Research on Cancer and Hard to Reach Populations: What to Learn From Social Sciences Methodologies

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Abstract

This case draws from findings of an ongoing long-term community-based participatory study anchor in low-income rural and peri-urban areas of Argentina, with the goal of providing insights into the role played by social determinants of health in cancer inequity during the first phases of the continuum of cancer control. It is based on a collaborative design oriented to equity; organized in a collaborative format; and work with communities. Eight health centers were selected through a strategic sampling that combined theoretical and empirical selection criteria. The populations of these communities have economic difficulties, low or no level of education and there were social problem scenarios in adverse environmental conditions. The strategy combined more specific forms of inquiry, mainly ethnography but also some other qualitative methods. These non-intrusive methods were enriched with the perspectives of the locals who were also researchers. The selected methodologies revisited in this essay tried above all, to respect and account for the particularities of the contexts, generating situated knowledge rooted in the realities for which this knowledge is intended. It concludes that the selection criteria of these methodologies are not only epistemological, but mainly ethical and political. They are chosen because they respect the needs of such communities with structural inequality conditions and led to relevant emerging topics of the living conditions in where participants had to live, the structural problems they had to deal with on a daily basis, and how they affected all the other parts of their lives, including health-care access.

Introduction

This case draws from findings of an ongoing long-term community-based participatory study anchor in low-income rural and peri-urban areas of Argentina, with the goal of identifying and providing insights into the role played by social determinants of health in cancer inequity during the first phases of the continuum of cancer control (health promotion and cancer prevention), addressing explicitly the need for an integrated and ethical approach to its methods and goals. Thus, the research aims to provide empirical evidence regarding the role of public health advocacy for health equity in practice, understood as the state in which everyone has the opportunity to attain full health potential and no one is disadvantaged from achieving this potential because of social position or any other socially defined circumstances [1].

Latin America has almost twice the overall cancer mortality than global north countries, and a greater proportion of the burden of morbidity, with inequities associated with this cancer burden [2]. Epidemiological data show that this panorama also occurs in Argentina, with a fragmented health infrastructure, limited health-care coverage, insufficient funding and human resources, heterogeneity in the distribution of them and insufficient implementation of cancer registries and national cancer plans [3]. Even when most of the determinants of health are outside the health-care sector, its role in tackling health inequities is widely recognized [4]. However, the role played by the first level of attention turned out to be an important determinant for explaining this gap, especially since it is much more easily modified than distal determinants, due to the fact that there are cancers that diagnosed in time are either preventable, such as cervical cancer, or treatable and curable if detected in early stages, such as breast cancer [2].

Research Design

The topic led us to engage with epistemologies action research that enable us to achieve this long-term purpose towards collaborative problem-solving in the quest for human rights and social justice through the coherent articulation of tools, protocols, designs, and the involvement of the study-subjects as active participants and co-researchers. McNiff and Whitehead [5] describe action research as a systematic inquiry with the collaboration of those affected, which enables changes to be

incorporated from within the group. The participants' points of view and tools enable them to record and objectify their daily practices. It is understood as the systematic and reflective study of own practices in the contexts of work and living places, with a special emphasis on actions and relations, and Lito identify those aspects that can be modified. Even though action research has a long history in social sciences [6-8], it is much less known or used within the mainstream public health arena.

There are many modalities of action research, and we decided on a collaborative design that implies three central elements: oriented to equity; organized in a collaborative format; and work with communities [9]. Among other positions also possible, we selected Riel's [10] definition of research teams as comprising external researchers working collaboratively with internal community researchers. In this way, collaboration implies an alliance between these internal and external researchers, which reduces the mistrust among parties involved during the whole cycle of the research, contrary to what happened in traditional positivist research with fixed and closed phases externally defined by the experts.

These types of designs cannot be fully anticipated in research protocols, and share characteristics with emerging designs, which are defined in dialogue with other participants [11]. There are open cycles in which those involved can discuss and modify the research design according to consensus, foundations and logics, taking into account issues such as identifying problems, the objectives to be addressed, which methods to employ, the type of analysis, access to sources of data, dissemination of findings, time and ways to close the research process. The research takes form while carrying it out and is aimed at carefully examining the evidence from multiple locations. It includes building channels for the flow of information demand in the different decision-making moments, establishing and redefining priorities together, with the aim being at community action [12].

