter¹, Philip Brown² and Annemarie Jutel & Sarah Nettleton³. The first had attention in diagnosis as a process and a categorization, the second emphasized the social construction of disease and was the work which used the term Sociology of Diagnosis for the first time, and the last one provided an important foundation on the SD as an area of sociology and added to Blaxter's proposal the consequences of the diagnosis for the person, his family and his network of care.

RLB: Please, tell us about your academic trajectory.

SK: I completed an undergraduate degree in Sociology at the University of Washington. At the time, I was interested in aging and intergenerational relations, and eventually I moved to San Francisco California and looked into the programme in the Social Psychology of Aging at UCSF there. That department was closing unfortunately and sent me 'up the hill' to the medical school and department of social and behaviour sciences started by Anselm Strauss where I applied and was accepted. So I did my PhD in a medical school! I became interested in ethics and technology associated with ageing and generations, and did my PhD on a national ethics committee on Human Fetal Tissue Transplantation for Parkinson's disease. I found ethics and fetal tissue to be fascinating sociologist subjects. I then did a post doc at Stanford university in the Centre for Biomedical Ethics, where I got interested in Genetics, STS and of course ethics. I studied prenatal screening and particularly the early development of noninvasive prenatal testing technologies which were at that time based on whole fetal cells in the blood of the pregnant woman, now on DNA fragments and very commercially successful. I took a post in sociology and genetics at the University of Louisville where I got deeper into Medical Sociology, and got tenure and promotion to Associate Professor. All with a small child! And mostly as a single mother!

Then I moved to the UK to be with my new husband Stephen, who is a professor of politics at Oxford. I got a job as a lecturer in sociology at Southampton university, was promoted to Senior Lecturer it then moved to Exeter where I am now. I got involved in the Sociology of Diagnosis via the sociologist Sarah Nettleton and became friends with Annemarie Jutel.

RLB: How happened your involvement in the Sociology of Diagnosis's field?

SK: I had a Research Fellow named Michael Morrison who had previously worked with Sarah Nettleton at York, and who got me involved in a seminar series with her, Charlotte Salter, Annemarie, and Andrea Stökle, funded by the ESRC. We held the first seminar at Exeter on technology and diagnosis. The seminar series was

very successful and we attracted a lot of interest. I became fascinated with the topic and the many ways it expressed concerns in medical sociology but ranged across illnesses. And technologies, which I tend to see in terms of sociotechnical systems.

RLB: Last year there was a workshop about Sociology of Diagnosis at the Universidade Federal Fluminense - Rio de Janeiro. How was the workshop?

SK: The workshop was fascinating. It was held in the medical school there and had a lot of support from that institution. It involved an interdisciplinary group of people including an audience of parents who had started or were members of rare disease associations, which was fascinating. We also had involved Jaqueline de Sousa Gomez, a bioethicist, Ileana Lowe, an historian in Rio from Paris, working on Zika, and Luiz Oswaldo Rodrigues, a clinician of rare childhood diseases and cartoonist. Annemarie Skyped in and we learned a lot about rare diseases in Brazil and applying the sociology of diagnosis in the Brazilian context. Which is particular! And different from the UK, the US, and New Zealand, which we as sociologists interested in.

Diagnosis is a central process in medicine and yet so easily overlooked. It is the moment at which the power of medical authority is both crystallised and taken for granted. It is profoundly social, as well as being a medical moment. And the acceptance or not of a diagnostic label has profound consequences for the patient or person in front of the doctor. It speaks of art as well as power and technology.

RLB: In your opinion what are the sociology of diagnosis contributions to the Brazilian context.

SK: I think it highlights the unique characteristics of medicine in Brazil, which is very traditional, patriarchal and powerful in terms of privileges of knowing. Parents of children with rare diseases seemed to welcome the opportunity to speak and be heard, outside the biomedical context in which they usually find themselves. As well as listen. So the Sociology of Diagnosis highlights different "ways of knowing" (Pickstone, 2000) as well as power relations in medicine. And the relationship of medicine with culture, which often goes unrecognised.

