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Ethical responsibility in the SBBrazil 2010 from the perspective of the managers of the population survey

ABSTRACT

OBJECTIVE: To analyze the ethical problems involved in the Brazilian Oral Health Survey – SBBrazil 2010.

METHODS: We carried out a descriptive qualitative case study from the perspective of the ethics of responsibility. Key informants (n = 14) involved in the planning and implementation of a population survey in the Federal District and 11 States were individually interviewed using a semi-structured questionnaire. The participants of this research belonged either to the Management Group or the Technical Advisory Committee of the Ministry of Health, responsible for the planning and implementation of SBBrazil 2010. Two coordinators, one municipal the other state were also involved. The results are expressed as collective subject discourse. Complementary information about the content of the interviews was obtained from the participants in order to clarify terms and to understand facts and contexts.

RESULTS: The following core ideas were identified: the teams need to feel responsible for SBBrazil 2010; fabrication of data compromised the DMFT (decayed, missing, filled tooth) in some places; non-adherence to field work protocol as moral problem. Data exam showed that in one capital the caries index at 12 years was well above the average expected for that place. A breakdown of the database led to the detection of solid evidence of registration error on the part of two examiners, which would indicate that there was either a failure in the training and calibration stage, or fabrication of data, or both.

CONCLUSIONS: The anomalous behavior of these examiners was detected in time and the fieldwork was redone. However, from the perspective of the ethics of responsibility, there was a transgression in the sphere of individual responsibility, the effects of which affected all the researchers involved and jeopardized the credibility of the research.

DESCRIPTORS: Dental Health Surveys, ethics. Health Manager. Data Collection, ethics. Oral Health.

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INTRODUCTION

Data on health conditions are essential in evaluating and planning public health interventions. There are various ways of obtaining these data and, depending on the resources available in each society, population surveys are carried out regularly. To ensure that these data are collected by qualified professionals, training, known as calibration, takes place before the field work, aiming to minimize variations and observation errors, contributing to the production of consistent results.¹⁹ Thus the researchers seek “to ensure a uniform interpretation, understanding and application of the codes and criteria on the part of all the examiners, of the various diseases and conditions to be observed and recorded”,^a so that the levels of concordance remain stable throughout data collection. However, in addition to these technical aspects, the data also need to be obtained by researchers with an elevated sense of professional responsible and ethical commitment.

A comprehensive epidemiological population survey, known as the *Pesquisa Nacional de Saúde Bucal* (SBBrasil 2010 – National Oral Health Survey), was carried out in Brazil in 2010. Given the size and complexity of this survey, which counted on the support of a large number of researchers, the technical requisite of calibration took on a methodological character of strategic importance.

Therefore, the calibration of the professionals involved was supervised by experienced instructors. It was the responsibility of the State Research Coordinators to “define, together with partner institutions and municipal coordinators, who would be responsible for the calibration stage in each municipality”.^b In the case of the SBBrasil 2010, this function was carried out with the support of an Examiners Calibration Manual.

In theory, only those examiners who achieved an acceptable level of consistency at this stage would participate in the field work. Acceptability was established using the kappa coefficient, the value of which expressed random coincidences and discrepancies in the interpretation of conditions which occurred in the calibration and also throughout the field work.²⁰

Bearing in mind that a survey of this type, involving human beings, leads to reflection on issues which go beyond technical aspects, the aim of this article was to analyze problems of an ethical nature in the execution of the SBBrasil 2010.

METHODS

A qualitative case study was carried out, from the perspective of ethics of responsibility.⁵ For Yin,²³ in situations in which there are no precise “limits between the phenomenon and the context”, the case study is appropriate for seeking detailed understanding of the topic.