Research Practicalities

As previously noted, a collaborative action research proposal sets, from the outset, different rules and facilitates a bond of mutual trust between the parties involved. In this project, the internal researchers were health-care personnel who also belong to the communities: Nurses, administrative staff and social workers mainly. The external researchers were professionals working in the academia sector, universities and research institutes. Both internal and external researchers work for the public sector.

Respect for the complexity of the contexts in which the phenomenon cancer inequities is anchored, was a priority of the research. Precisely to avoid replicated researches on access to cancer care and prevention programs designed and carried out for upper-middle-class contexts, primarily recognition of the specificity of the territories was addressed because the project was embedded within the margins of the social system, not only because many of the health centers were in remote rural areas but also because there were poor peri-urban neighbors of two large cities in a province of Argentina. Eight health centers were selected through a strategic sampling that combined theoretical and empirical selection criteria [13]. The theoretical criteria included indicators that represent aspects that had been marked as relevant to inequities in health from the models of social determinants of health perspective [14], such as socio-economic, environmental, cultural and epidemiological factors. The empirical criteria revised programmatic areas of the centers, geographical influence, population socio-demographic

characteristics and type/number of members in health personnel, etc. in order to make the health centers comparable.

Some of the principal features depicting these communities are that they are located in zones intersected by streams, rivers or lakes with pollution, territories with the presence of major rubbish tips, floodplains with the risk of imminent collapse due to geological faults (such as cracks), among other adverse ecological conditions. In terms of the infrastructure, there are marginal settlements with low-quality services (sewers into the street without evacuation systems, poor-quality drinking water, poor-quality housing, etc.). The populations of these communities have economic difficulties (unemployment, precarious employment, activities such as informal rubbish collecting, etc.), low or no level of education and there were social problem scenarios, such as high violence index rates (homicide and suicide), early deaths by firearms, consumption of illegal substances, juvenile delinquency, lack of public safety, among many others.

Method in Action

Kaplan [15] defines reconstructed logics as the evaluations of logic-in-use, which is the logic of research actually used. This reconstructed logic is the axis of this work, with special emphasis on showing the justification of the strategies chosen to build a type of knowledge that cannot, a priori, be reduced to categories by its complexity and uncertainty. This involved addressing the symbolic aspects of a phenomenon, the territoriality, the reproduction of everyday life, lifestyle and other constituent dimensions of the problems in context of inequality in Latin America.

Within the collaborative general strategy, we also combined more specific forms of inquiry according to the goals. In the first cycle we basically relied on reciprocal ethnography [16], institutional ethnography and ethnographic documentary, combined with some other qualitative methods (analysis of narratives, interviews with natural groups, audiovisual methods). We considered as a criterion for choosing these methods the unpredictability of these scenarios, with the need to know them in all their complexity, as also suggest by Foley and Valenzuela [17] from critical ethnography. The flexibility and openness toward what was emerging in the territories was a central component of the project, so in ethnography there is the possibility that the actors themselves were the ones who gave meaning to their practices in their everyday world and the contingencies of these lives in contexts of extreme vulnerability. In the first two-year cycle of the fieldwork we were able to get involved with key informants, define alliances with people ready to participate as internal researchers, establish a hierarchy of local priorities, identify emic or native categories, avoid issues that might be problematic to include for that specific community, and so on. In a second one-year cycle we also relied on institutional ethnography [18], since we needed to inquiry empirically with an analytic focus on the health centers, emphasizing the ongoing activities of personnel under precise actual material and symbolic conditions [19]. This method allowed us to detect the activities that took place in the institutions on a daily basis, within the framework of more limited times and institutional scenarios, as opposed to the ethnographic work in the districts, and with the focus on the work of the health personnel (professionals, administrative, etc.). One of the problematic issues that became apparent was the opening hours and services offered, which, while formally appearing as the norm, were, in reality, very different to what actually takes place in the health centers on a daily basis. This was of special concern and based on the profession's tradition of doctors' being at the health centre

