

Critical notes on stigma and medicalization according to the psychological and anthropological view

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Abstract *This article aims to reflect on ethical aspects involved in the social sciences and humanities researches conducted in the educational context. In this debate, which goes beyond the limits of Resolution 466/2012 and the Plataforma Brasil bureaucracies, we refer to Psychology and Anthropology critical readings in order to emphasize the ethical risks in the medicalized view of education and human development, which has contributed to the production of stigmas that reinforces school exclusion. As central elements of this questioning, we highlight: the debate about the illusion that research in humanities and social sciences do not imply ethical risks and the false dichotomy of biomedical sciences x social and human sciences within the research in psychology and anthropology in education. Attesting to the importance of such problems we referred to researches of national and international authors in the field of school /educational psychology and neuroscience. Through these considerations, the article concludes for the importance of ethical rigor in humanities and social sciences researches, focusing not only in the construction of the project and the methodological procedures of data collection, but also in the research results interpretations and in the publication of reports and scientific articles.*

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This article aims to reflect on the ethical dimension in the research surveys carried out in Brazilian public schools, giving emphasis to criticism of the medicalizing explanations which, by viewing human development as primarily biological and maturational, produce classifications, standards of normality and abnormality, and stigmas that reinforce exclusion as a phenomenon in schools. In this analysis we adopt as a reference, especially, critical readings in psychology, school psychology and social anthropology, which help us greatly in setting parameters that explain the challenges of schooling.

The debate on ethics in research in Human and Social Sciences involving human beings is increasingly present among investigators, questioning, among other aspects, the way in which ethics has been evaluated by the system of Research Ethics Councils (CEPs) and the National Research Council (Conep), with special focus on the tool which is applied to research projects to be evaluated¹⁻⁵.

Among the leading criticisms found in the Human and Social Sciences literature is the predominance of the biomedical point of view in the analyses made by the CEPs. Examples of aspects mentioned by investigators, especially those who adopt qualitative methodologies – which are characterized for being open and artisanal – are: the need to present a complete, closed design for the study, with absolute specification of the parameters of participants before it is begun; and the obligatory prior signature of the Informed Consent Form.

Within this criticism, some comments question how relevant it is direct attention to the alleged risks of a survey: there might be comments such as, for example, “the majority of surveys in psychology do not present risks for the participants”³, or that social research “presents only a risk similar to the risk that exists in day-to-day life”⁵. This at once raises the question: could it be that reflection about risks implied in social research in the field of education is in fact unnecessary?

At times when the debate on ethics in research tends to be taken over by the bureaucracy involved in the Brazil Platform [*Plataforma Brasil*], and is a subject that researchers refer to as a source of irritation, we again raise questions that go straight to the heart of ethical issues about surveys in the field of education. This is an aspect that does not cease to be a concern with the approval by the Research Ethics Committee, the permission given to the investigator to col-

lect data, or the delivery of the final report. It is, and should be, constantly a part of the work of the investigator – considering, especially, that research surveys serve as a base for preparation and implementation of public policies, thus having a direct impact on the practice of a wide group of professionals.

In this direction of our attention, it is appropriate that we should state the problem of surveys that have been produced which contribute to justification of the failure of schools in a manner that focuses on individuals. These are surveys which, although they are supposed to be neutral and objective, and are even accepted by the CEP to which they are submitted, have a methodological design, in terms of both fieldwork and analysis of material, which, rather than helping explain the educational problems we have historically suffered, need, themselves, to be explained critically, due to their ideological character^{6,7}.

These elements highlight the importance of building mechanisms of social analysis of surveys in the human and social sciences that can overcome the situations in which they contribute politically to maintaining social inequalities – by leaving complex historical questions out of account, and analyzing the failure of schools as allegedly a fair reflection of supposedly individual differences⁸.

While it is consensus that evaluation of the ethical aspects involved in surveys in human and social sciences on the school floor needs to be revised – to overcome the biomedical point of view built in to the criteria of ethics set out by the System^{1,4} – this need should not be interpreted as meaning that surveys in this field produce less ethical risk than biomedical surveys. On the contrary, we argue the need for rigorous ethical evaluation by peers and interlocutors to ensure that the knowledge produced in educational research surveys does not violate human rights, nor Brazil’s Law on Children and Adolescents.