Weber,²² in a conference at the end of the second decade of the 20th century, stated that “all activity guided according to ethics can be subject to two entirely different and irreducibly opposed maxims (...)”: ethics of responsibility and ethics of conviction. For him, the two differ, essentially, in that adepts of the former believe that the “foreseeable consequences” of their actions need to be taken into account. Although classical authors such as Plato and Kant have discussed the question of responsibility, Jonas is recognized as having made innovative shifts away from the traditional concepts. In his work *The Imperative of Responsibility* (1979), Jonas deals with the deadlocks due to scientific and technological advances and suggests an ethics of responsibility which is also concerned with generations yet to come.⁹

In the SBBrasil 2010, each Oral Health Surveillance Collaborating Center of the Brazilian Ministry of Health designated an individual responsible for keeping in contact with the states and municipalities, producing the Managing Group (MG) of the research. Members of this MG were, in this study, key interviewees, as they participated in the field work – the stage at which the main ethical implications of a study generally manifest themselves. They were identified using the SBBrasil 2010 Project results document.^c

The data were collected in 2012 using individual, semi-structured interviews, with the following guiding questions: a) “In your experience of the SBBrasil 2010, what difficulties stand out in a population survey of this size?”; and b) “Throughout your participation in the survey, did you experience or hear of any situations which, in your opinion, could be considered an ethical dilemma?”. Bearing in mind the need to ensure the existence of a set of possible opinions on the problem in question,¹⁴ the “snowball” technique was used.¹⁷ At the end of the first interviews, members of the MG indicated new interviewees. Their suggestions included members of the Technical Advisory Committee (CTA-VSB), who stood out due to working closely with the MG, as well as state and municipal coordinators of the SBBrasil 2010 who, for various reasons, stood out from the others.

^a Organização Mundial da Saúde. Levantamento epidemiológico básico de saúde bucal: manual de instruções. Trad. de AGRC Oliveira, B Unfer, ICC Costa, RM Arcieri. Geneva; 1987.

^b Ministério da Saúde (BR). Coordenação Nacional de Saúde Bucal. Projeto SB Brasil 2010 – Pesquisa Nacional de Saúde Bucal: manual do coordenador municipal. Brasília (DF); 2009.

^c Ministério da Saúde (BR). Coordenação Geral de Saúde Bucal. Projeto SB Brasil 2010: Pesquisa Nacional de Saúde Bucal – resultados principais. Brasília (DF); 2011.

Interviews were conducted with 14 individuals resident in the Federal District and in 11 states (Goiás, Mato Grosso, Minas Gerais, Paraíba, Paraná, Pernambuco, Rio Grande do Norte, Rio Grande do Sul, Rio de Janeiro, Santa Catarina and São Paulo), nine of whom were members of the MG, three of the CTA-VSB, one was a state and another a municipal SBBrazil 2010 coordinator. There was one refusal to participate. The interviewees were contacted in person or by e-mail to choose a time and date for the interviews, which were recorded.

In order to organize the statements systematically, a technique called Collective Subject Discourse (CSD) was used, which is based on the Theory of Social Representation,¹⁴ and seeks to sum the individual statements of the interviewees so as to express the thinking of the collective. The stages of CSD were followed as recommended,¹³ in the following order: isolated analysis of the constituent issues of the script; identifying key expressions; composing sets of semantically equivalent or complementary key expressions, summarized as Key ideas; and creating the CSD, which “is a synthesized discourse in the first person singular and opposed of the [key expressions] who have the same [key idea]”.

The research fulfilled the criteria established in Resolution 196/96 of the Conselho Nacional de Saúde, and the project was submitted to and approved by the Research Ethics Committee of the Faculty of Health Sciences of the Universidade de Brasília, protocol number 007/12 and approved on 21/03/2012. Participation was voluntary and all subjects signed a consent form.

RESULTS

Of the 14 interviewees, eight were female, and professionals connected with state or municipal health departments or to universities predominated. The majority reported experience in carrying out similar surveys, including the SBBrazil 2003 – the precursor to the SBBrazil 2010. The following key ideas and CSD involving ethical aspects were identified:

Key Idea 1 – The teams need to feel responsible for the SBBrazil 2010

CSD 1: “There are three essentials needed to occur in contact with the states and municipalities: identifying, passing on knowledge and motivating the individuals. We need to make them feel involved, responsible for the project. During the workshops, I frequently called their attention to the problems which could stem from teams falsifying data. I had a slide talking about exactly that, the attributes and responsibilities. This is because many of the data from the SBBrazil were totally exaggerated, ridiculous, unrealistic. So I reinforced this a lot during the training: ‘We are going to conduct a preliminary analysis of the database and data which are completely

different and unrealistic will be eliminated because it indicates that there has been some kind of falsification’. Each team in the state capitals was responsible for at least three tracts. The professionals were numbered and the municipal coordinators passed this information to us. So, I explained that: ‘You are going to be numbered and be responsible for x tracts, if there are exaggerations, we are going to identify them’. Today we have *ex-post facto* mechanisms to identify: ‘Who was in that census tract? Who produced this anomaly in the data?’. There is a way of discovering, returning to the field and making teams and departments responsible. So, I put a lot of emphasis on this, that this was a serious issue, that they could not cheat and defraud research which was going to benefit the population. We practically have an ethical imperative to produce national data, to advance socio-epidemiological diagnoses in the Brazilian population, with solid, robust methodology”.

Key Idea 2 – Falsifying data compromised the DMFT (decayed, missing, filled permanent teeth) in some places

CSD 2: “There was a problem with someone falsifying data and this affected the DMFT for the entire state and even for Brazil. This individual should be sued on ethical grounds because they did not understand what they were doing, what the consequences of their actions were. There was another irregular situation in a state capital. The municipal coordinator was very competent and committed. He did everything he needed to, but this particular tract which caused the problem was not in the 10% which he supervised. When we consolidated the data and calculated the DMFT for 12 years olds, this capital had a higher mean than that found in 2003. Nothing significant, two or three decimal points, but it was difficult to understand because all of the others had decreased slightly. Moreover, this was a place with fluoridated water and an important oral health care network, it has had PSF [*Programa Saúde da Família* – Family Health Care Program] for years now, this is not something which began to happen overnight. So, we monitored each census tract and discovered one with a completely different pattern of incidence. When we began to check the streets which the professional had covered, we verified that they were not included in the pre-defined map of the census tract. So, a new tem, which was not even paid for this work, re-did the tract and, then, it had reasonable results. I doubt very much that this was a problem of lack of understanding, as each team had a physical map, you know? Why would someone disregard such clear guidance?”.

Key Idea 3 – Not adhering to the field work protocol as a moral problem

CSD 3: “I went to the area to monitor the data collection because, to be honest, I was worried that the thing would not happen. I cannot assess the real nature of the intention, but there were methodological deconstructions at

the beginning; some of which I found by chance. There was a pattern of the number of potential individuals, on average, which you would find in a census tract. For example, it was expected that in one tract you would find maximum 10 to 12 children aged five. This was a national parameter. In this municipality, in particular, there were 35 children. We held a meeting with all of the municipal coordinators of the state and began to look at their results. When the coordinators of this municipality began to speak, everyone was like: 'What's going on here? We never found so many children in one tract like that'. So, the coordinators said they assumed it was an unusual tract and, when asked, provided a written statement that they had re-done the tract and got the same result. For me this is a very serious moral problem, because first they made the mistake, then they ratified it".

Complementary data indicate that at the stage of calculating the SBBrasil 2010 data, after obtaining the first results, one state capital stood out for having a mean DMFT index for 12 year olds far above what was expected. The outlier, according to basic epidemiological criteria, was two times higher than the mean found in other state capitals in the same region. In this municipality, there was no record of any significant alterations in risk factors which could justify such a notable increase between 2003 and 2010. The team carrying out the calculations broke down the database, searching for inconsistencies in the records. The SBBrasil 2010 used census tracts as the territorial unit on which the "selection and identification of the households" were based,^d and each examiner/note taker was responsible for, on average, three tracts. In this way, it was possible to segment the analysis by tract. Using this procedure, the origin of the incongruences and those responsible were identified, confirming recording errors on the part of two examiners. Moreover, although there was a parameter as to the expected number of individuals found per age group for each tract, these figures were well above this pattern. This finding strongly suggests that there was an infraction, intentional or otherwise, of the rules for covering the field, on the part of the above-mentioned examiners. The content of the interviews indicated that there were similar occurrences in other municipalities, although to a lesser extent – in terms of number of census tracts excluded not in terms of importance. Faced with such facts, there are two hypotheses, or a combination of the two: 1) failures at the training and calibration stage; 2) fabrication of data. Irrespective of the cause, the only possibility in these situations is to disregard the discrepant data. The interviews indicated that, in the case of the aforementioned municipality, the initial data were disregarded and new data was collected from the field, as the original data were irredeemably

compromised. The problem was solved by having new teams conduct new oral examinations in the census tracts in question. Spurious data were kept out of the database produced by the SBBrasil 2010, but at the cost of material, financial and human resources.