for less than a quarter of the time actually demanded by the schedule. This was even worse in the case of directors, who rarely appeared except in specific circumstances, as we noticed in other studies [20]. We were made aware of this due to the fact that the team included internal researchers, colleagues who were in the health sector and knew perfectly well the reality of the situation is very different to what is seen on the surface. Due to the collaborative approach of the study they had the confidence to be able to reveal this, knowing what we would do with the findings. It is much easier to access experiences and what people really think if participants/researchers have control over the whole process, which includes dissemination and symmetries in the relationship. The main commitment was that this co-generation of knowledge would not expose them, and the inclusion of so many centers would be a modality with which to provide rich details but in a much more anonymized way when concerning sensitive topics such as this. On the contrary, visibility of their daily job and problematic encouraged collective publications, prior to consensus.

Through institutional ethnography we were able to detect and describe those routine practices that excluded or ignored the needs of specific groups of users and therefore produced and reproduced inequity in cancer care, which was the aim of our research. In our research, we identified that the priority target population in the first level was always focused on the care of pregnant women and mothers with their children, but very few or even none in most of health centers were targeted at older women, who were left out of promotion of health and prevention programs.

This method also led us to identify informants that we should decide not to include even if the protocol identified them as relevant. For example, during the research some professionals asked the administrative staff to change the patient's schedule so that the professional could participate in their search interview. In such settings of human resources shortage, rescheduling an appointment would imply at least a month's delay or longer for that patient. So, we decided as a team that those professionals unable to have the interview outside of working-hours would not be included.

That was with regards the professionals. In relation to the users of the health centers, when we arrived at the institutions we noticed that at certain times we could not do the interviews, due to the number of people coming together, the lack of space to maintain an intimate atmosphere, the lack of time, the number of health personnel circulating, among other things, and in these cases we gave up and returned to the fieldwork outside the institutions. Simply by walking through the communities, without any specific place to go, we could make contact with people in their homes: for example, that sitting outside drinking mate (type of tea) was an indicator that they might have free time. After chatting we would inquire about their willingness or not to hold an interview, without the constraints of the institution operating as a subtle factor of pressure to participate. Our goal was to understand the social world as an accomplishment of human actors. In these interviews and informal conversations, the only thing that we were faithful to was the person who gave us (or not) a space to share his or her life at a time to suit them, the hierarchy of relevant topics to be treated, etc. This meant we had to adapt and reformulate, in the field, multiple aspects of the protocol that we had formally presented to the university, health institutes and ethical board committees.

Participant observation and non-directive interviews main component methods in ethnography led us to relevant emerging topics of the living conditions in where participants had to live [21],

the structural problems they had to deal with on a daily basis, and how they affected all the other parts of their lives, including health-care access. Just to illustrate, it is worth mentioning the overflowing sewers through which faecal water streams flowed in one of the streets of the place, with boys running barefoot there, with open wounds and injuries to their legs from scratching or rashes; accumulated rubbish, with animals in poor conditions foraging there, and also people taking food for their own consumption, or for their domestic animals; Smokey and polluted air from burning rubbish, making the environment unbreathable at certain hours; the number of young people armed at an early age, without any formal employment and not in the education system, dedicated to the 'drug circuit' as the main activity for the provision of resources; concerns about vector-borne diseases such as mosquitoes, particularly dengue, in view of the amount of water accumulated in the ponds of the yards or houses without weeding; young people in a deteriorating condition as a result of the consumption of cheap drug mixtures called alita de mosca (a mixture of cheap drugs, also known in other places as paco); the hostilities between families that historically disputed the selling of drugs in the neighborhood, the number of undernourished children and many others.

These structural issues were exacerbated according to the circumstances, such as the impact of the change of government management in that is and the resulting political frameworks that according to the informants exacerbated the mistrust and violence of the area but that also affected our research, since in one of the centers the social worker who was also the director and an internal researcher of the team was replaced and the new direction no longer allowed us to continue our research there. The unpredictability of being able to anticipate what will be significant in these contexts is then compensated with these flexible, open and attentive methods to capture emerging themes and circumstances based on the inclusion of the local perspectives. An interesting example was how, by participating in the meetings of a communitarian network in which the local health centers, church, kindergarten, drug- prevention association and other institutions were a part, we found a crucial informant for the type of data we would not otherwise have been able to access. This person was the funeral worker, who was a privileged witness to the neighborhood events with relation to youth and violent deaths; he knew of the rivalries among 'gangs' and about the disputes derived from the sale of prohibited substances.