Here it is important to think of the ethics in educational research beyond the traditional instances that have been established or are in the process of being established. That is to say, the call is to think about ethics, especially from the assumption that scientific knowledge is historically and socially dated and, for this reason, *science* is a space for discussion and reproduction of ideologies and social tensions.

Before going on, one reservation attests to the complexity of the debate in question: according to Severino⁹, the growing occurrence of “fabrication and invention of data, falsification of results,

plagiarism and self-plagiarism” in the production of academic work and surveys is a source of concern, bringing with it a “relaxation in the investigator’s commitment to the truth and reliability of his scientific actions”. This present article is situated in this tense scenario, seeking to think critically about ethics in the production of knowledge in the ambit of the human and social sciences on the floor of the school, seeking to recover its deeper aspects.

The school as a field of research: tensions in the interior of psychology and the Human and Social Sciences

The Brazilian public school network establishes an intrinsic relationship with educational research surveys, in which it is common to find studies in psychology and social sciences that focus on the school context, aiming to understand questions that are a part of the process of schooling of children and young people. It is also common that such surveys serve as a basis for the construction or consolidation of public educational policies.

A diligent analysis by Patto⁷ gives rise to recognition that surveys in the field of education necessarily take a position on the subject of the power relationships that materialize in education and in the school. The fact is that, in a hegemonic manner, Brazilian school and educational psychology has helped conserve relationships of dominance – for example, by justifying the hierarchical form of school organization, by legitimizing the implementation of verticalized public policies, or by blaming students, families and teachers for failure of schooling which, not coincidentally, affects precisely the poor population which most depends on the public network to ensure the social right to school education.

Among the various elements that are susceptible to criticism, an aspect of surveys in psychology in the field of education that calls attention is the materialization of an important ethical risk: many surveys have in fact served to *scientifically justify* social inequalities, presenting them as simple reflections of individual merits. Society and the school, in these conceptions, appear naturalized, being only the location where socializing and schooling take place⁷.

It can be considered that the work of Patto produced incisive impacts in the production of knowledge in the field of school and educational psychology in Brazil, as from the 1990s. As a

consequence of its depth, many psychologists assumed the ethical challenge of putting psychology back onto other bases, making a break with the cycle of (re)production of stigmas and prejudices in relation to poor pupils, their families and teachers. The following deserve mention: Machado¹⁰, Machado and Souza¹¹, Tanamachi et al.¹², Freller¹³, Viéguas and Angelucci¹⁴, Meira and Facci¹⁵, Rocha et al.¹⁶, Souza¹⁷, Patto¹⁸, Roman¹⁹, Souza²⁰, Checchia²¹, Souza et al.²², and Ribeiro²³.

In common, these studies understand schooling as a complex process which should be observed in various dimensions: historical, political, economic, social, institutional, pedagogical, relational... As an ethical orientation, one highlight is the concern with the risk of helping to build social stigmas in the field of educational research, allied to the commitment to de-construct stigmas that have been socially consolidated, which had to deal with the heavy hand of the ‘scientific’ surveys that were not concerned with the question.

It is in this contradictory scenario that the universe of research in school and educational psychology on the floors of Brazilian schools is constituted: at the same time as there is an increasing number of surveys that make greater use of social analysis and analysis of the school context to explain failure and success in the process of schooling, there is also a growing number of surveys that deal with the school as a privileged location for corroborating organicist theories with a strict focus on the biological body of the pupils²⁴. The latter, although they are part of the larger area of human and social sciences, operate through the biomedical point of view in understanding the phenomenon, which marks the questions that are asked, and also the procedures of investigation and of analysis of the material collected.

On this line of thinking, we question, together with Fonseca²⁵ and Porto²⁶, the meaning of the distinction made by the anthropologist Oliveira²⁷⁻²⁹ between surveys *with* human beings (surveys in the context of the subjects of the research, “qualitative” surveys and surveys in the human sciences), and surveys *on* human beings (surveys with experiments on the bodies of the subjects, and biomedical surveys). If, on the one hand, this distinction may be productive for considering the history of how the “hard” sciences were constructed to the detriment of the “soft” sciences, on the other hand, it can obliterate the historical fact that investigators in the human sciences are not free from ethical infractions. As an

outstanding, if exaggerated, example, we refer to the experiments carried out in the Nazi concentration camps, which took place in accordance with the legislation of scientific experimentation of Hitler's Germany; thinking now of the Brazilian territory, we remember that collection of Yanomami blood was carried out in the 1960s in a scientific mission that had the support of anthropologists.

