

QUALITATIVE METHODOLOGY OF SENSITIVE TOPICS IN PUBLIC HEALTH CONTEXTS

METODOLOGÍAS CUALITATIVAS DE LO SENSIBLE EN CONTEXTOS DE SALUD PÚBLICA

METODOLOGIAS QUALITATIVAS DO SENSITIVO NO CONTEXTO DE SAÚDE PÚBLICA

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ABSTRACT

Subjectivity is always present in qualitative methodologies where emotions, feelings, culture and background of participants and researchers are involved. This is especially relevant in the health area, where sensitivity is present in many of the topics addressed. According to Lee, sensitive topics are those where research invades the private sphere, digs into some deep and personal experiences, addresses deviation or social control, and affects the interests of powerful people and/or the execution of coercion and domination. The following article is divided in two parts: the first one is related to theoretical foundations of the study of sensitive topics in public health, from the perspective of participants and the research team, revealing the importance of safety and physical, psychological, moral and legal security of all the members involved. In the second part, the author reflects upon her experience in investigation of sensitive topics, and, finally, methodological strategies are proposed to address the study of these subjects.

Keywords: Qualitative Research, Public Health, Ethics, Researcher-subject Relationship.

RESUMEN

La subjetividad siempre se encuentra presente en las metodologías cualitativas, en que se vinculan las emociones, sentimientos, cultura e historia de los participantes e investigadores. Esto es especialmente relevante en el área de la salud, donde lo sensible está presente en muchos de los temas estudiados. Según Lee los temas sensibles son aquellos en que la investigación invade la esfera privada, escarba dentro de alguna experiencia personal profunda, hace referencia a la desviación o control social, afecta a los intereses de personas poderosas o el ejercicio de la coerción y la dominación. Este artículo se divide en dos apartados; el primero tiene relación con la fundamentación teórica del estudio de temas sensibles en salud pública, desde la perspectiva de los participantes y del equipo de investiga-

ción, relevando la importancia de la seguridad e integridad física, psíquica, moral y legal de todos los actores involucrados. En la segunda parte, la autora reflexiona en torno a su experiencia en la investigación en temas sensibles, presentando algunas estrategias de abordaje del trabajo de campo. El objetivo de esta investigación fue describir la producción del conocimiento en relación a la investigación de temas sensibles en salud.

Palabras clave: Investigación Cualitativa, Salud Pública, Ética, Relaciones Investigador-sujeto.

RESUMO

A subjetividade está sempre presente nas metodologias qualitativas, onde se vinculam as emoções, os sentimentos, a cultura e a história dos participantes e pesquisadores. Isto é especialmente relevante na área da saúde, onde o sensível está presente em muitos dos temas abordados. Conforme com Lee, se considera uma questão sensível quando a pesquisa invade a esfera privada ou examina, indaga alguma experiência pessoal profunda. Refere-se ao desvio ou controle social, afeta os interesses de pessoas poderosas ou o exercício da coerção e dominação, se lida com coisas sagradas para as pessoas estudadas e não querem ser profanadas. Ele é dividido em duas seções; a primeira está relacionada com a fundamentação teórica do estudo de questões sensíveis na saúde pública, a partir da perspectiva dos participantes e da equipe de investigação, relevando a importância da segurança e da integridade física, mental, moral e legal de todos os atores envolvidos. Na segunda parte, o autor reflete sobre sua experiência em pesquisa sobre questões sensíveis, apresentando algumas estratégias de enfrentamento trabalho de campo.

Palavras-chave: Pesquisa Qualitativa, Saúde Pública, Ética, Relações Pesquisador-sujeito.

INTRODUCTION

This article stems from the initiative of The Summer School of Qualitative Methodologies for Social Transformation in Border Zones of University of Tarapacá, as a way to spread and offer the highest number of interested subject courses and workshops developed on that opportunity in the city of Arica. As a nurse and scholar, the subject I presented was “Qualitative Methodologies of sensitive topics in the context of public health in Chile”¹¹.