RLB: One of your works, there is a discussion about the diagnosis as a social determinant. What is that and what are the consequences of taking the diagnosis as a categorization, a process, and an event?

SK: Ginny Russell, a few others, and I looked at consequences of being labeled, in the case of autism, and found that when symptoms were so labeled it had no consequences for health. Specifically, we found that the development trajectory of prosocial skills of children in England before and after ASD diagnosis was not changed by the presence of a formal diagnosis. A multi-factorial analysis suggested the prosocial behavior was not significantly modified by ASD diagnosis. The results suggest prosocial behavior may be resistant to typical interventions triggered by diagnosis. We recommended further research where the diagnosis is considered as a social determinant of child health outcomes. We published this work as "Diagnosis as a social determinant: The development of prosocial behavior before and after an autism spectrum diagnosis" in the journal *Social Science and Medicine*, in 2012.

RLB: Another paper, with almost 10 years, there is an interesting discussion about choosing not to choose when we have a genetic diagnosis influence. It is possible to note some stress between parenting a child with a genetic condition today and the parent's future plans. One of the conclusions is that needs to better understand the risk between a newborn with a genetic condition and parent's reproductive decision making. On the other hand, in the last decade, the production of drugs to genetic "disease", the orphan drugs, have been increasing. In your opinion, the understanding pointed in your work have developed in parallel with the orphan drug production?

SK: I agree that we need to better understand the relationship between the risk of having a newborn with a genetic condition and parental future reproductive decision making. I don't actually know much about the connection with the development of orphan drugs, which is not to say that this does not exist, it was just not the focus of my research which was on the parental experience of having a disabled child. I did identify the tensions you mention and found that, for various reasons, but largely due to these tensions, parents of disabled children, who were positioned

by the medical profession as most likely to use reproductive technologies, chose not to choose in the intolerable situation of choosing against the life of the child they already had. Rather than use prenatal diagnosis, the most common response of parents to the birth of a child with a genetic condition was to be sterilised and do not have future children.

RLB: About the project Mainstreaming Genetics: Re-contacting patients in a dynamic health-care environment, what were its principal results and where the professionals and patients were converged and different?

SK: Parents were interesting in that they tended to welcome being recontacted but saw it as a lesser priority to the health system than new cases, in a health system already under stress. Although they did recognise some psychological stressors involved with being recontacted “out of the blue” as it were. While HCPs tended to see recontacting former patients as not a legal duty but as “good care” – they saw this as part of their professional responsibility to former patients. They worried however that establishing a precedent to recontact could result in a legal duty being established, and worried about the resource consequences of this. Overall, there was support for sharing the burden of recontacting with patients, by asking them to keep in touch, and laboratories, which will do the reanalysis of results and in some sys-

tems have contact with patients but could at least contact the patient’s primary HCP. There was agreement that the possibility of recontacting should be discussed with patients, as well as that they should be asked their preferences and that these should be recorded.

RLB: Nowadays, what the genetic diagnosis represents?

SK: Nowadays, we are as likely to talk about a genomic diagnosis as a genetic diagnosis. Meaning that it is becoming increasingly cheaper and faster to sequence an entire genome, or exome, than to do a test for a single gene. It is not clear that mainstream HCPs (cardiologists, oncologists, and paediatricians mostly at this stage) feel confident conveying the results of genomic tests to patients. It is also not clear what patients want and expect from HCPs, particularly regarding all of “unsought” information that may be generated. Imagine you had a genetic test for a suspected condition in one of your children, and found out through genome analysis that you carried a recessive gene for another serious condition. Would you want to know this? How would it affect your future reproductive behaviour? Would you ask your current and/or future reproductive partner(s) to undergo testing? How would you feel about any of this? This goes back to the point about needing more information about parents’ future reproductive decision making.

References

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