In the school, this division between researchers in the human sciences and in the biomedical sciences is an old one, and shows the tensions and the dangers of its reification. This division between fields of knowledge, as well as being an artifice for argument, can generate two false images: the image that surveys in the human sciences are 'weak', in terms of being 'soft' science'; or, more dangerous still, that such surveys offer less risk to the participants^{25,26}. This point is crucial in understanding the position of the school in the discussion on ethics in research.

Are surveys in human and social sciences on the schoolroom floor inoffensive?

Reflections on how surveys in the 'soft' sciences affect the populations studied are a long tradition in the human sciences themselves, especially in anthropology^{30,31}. In the context of school psychology one can indeed remember, following Patto³², the theory of cultural deprivation developed by 'task-forces created by state bodies, bringing together psychologists, sociologists, anthropologists, economists, teachers, educators, social assistants, and linguists' with the aim of creating an official and scientific discourse that would justify social inequality and the institutional racism that was in place in the 1970s in the United States. Within this theory, black pupils and those from the poorer city areas would allegedly have less success in school and in social life due to their 'cultural deprivation', that is to say, their biological inferiority was now no longer stated, and the situation was now re-stated in social-environmental terms.

The history of science and various studies of the anthropology of science show how the perception of difference between the scientific and lay approach, and/or between 'hard' and 'soft' science, consists of conventions associated with forms of presentation of data and in which groups of surveys they are associated³³⁻³⁶.

On this aspect, we call attention to the fact that any assumption that surveys which do not

intervene in the biological body are less dangerous corroborates with the tradition of surveys carried out in the school context which show how the social constitution of a specific class of socially maladjusted pupil is historically built and politically determined; – and principally, that these productions and control of maladjusted bodies take place through 'soft' artifices. Indeed, many researchers in the social sciences who study schools do so through questionnaires and interviews that are apparently inoffensive, but often applied in vertical context and not always with the due questioning and reflection. These researchers tend to act as if the school was at their service, and not the contrary, making many schools ask themselves what in fact is their commitment.

On this point, it becomes essential that there should be reflection on the risks of investigations in human and social sciences in the school, which means analyzing the theoretical-methodological construction of the investigation, expanding the scope of the ethical analysis, so that it no longer applies only to the protocols relating to the manner of being in the field, but also focuses on the form of analyzing the material constructed in the survey and the way of writing, afterward, reports and publications.

We emphasize that the ethical concern should continue in the post-data collection phase, a context that is decisive in the construction of knowledge in the human and social sciences. However, this is an element that is treated with little attention in discussions on the subject. What one observes, repeatedly, according to the indications of Bruno Latour^{33,37}, and anthropologists of science, is a process of 'purification' of the scientific data; in other words, a process similar to the one that psychologists carry out when evaluating children, adolescents and adults through classifying reports that are centered on reductionist explanations about human development and schooling. According to Patto, such documents produced by psychologists,

speak, with authoritarian conviction, of an abstract subject person, reduced to numbers and to clichés full of arbitrariness and prejudice; they keep absolute silence about the social reality, about educational policy, about daily life in the school, and can, for this reason, blame the victim, situating the origin of schooling difficulties as invariably in the pupil and the pupil's family environment per se³².

That is to say, independently of being carried out in the area of human or biomedical sciences, scientific surveys, because they are within a historical and social context, are susceptible to re-

producing stigmas and prejudices which, rather than helping explain the challenges of the construction of the successful school, reinforce difficulties. This situation, thus, points to the importance of placing a clear focus on the scientific production of stigmas and social prejudices.