For the elaboration of the course-workshop, firstly, I carried out an introspection regarding my experience as a nurse and Latin woman who does research on sensitive topics. I wondered about what kind of emotions are born from such experience. The way I addressed the different subjects, in many cases, was only known by me as both theoretical approaches and statistics, neither associating nor knowing the story of the people who joined the numbers. After this process, I did some bibliographic research, going through classic literature and recent publications and, ultimately, designed the course and workshop with the intention of absorbing this blend of past experiences and scientific knowledge. In writing this document I did not make use of the word Chile, so as to un-biased and effectively share our experiences as human beings. The research question asked was: What knowledge is available regarding the research on sensitive health topics? And the aim of this research was to describe the knowledge production about of sensitive topics research.

METHODOLOGY

In this research, I worked with interpretive autoethnography. According to Denzin (2014), it is the methodology that uses the experience and personal write to comment the experiences and cultural practices, to denounce the vulnerability and to create reciprocal relationships with the audience to get an answer (1).

The methodology in this article has two parts. The first one explains the methodology of the bibliographic revision, and the second one shows some deep reflection about my experience as a researcher. In order to do so, an introspective writing process was carried out to discover its epiphany and path so as to able to research about these topics.

The research question asked was: What knowledge is available regarding the research on sensitive health topics? The objective was to describe the production of knowledge when dealing with the research on sensitive health topics. With this purpose in mind, the available literature was fully revised on the Scielo, Scopus, Web of Science and EBSCOhost research databases, in conjunction with the available literature of updated books dealing with research on the subject.

1 School of Updating in Qualitative Methodology, organized by the School of Psychology and Philosophy of the University of Tarapacá in the city of Arica on January 12 and 13, 2017.

RESULTS

The study of sensitive topics arises as a consequence of the understanding of health in the whole human being spectrum; thus, including psychosocial, physical and spiritual aspects. This has been joined with an increase in research on topics such as living with AIDS, suffering from highly contagious diseases, addictions, gender, sex, marginality, violence, among others, which are regarded as “sensitive topics” according to the available literature (2).

According to Lee, sensitive topics are those where research invades the private sphere, digs into some deep and personal experiences, addresses deviation or social control, affects the interests of powerful people and/or the execution of coercion and domination, and, finally, deals with things considered as sacred that must not be profaned by the participants (2).

In addition, Sieber and Stanley (1988) define the study of sensitive topics as the one in which there may be consequences or potential implications in the participants of the research (3).

The research on people’s private worlds and experiences, where complex emotional responses are created and intimate problems revealed, compels scientists to dig deeper in areas where emotional, physical and spiritual implications of the participants are unknown, both in the short and long term, affecting users, researchers, transcribers and research assistants (4).

When working with sensitive topics, it is important to identify aspects which are desired to be kept confidential, taking into account the fact that there are people, institutions and/or, sometimes, governments that are interested in concealing such subjects. It is recommendable that the researcher knows the topic to be studied as a whole in order to design strategies to befriend the participants; protect their physical, emotional, social and legal integrity; and to efficiently save the collected information.

Historical data from research on these sensitive topics starts with research done by sociologists from the Chicago School, who, not fully understanding the impact of their research, had access to the private lives of people who were part of their studies.

These studies were resumed by women liberation groups in the sixties’, who along with lunching campaigns against the objectification of women and violence, developed research methods of a non-hieratic kind between the researcher and the studied subject. These methods, also currently used, study relationships between power, domination, violation, eating disorders, among others (4-6). Feminist research particularly develops human interpersonal relationships due to the intimate nature of the interviews and conversations (6).

Studies on sensitive topics are generally performed using qualitative methodologies and, in that sense, in order to work with such topics, researchers have already walked down the path leading to them. As an example, Berger (7), says he came clos-

er to qualitative methodologies and sensitive topics when he studied his own family, which survived the holocaust. He consolidated himself in this research area when he started studying mental disabilities, which affected his own daughter.

The interview is one of the most used techniques in the research of sensitive topics. DeMarrais and Tisdale, quoted by Ashton identified the importance of creating a space in which a person could express his/her emotions. According to them, if it is possible to create a space, it is then likely to share intimate experiences in profound interviews (8). Elmir recommends that, previous to the interview, the participant is contacted via telephone call, so that a certain level of rapport is achieved. Furthermore, it is recommended that communication be bidirectional and that the researcher share some of his/her own history, thus not exerting pressure on the participant (9). Petersen states that the sole fact of narrating an story is emancipatory for the participant, as it allows him/her to express his/her feelings, ideas, and emotions starting, in that way, a liberation process (10).