DISCUSSION

Epidemiological knowledge generated by surveys such as the SBBrasil 2010 have immediate and mediating effects. The immediate effects concern use of its results by both health care institutions and society, through social organizations and movements. The mediating effects concern the possibilities of studies and analyses to be carried out by future generations. Without data produced in the present, it would be impossible for these to create new designs and studies. From this aspect, ethics of responsibility, from the perspective indicated by Jonas, constitutes a relevant contribution as it shows that, even in the area of epidemiology, present actions have future repercussions, and therefore require those involved to also take this dimension into account in the work they carry out as public agents.

Incidentally, one characteristic of the SBBrasil surveys is that it was deliberately chosen to use professionals connected to the public health care system to collect the data, so as to contribute to the qualification of the teams of these services, in terms of epidemiology and surveillance.¹⁶ Therefore, the majority of the professionals who took part in the data collection were not experts in these activities, although some had accumulated experience in local studies and the SBBrasil 2003 itself. In the context of the difficulties reported by the interviewees, therefore, it is important to differentiate between falsification and honest mistakes.⁸ In the SBBrasil 2010, each team had the support of an electronic device, a Personal Digital Assistant, provided by the *Instituto Brasileiro de Geografia e Estatística* (Brazilian Institute for Geography and Statistics). The researchers used this device to record the data obtained in the households. The interviews contained strong indications that the PDAs contained deliberately wrong invented data. In contrast to falsification, in which data are intentionally omitted or altered, fabrication of data is when they do not exist and are created.⁸ Improper conduct on the part of the teams may have occurred either by creating the data or by not following instructions contained in the field work protocol.

In the Latin American Dictionary of Bioethics, Estévez⁴ deals with the words intention and responsibility in one single entry, as it is understood that there is a symbiotic relationship between them, both in moral and legal terms. For the author, it is *intention* which makes what

^dMinistério da Saúde (BR). Coordenação Nacional de Saúde Bucal. Projeto SB Brasil 2010 – Pesquisa Nacional de Saúde Bucal: manual da equipe de campo. Brasília (DF); 2009.

would otherwise be just a natural event, due to chance, meaningful and human. Pereira¹⁸ emphasizes that there is “a big difference between strong wind bringing down trees, or a forest fire, and human activity cutting down the same trees or setting fire to the forest. They are both actions, they both provoke change. But the action of the human is *theoretical action*, action with reflection, with meaning”. In other words, it is the intention which characterizes a specific human action, as it reveals the rationality.⁴ For Kuiuava,¹² “an individual is responsible when their motives of their action include foreseeing possible effects of that action”.

This situation can be reflected on from the perspective of legal responsibility: penal, civil and administrative.¹⁵ As established in the Brazilian Constitution, “the direct and indirect public administration of any of the powers of the Union, States, Federal District and municipalities shall follow the principles of legality, impartiality, morality, publicity and efficiency”.² It is well-known that the public servant does not act in their own name, but in that of the authorities, and should display conduct appropriate to the customs in effect in the society. Thus, morality, a principle which is of particular interest in this article, advocates the place of public interest above those of the individual in the activities of public servants. The existence of administrative and legal procedures is, without a doubt, important, but “we cannot rely on the laws and the legal system to resolve the deadlocks and contradictions of modern society”.¹¹