Finally, it is our view that, whether when going out into the field, or when there, or even after leaving it for the university offices, researchers in education should be attentive to not (re) producing the historical relationships of authoritarianism with the school's actors (pupils, family members, teachers, etc.) – if they do not, they may be interpreted as distant from, and hardly attuned to, the challenges faced in carrying out a successful process of schooling. Anyone who researches Brazilian public schools recognizes the tension that is present in the relationship between researcher and researched, and it is common for schools to show their discomfort with the presence of researchers within them. We argue that this resistance should be interpreted politically, removing its supposed intra-psychical character. What is it in our stance as researchers (as a group) that has contributed to the distrust in relation to our entry into the schools? What can and should we do to overcome this obstacle?

Research in the human and social sciences as compared to biomedical research: Intersections that medicalize

In the present scenario, the school and its context are researched on the basis of two major paradigms that have been confronting each other since the 1990s: on the one side, surveys which, in the light of the historical-critical reference frame, show that various psychological and biological categories have been used as a form of reproduction of inequality and prejudices, especially questions around race, gender and social class; on the other side, surveys with a strong biologicist accent, which, after innumerable criticisms of the absence of grounding on myths such as malnutrition, ophthalmological problems or presence of verminosis, began to scrutinize the brains of pupils, in search of the causes of school failure³⁸.

This latter paradigm, due to the voluminous financing from the government of the United States, and from the pharmaceutical industries, has been a defining trend in the agenda of surveys, achieving a decisive influence on contemporary explanations about the challenges lived through in the day-to-day construction of the

school, to the point at which the 1990s were announced as the “decade of the brain”³⁹.

More critical authors, such as the neuroscientist Molly Crockett, in response to the avalanche of ‘neuro-statements’, opine that now is the era of ‘neuro-bunk’⁴⁰.

Under a biologicist focus, there has been a growth in the number of surveys about school failure in the field of the neurosciences, which has only become possible with the flexibilization of the parameters for identifying learning disorders and deficits, such as Attention Deficit Hyperactivity Disorder, Dyslexia, Dyscalculia, Auditory Processing Deficit, etc. Such surveys tend to treat the school as an especially privileged statistical cohort for defining and specifying the differences in the processes of learning in nosological disorders and entities described in manuals of medicine and psychiatry, but widely popularized through questionnaires and tests which, although they indeed do not withdraw any biological substance from the participants of the survey, finish up inventing stigmas and bio-identities in the subjects of the surveys.

A paradigmatic example of this statement is the questionnaire to diagnose Attention-Hyperactivity Deficit Disorder, known as SNAP IV⁴¹. The name of the questionnaire, constructed to be filled in by parents, teachers and professionals refers to exactly the Diagnostic and Statistical Manual of Mental Disorders IV⁴², the same that has been profoundly criticized, for example, by Jerusalinsky and Fendrik⁴³.

However, in the ambit of the ethical evaluation in the CEP/Conep system, these surveys enter the field of human and social sciences depending only on the affiliation of the investigator, either in terms of his/her education and qualifications or by his/her being part of certain research groups. The aseptic separation between human and social sciences, on the one hand, and biomedical sciences, on the other, does not become real in this territory. What we see, in practice, is a significant group of surveys carried out in the school context under the label of “epidemiological surveys in mental health and human development”, which are mere applications of questionnaires created in the biomedical area in segments of schools, usually public schools, in the major urban centers. There is an urgent need for a profound analysis on the ethical evaluation of these surveys, starting from the recognition that they transit between the human and social sciences, and the biomedical sciences, causing reifications to be exceeded.

One factor which attests to this urgency is the important study on the scientific measurement of human learning and behavior, carried out by Gould⁸, which, starting from the pre-Darwinian creationist-era craniometry and going up to the creation of metric scales of intelligence, points to the following recurrent factors: their speculative nature –although they are supposedly pure science; the declaration of interest in the good of humanity; and the predominance of biological determinism as expressed in scientific racism. As a result, they are studies that operate with the reification of intelligence and behavior, observed as separate entities, independent and susceptible to abstract analysis, out of context. To these elements is added the impact of prejudices on the findings of the surveys, that is to say, the conclusions are strongly determined by the investigator's expectations, influencing procedures of collection and analysis. According to Gould⁸, it was on the basis of prejudices that Lombroso affirmed, in 1887, and in 1911, respectively:

We are commanded by silent laws that never cease to operate and which rule society with more authority than the laws written in our statutes. Crime ... seems to be a natural phenomenon.