From the ethical point of view, a crucial matter is to keep the identity of the participants anonymous. Janesick states that it is recommendable to ask the participants how they want to be called during the research, whether by nicknames, name initials or symbolic names that may help them to understand their narratives ;thus, meeting the criteria of anonymity (11).

Regarding the difficulties of the study on sensitive topics, Lee mentions that the researcher faces methodological and technical problems, among which are: conceptualization of the studied topic, definition and access to the participants, mistrust, cover-up of information, and insecurity in all the involved subjects (2). Besides, there may be physical symptomatology, especially in the field work, that includes headaches, insomnia, nightmares and gastrointestinal pain, being these more frequent in novice researchers. With the end of minimizing these effects, it is recommendable to previously discuss the possible material and psychological consequences the research may incur in.

Despite the inconveniences present during the research, Dickson-Swift consider that scientists must study these topics moved by both the ethical and the social responsibility of science (12).

Along these lines, Gilbert on Dickson-Swift states that the combination of topics, with a high sensitive load and prolonged contact, may lead to a loss of boundaries in the researcher-subject relationship, whereby these limits must be constantly set and reset, thus trying to achieve a balance between the costs and benefits of being close to the studied subjects (12).

It is interesting to mention a study made in Australia, in which 30 researchers, who study sensitive topic like homeless people, sexuality, cancer drug abuse, alcohol, violence and suicide, were interviewed. Using the funded theory, researchers identified the categories: being a "professional" researcher, research or therapy?, boundary between friendship and potential im-

plications of a non-responsible management of limits. In the first category, being a professional researcher, the participants stated the importance of making an efforts on being professional, keeping safe limits in their relationship with the studied subjects, these being of an emotional kind. However, they also said that qualitative research is inherent to an emotional connection between people. Regarding the category, Research or therapy?, they stated that in some occasions they had difficulties in the interviews distinguishing, when the objective is to research and do therapy, feeling that, inevitably, their intervention had a therapeutic effect (13).

Regarding the limits between friendship and research, the researchers involved stated that, an important proximity often occurred with the studied subjects, somewhat close to friendship. This gets complicated when the research comes to an end, it is time to say good bye, and severe connection with the participants. The potential implication of an inadequate management of limits results in emotional exhaustion, and a risk of developing a burnout syndrome (14).

Manders observed the course of the research in a Sikh Punjabi community in England. The purpose of the research was to explore the feasibility of developing a communal program for the treatment of alcoholism inside the community, in which the excessive consumption of alcohol by men is regarded as normal. As a conclusion from the research experience, the authors state the importance of mastering the language of the study group, getting an adequate rapport, past from being a stranger to a "professional who helps". They also advise, in participants, to leave aside the use of labels associated to their customs. Finally, they also suggest an attitude of commitment, honesty and patience regarding the postponement of appointments without previous notice (15).

The mentioned authors coincide in the importance of a good rapport, empathy, and honesty in order to leave aside judgments, to have a full knowledge of the subject of study, (which also includes customs and habits), and to know the language in the case the research is performed in a community different from the researcher's. Besides safeguarding ethical, legal and safety aspects inherent to the study of sensitive topics, they also recommend to talk to the entire research team regarding the significance of the results of the study has for each one of them.

In the following part of this article, I will present my experience as a researcher of sensitive topics, for which I used the performative auto-ethnography as methodology. I will also present different methodologies for teaching, some of which were applied in the workshop from where this publication originated.

DISCUSSION

I always search for the best time to write, one when ideas and memories flow. I close my eyes and remember, trying to connect myself with the emotions that come from my previous study of sensitive topics.

My relationship with the research of sensitive topics started when I entered nursing school, where care has always been viewed from a personal relationship perspective. When I make the clinical history of my patients, I am really interested in their experiences, I wonder about the personal and sociocultural factors that affect them. However, looking back, my epiphany occurred the moment when, being still a student, I was actually able to attend a course about Social Medicine.

According to Denzin, an epiphany is an identifiable moment of the living experience that one can identify as a turning point in the comprehension of oneself and our own relationship with the world. Thus, the epiphany forces the researcher to return and explore such life-changing moment. In such way, the emotional urgency induced by the epiphany transforms the methodological instruction- you must constantly return to in that moment- into an imperative, meaning one has to constantly examine the epiphany (1).