Another way of approaching the issue of responsibility is through the theoretical framework of Deontology which, in the context of the health care sector, “is directed preferentially at the moral duties and obligations of the participants in a specific professional community in the area of biomedics”.⁵ It concerns, therefore, the encoded aggregate of duties assigned, in this case, to dental surgeons, and oral health assistants and technicians. Thus, it is possible to think about responsibility of professionals who fabricated data in the SBBrazil 2010 in terms of the Dental Code of Ethics, the 2010 version of which sets down that “it is up to orthodontic professionals, as members of the health care team, to act so as to satisfy the health care needs of the population”,^e as in the case of an epidemiological survey. It is worth noting that there are municipalities which establish their own codes of ethics for their public sector workers. The teams in these locations would have, then a double ethical obligation. However, moral obligations are losing their motivational force in modern societies.⁷

There is, however, no doubt that this problem leads to wider reflections, as it cannot be limited to establishing local penalties for individuals supposedly involved in

moral infractions. Thus, legal responsibility is necessary, although not sufficient. On the other hand, the debate on ethics in health care should not be limited to responsibility regarding the codes of the different professional categories.³ for Kipper & Clotet,¹⁰ “reflection on a moral conflict in exercising the profession, carried out only after referring to the code of ethics, is probably a short-sighted and restricted vision of the problem therein”. On this point, we emphasize the important of a public sector health care worker’s ethics and commitment to developing the *Sistema Único de Saúde* (SUS, National Healthcare System) and the country⁶ and consider what they do or do not do from the perspective of ethics of responsibility.⁵

Different kinds of ethical irregularities have contributed to consolidating a gap between the SUS as projected by militants, intellectuals and managers in the Health Care Reform Movement and the everyday reality of the SUS. However, “little has been done (...) about the duties and obligations of the different actors directly and indirectly involved in the various activities and levels concerning the SUS”.⁶ Garrafa⁵ addresses the ethics of responsibility under three headings: individual ethics of responsibility; public ethics of responsibility; planetary ethics of responsibility, based on Jonasian reflection. Individual ethics of responsibility is concerned with:

“[...] the moral commitment and personal, non-transferable responsibility of each citizen to others. It is a vision of the similar, of the other, especially those who are most vulnerable and unaided. It also underlines responsibility and ethics in dealing with public questions on the part of public sector health care workers”.⁵ It should be noted at the outset that the “qualitative question of ethical responsibility does not differ when comparing the roles of the lowliest employee in a health care center who mistreats the users [with the role] of a higher authority in a determined hierarchy (...)”.⁶ It is the same from the highest positioned manager of the SUS, the Health Minister, down through state and municipal coordinators to the inhabitant of the selected household, all of them, without exception, have an “ethical responsibility” to the SBBrazil 2010.

Various thinkers have approached the question of otherness “throughout the history of philosophic thought”, but there is a certain originality in the way in which Lévinas thought about this concept.²¹ Concerned with indifference towards the other, he established that “the I does not exist first, to then interact with the other, as modernity claims. The I is always constituted based on its relationship with the other. Therefore, the other is the first condition of being and gives existence to subjectivity”.²¹ Despite this, “the overvaluing of the interior experience is even today gradually occupying

^e Conselho Federal de Odontologia (BR). Resolução nº 118, de 11 de maio de 2012. Revoga o Código de Ética Odontológica aprovado pela Resolução CFO-42/2003 e aprova outro em substituição. *Diário Oficial Uniao*. 14 jun 2012; Seção 1:118.

the public sphere and inflating the inter-subjective space with private, idiosyncratic, individual interests and personal satisfaction”.¹ This fact can be seen as a substantial obstacle in developing collective actions, the individual benefits of which are essentially indirect, such as the SBBrasil 2010.

Although the anomalous behavior of the aforementioned examiners was detected in time and the field work re-done, from the point of view of ethical responsibility, it could be said that there was an infraction in the dimension of individual responsibility, the effects of which affected all researchers involved, placing at

risk the credibility of the research. The individualism which predominates in the capitalist mode of production and which is reproduced in the public health care services does not take into account that experience with the other is an essential condition for constituting the subject. From the perspective of ethics of responsibility, responsibility for the other precedes autonomy. Thus, technical and ethical aspects are equally structured in surveys such as the SBBrasil 2010, as professionals need to be not only duly trained but also ethically committed to the credibility of the data and its faultless collection, whether this is relevant to the present or to the future.

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