Anthropological examination, which points to the criminal type, the development of the body, the lack of symmetry, the small size of the head and the exaggerated size of the face, explains the failings in schooling and discipline of the children that present these features, and makes it possible to isolate them in time from their better-endowed companions, and to orient them toward careers that are more appropriate to their temperament.

It can be stated that such surveys not infrequently serve as a basis for construction of public policies, in which Gould highlights the mass sterilization of American women who scored below average on the Stanford-Binet IQ Scale⁸. The meeting point between psychological research and the policy of sterilization is summed up, by the author, in the publicity given to a court judgement in favor of violence against a woman in 1927. The judge stated: "We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices ... Three generations of imbeciles are enough"⁸.

What separates the researches of Lombroso or Binet at the end of the 19th century and the early 20th century, both criticized by Gould, from the contemporary researches on ADHD and other supposed disorders of learning and behavior? And what unites them? Patto⁴⁴ does not allow us

to be ingenuous, when, in 2000, he states: "All the indications are that, in the matter of psychological evaluation, neuro-psychic diagnoses of the non-empowered will shortly replace common psychoanalysis and the shallow cognitivism of present diagnoses".

Indeed, as Pereira⁴⁵ points out in his Master's Dissertation in the history of science and health, in the version that is dominant in the psychiatric field:

ADHD is a biological and atemporal factor and, if the number of diagnoses is increasing, it is because the disorder was being under-diagnosed and sufferers deprived, thus, of the benefits that knowledge of the disorder and its treatment would bring to their lives. [...] In this vision, the medical fact is an independent, definitive, reality, not conditioned by temporal and social factors; it is a purely objective event and its discovery results from the progress of the sciences that investigate it. (Our emphasis.)

Armed with this belief in the atemporality of science, there are many psychologists and educators who take ADHD as a *fact*, few of them asking about its historical construction. With this perspective, when they go into schools they do it in search of children on whom to apply medical scales of diagnosis of this supposed, but unquestionable, disorder⁴⁶⁻⁴⁸.

If Gould presented, in a clear and evident form, the articulation between surveys that are producers of stigmas and the production of public policies of extermination, we cannot omit to recognize that this point of view proceeded with the "advance of science", although, to use Patto's⁴⁴ expression, softening the forms of captivity.

It is based on this realization that we attended, ethically stunned, the holding of the Sixth National Forum on Medications in Brazil, in the Federal Senate, in 2014. Starting from the text of its presentation, the event, sponsored by innumerable drug manufacturers (in particular: Sanoft, Medley, AstraZeneca, MSD), in partnership with the federal government, made its intention explicit: To *expand* even further "the *market* for pharmaceuticals and drugs in Brazil", dealing with it as a sector of the economy, and not as a social right. Thus, the pharmaceutical companies regard the increase in the purchasing power of the C & D income groups with satisfaction, since such growth, allied to amplification of government policies, puts Brazil on the "path of potential investment by large pharmaceutical groups". Among the subjects debated at that event, a topic presented as essential is: production of research surveys aiming to expand the market and to ex-

pand access to drugs⁴⁹. It would be ingenuous to suppose that such surveys are restricted to the biomedical area. Thus, we need to question the actual risks that the production of knowledge in the field of human and social sciences has to contribute to maintenance of a medicalized view of education, although, apparently, there is another logic operating in their construction.

Final considerations

So far we have made reflections about the field of ethics in the context of school surveys, calling attention to the 'naturalization' of the dichotomy between human sciences and biomedical sciences. Having said that, we argue for the need to express such issues in relation to the current functioning of the system of regulation of ethics in research, and we point to challenges which in our view are facing the system as a whole.

The surveys in educational and school psychology and in the Human and Social Sciences show the power with which the biomedical logic penetrates the school and determines the standards of normality within school life and the standards of surveys carried out in and about the school – this is defined as medicalization of education. This is why, in spite of the obstacles and difficulties, whether of dialog with the researchers in other areas, or in the filling in of forms for the Brazil Platform, the real challenge, of ethics in research, should not be left out of account.