The subjects that were related to poverty, inequality, dictatorship and fear were not openly discussed in nursing school. The legacy of my country's dictatorship limited teaching to a biological perspective. In this course, I understood that diseases were much more than biological agents or life styles, they were impregnated with hunger, poverty and inequality. I understood that tuberculosis was not only a Koch bacillus, but it was joined by poverty, hunger, overcrowding, sadness and fear. When understanding these relationships, I could connect moments of my life (which could be summarized as a childhood lived under a dictatorship), with my dying mother suffering from tuberculosis, both hospitalized and receiving antibiotics for an entire year.

After my internship as a nurse specialized in nephrology, I focused on people suffering from chronic renal diseases. I went into postgraduate studies, starting with a Master degree in Community Psychology and ending in a doctorate in Nursing. Consequently, I started to get involved in the study of sensitive topics. My first approach happened when I studied the expressions of the chronic renal disease on people with peritoneal dialysis. There were hours of interviews, which according to Valles, the interviewee must feel as being in a conversation, not noticing the questioning structure, the order of the questions or the objectives of the interviewer (16). In this research, I could observe and feel all the suffering associated with renal disease, when people on dialysis told me their stories where emotions like anger, guilt, resignation, fear and frustrations arise. I could physically feel their suffering, sometimes I felt like crying with them, but instead I held their hands and asked them to rest, and that I could stop the interview if they wanted to. But, differently to what I thought, they continued with the interview and said good bye to me thanking me for the opportunity of talking and being listened to.

With my academic development, centered on qualitative research in health, I moved further doing research on sensitive topics. One of the most interesting experiences, I believe worth mentioning here, was the time I led a Thesis of the Master in Public Health, where the experiences of men who, having sex

with other men inside dark rooms (meaning spaces where there is sexual contact between strangers, without precautions or protection of any kind) were studied. Even though I did not make the interviews, I participated in the analysis, so I had to read the transcripts many times. The interviewees went into details about non-traditional sexual practices, involving teenagers who, despite being underage, practiced solicitation forced by economic needs. I have always considered myself as a prejudice-free person; however, these statements physically affected me, and I ended up suffering from headaches and nausea at times- as Cowles said- and I had to stop, go outdoors, and take a deep breath so I could leave aside the feeling of powerlessness and anger that hearing about sexual exploitation provoked in me (12).

In another opportunity, I could experience what studying sensitive topics in institutions meant. I wanted to do research among last year students about the cause of desertion in nursing students, which in one university in Chile reached a 30% peak during the first two years. When we analyzed the results, we could see that students deserted because they felt mistreated and humiliated by teachers who monitored their clinical experience. These teachers were clinical nurses hired for such effects. Due to aspects related to teaching methodologies, the students considered the level of demand in the clinical practices had no relation with the theoretical knowledge they were given, being the latter of inferior quality. Because of these results, distant from the spirit of nursing schools, an urgent meeting was convened, where it was decided that all future researches should go, alongside the Ethics Committee, under the evaluation of career teachers. Moreover, the public degree thesis presentations were suspended during that year. The research team did not foresee the impact of the results and thought it would be a contribution to prevent desertion, establishing the corresponding improvements, but this did not happen. Lee states there are sensitive topics as enquires into social control, in this case, given by institutionalism, affecting the factual powers by making use of coercion and domination (2).

The research of sensitive topics has taught me several lessons. The following conclusions agree with authors mentioned in this text:

- It is of most importance to know the subject of study, for that it is necessary to go through the revision on context aspects like statistics, juridical and legal frame, regulatory policies of countries, and it is also mandatory to revise the state of the art and theories supporting the subject.
- It is necessary to go through an individual process of analyzing the ideas, stereotypes and judgments surrounding the chosen subject. In phenomenology, this is regarded as epoch, which designs the suspension of our implicit belief in a world independent from consciousness (17).
- The meetings held by the teams to talk, discuss, and befriend the subject of study are extremely important as to allow to create awareness regarding what is happening to

each one of the members when faced to a topic that both humanizes and get people closer to each other.

- The presence of key informants that know the functioning of the community and the “non-mentioned” aspects, as they may serve as a link for researchers, is also important.
- Another vital aspect is to have a real interest, not only in the study subject, but mainly in the people we hope to be able to help with this study. From the right interest on others, an adequate rapport arises. I think the study subjects can feel when the researcher is really interested in them as people, beyond the information that can be obtained from them.
- It is also necessary to have previously made the bond as a reference for psycho-social support, in the case that participants or researchers need it.
- As mentioned in the text, the boundaries in the relationship can be blurry. I believe that, in that case, is necessary to make clear to the participants and researchers that the relationship ends at the end of the study. This must be stated with respect and honesty. Regardless of that fact, I think it is possible to maintain some personal contact, safeguarding the professional codes.
- In certain occasions, to study sensitive topics may be of a healing sort for the researcher, as he/she may find his/her own story reflected upon the other person's.

CONCLUSIONS

The study of sensitive topics requires of considerable knowledge, conscious emotions, feelings, commitment, honestly and, in some cases, compassion for oneself and the other. However, sensitive topics research is more than that; despite of using the scientific method rigorously, it must confront the imprecision of the human being and the emerging difficulties of non-traditional inquiries, which are usually on the edge of conventional limits and sometimes even out of the law.

When we inquiry these kinds of topics, the researcher must explain within the methodology, the difficulties and limitations along the way. However, this situation is infrequent and the publications only shows results, without presenting the whole meaning of studying sensitive topics and the intricated mixture of facts and subjectivities implied.

Given the complex reality of the 21st century, with the neoliberal model so established in the occidental culture and a persistent sense of dissatisfaction within the citizenship, demanding fairer and more tolerant societies, it is increasingly urgent to study these subjects that defy the traditional canons of science-making and that connect us to the otherness present all around us.

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REFERENCES

1. Denzin N. *Interpretive Autoethnography*. California: SAGE; 2014.
2. Lee R. *Doing Research on Sensitive Topics*. California: Sage Publications; 1993.
3. Sieber JE, Stanley B. Ethical and professional dimensions of socially sensitive research. *Am Psychol*. 1988; 43 (1): 49-55.
4. McCosker H, Barnard A, Gerber R. Undertakin Sensitive Research: Issues and Strategies for Meeting the Safety Needs of All Participants. *Forum Qual Soc Res*. 2001; 2 (1): 1-14
5. Finch J. It's great to have someone to talk to: The ethics and politics of interviewing women. In: Bell C, and Roberts H, Eds. *Social researching: politics, problems, practice*. London: Routledge & Kegan Paul; 1984. p.79-88
6. Oakley A. Interviewing women: a contradiction in terms. In: Roberts H, Ed. *Doing feminist research*. London: Routledge & Kegan Paul; 1981.p. 30-62
7. Berger R. Disability and Life History Research an Autoethnography of Qualitative Inquiry. *Int Rev Qual Res*. 2016; 9 (4): 472-488.
8. Ashton S. Researcher or nurse? Difficulties of undertaking semi-structured interviews on sensitive topics. *Nurse Res*. 2014; 22 (1): 27-31.
9. Elmir R, Schmied V, Jackson D, Wilkes L. Interviewing people about potentially sensitive topics. *Nurse Res*. 2011; 19(1): 12-16
10. Petersen A J. Research with individuals labeled “other”: Reflections on the research process. *Disabil Soc*. 2011; 26:293–305.
11. Janesick V. *Contemplative Qualitative Research*. Walnut Creek (California): SAGE; 2015.
12. Cowles K. Issues in Qualitative Research on sensitive topics. *West J Nurs Res*.1988; 10(2): 163-179.
13. Dickson – Swift V, Lyn E. *Undertaking Sensitive Research in the Health and Social Sciences: Managing Boundaries, Emotions and Risks*. New York: Cambridge University Press; 2008.

14. Dickson-Swift V, James E, Kippen S. Blurring Boundaries in Qualitative Health Research on Sensitive Topic. *Qual Health Res.* 2006; 16(6): 853-871.
15. Manders G, Galvani S. Learning from the Research Process: Discussing Sensitive Topics as a Cultural Outsider. *Social Work Education.* 2015; 34 (2): 199-212.
16. Valles M. Técnicas cualitativas de Investigación social. [Qualitative Techniques of Social Research]. Madrid: Síntesis; 1999.
17. Escudero JA. La actualidad de la fenomenología husserliana:: superación de viejos tópicos y apertura de nuevos campos de exploración. [The current of Husserlian phenomenology: overcoming old topics and opening new fields of exploration]. *Eidos*; 2013, 18 (Jun-Jul): 12-45.