We take a position on the importance of going forward with the debate on ethics in research, moving in the direction of establishing a distinction in fact between issues relating to the bureaucracies of the ethics research committees, which need to be overcome, and the elementary issues for the consolidation of surveys that should not lose the ethical-political relationship in their construction, above all in relation to the challenges imposed in today's context. This discussion should be conducted taking into account the specificities of the projects presented and respecting the different ways of carrying out research. In the debate on the CEP/Conep system, we feel it is important that we should not stray from what is really of interest, if we wish to build a knowledge that can contribute to confronting the challenges that have historically been imposed on school education. Based on this concern, we ask: What is the place of the person being researched in the production of scientific knowledge? Or, in other terms: Following the rhetoric that has been in vogue since promulgation of the 1988 Brazilian

Federal Constitution⁵⁰: what is the role of social participation in scientific research?

These questionings are based on the principles of the Health Reform in the context of the re-democratization of Brazil, of functional importance in the construction of the Unified Health System and of the processes of social participation in the maintenance of public policies, in which social movements have been a highlight. Continuing in this debate, we question: How to ensure popular participation in decision on the scientific agenda, and questioning of it? What mechanisms of social and popular participation can be created to guarantee this?

Social participation, as well as guaranteed by the Constitution⁵⁰, is a clause in various international documents, such as the Indigenous and Tribal Peoples Convention (ILO Convention 169) of 1996⁵¹, and has been used as an argument to question researchers on the reasons and uses of the surveys carried out in traditional populations which are often carried out with major government interventions and rarely have their content discussed with the groups that are being researched.

In the field of schools, this agenda has not yet become officially present, but has been a demand made by the schools, especially in the context of the reaction to field researchers in which managers, educators, pupils and family members ask in whose service we are working when we ask to enter the institution to carry out a survey.

Indeed, it is considered that little has been discussed about social participation in the CEP–Conep System. Since its creation, there has been almost no pedagogical and educative approach brought to bear on ethics in research, in large part transforming the CEPs into bureaucratic arenas of certification by primarily assuming the task of supplying certificates of ethical standard to research projects. In this scenario, results of research surveys – an aspect of the greatest importance for society as a whole – continue not to be publicized as much as they should.

On this aspect, we believe that there has been a retrograde development in the CEP–Conep System since the implantation of the Brazil Platform, in 2012, since the data of the surveys carried out ceased to be publicized on its website, and have only become known following requests based on the 2011 Law of Access to Information.

The absence of a more comprehensive epistemological discussion about the uses and the motivations of science, in all the areas that carry out surveys involving human beings, generates the false image of scientific neutrality, although

the data of the surveys serve as an input for the creation of consolidation of public policies.

Finally, we argue for the need to insert the discussion on ethical regulation in research into other agencies of control of scientific output, above all Capes and CNPq. As a key point of the discussion we emphasize what in the literature in the English language is being called *Audit Cultures* (Cultura da Avaliação)⁵²⁻⁵⁴, which installs the neoliberal way of thinking in the academic world. What happens is that complex contexts are replaced by forms and numbers, such as in the ranking of postgraduate publications and programs and in the opinions issued by the CEP. It needs to be considered that this “productivist” logic has an effect on the quality of scientific output.

In the neoliberal rhetoric in which the dialectic of crisis/solution becomes a model to be followed, we do not propose any specific model of regulation of ethics in research, but the carrying out of a consensual effort by the areas of knowl-

edge, to construct ethical-political principles that orient practices in research and the explanations presented by science for social facts. The bases for such a task are to be found in fundamental documents on ethics in research, which have their roots in suffering, and in the foolishness of those who, by de-humanizing knowledge, justified practices of violence, torture and terror – examples of these documents are the Nuremberg Code (1947), the Universal Declaration of Human Rights (1948), and the Helsinki Declaration (1964), to cite only a few.

We believe that only when we actually face this debate with the density that it calls for will we be giving the discussion on ethics in research in human and social sciences the importance that it in fact deserves; giving explicit shape to the conceptions of mankind, of the world and of society underlying the interpretations and certain formats that constitute research that is said to be scientific; and working for overcoming of the neutrality of science.

Collaborations

LS Viégas, RM Harayama e MPR Souza participated equally in all stages of preparation of the article.

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