These non-intrusive methods of community dynamics enriched with the perspectives of the locals enabled us to investigate cancer in areas in which the health system usually did not do so because of the danger it entailed. So, even active health-promotion campaigns or 'rakings' (when nurses, doctors and social workers go to the homes in order to identify people not in the health system) would not be possible without a clear panorama of the context.

It is difficult to establish a priori an intensive research in the field, techniques and instruments for data collection structured. It is important to know first who will be the informants; the places included or left out. In one area, for example, there were 'black holes' where it was not possible to enter, even for the local people, due to the dangers of being assaulted, demarcated territorialities of different danger even within the same geographical zone. More often than not in this type of research you lose the focus, and that can happen even when researching cancer you can find yourself wondering what the funeral worker's perspective has to do with the research interest, but still, you stand firm and remain loyal to what is emerging.

It is important to know the specific epistemological foundations of the methods, but where exactly they might lead you is uncertain. That is why, even though you immerse yourself in the turbulent seas of these contexts of vulnerability, you are able to find the way out by keeping the goals present, as guides or "seat belts", but without any short-term anxiety or pressure as regards specific contents. In this particular case under revision, even in interviews that did not focus on cancer, important data sooner or later appeared information that turned out to be important in explaining the failures in the implementation of cervical cancer prevention programs at the first level of care, for example. One of these central findings came after almost one year of non-directed interviews, and it was the population's distrust of the public biomedical system. They knew not just perceived that they would receive lower quality medicine on the basis of negative experiences with public health institutions, which lead to a continuous discomfort and skepticism about what they can offer them. This negative evaluation that people have about biomedicine interventions in the contexts of poverty and multiple vulnerabilities can be illustrated in many different ways as it continuously appeared, as can be clearly seen from my personal diary transcription (2016): 'I had promised Nora to spend some time with her in the afternoon. After this year she and her family have been very close to me. Nora, who at 55, with 7 daughters, lived in front of the health centre where they perform free papanicolaou (PAP test), had never had one. During the hours of exchanges that we had, every time when I tried to find out why she did not take the text, having lost a sister from cancer, and insisting her own daughters to do it- which I had witnessed she always simply said: ´I haven't done it because…'. That day, we began to talk about everything, as always, without any specific topic: Work, family, and children. In that moment she began telling me about her eighth child, the one who was stillborn. Weighting three kilos at full term, she had no problems at all during pregnancy. [He was a] Chubby curly baby, beautiful', she said with emotion. For the rest of the conversation she spoke only of him, of that pregnancy, how good it had been until she entered the hospital when everything changed: the eternal waiting, the lack of beds, the lack of supplies, the mistreatment by the nurses because nobody had accompanied her, the doctor who did not show up until the last moment, the obstetrician who insisted on delaying the call to the doctor because she could manage the situation and more. From there directly to hell: The lifeless birth of the baby, the failed attempts at resuscitation, the explanations about the amniotic fluid that he had swallowed, and the most heartrending moment she had to go through when the lifeless body was delivered to her. "Me lo mataron" [he was killed] said before closing the conversation. That medical system that I had been asking for so many times previously, without getting any word. Finally, I understood her existential anger/hatred/distrust towards a system she identified as being solely responsible for that death.

Another method we used to examine the bureaucratic practices of these institutions was through the ethnographic analysis of the documents that these centers generated, such as the registration forms. The analysis of documents from an ethnographic perspective implies considering these documents not only as sources of data from which information is extracted, but also means constructing them as a field of inquiry and involves analyzing the context in which they were produced: The intervening actors, the underlying logic in their writing [22], how they are conserved, for how long, how they are filed, who is in charge of the filing, how they are circulated, whether they are accessible, how they relate inter-sectorially, what vocabulary and language they use, how they are updated, who controls them, what categories they use.

Unraveling the production context enables the tracking of the ways in which actors put into practice bureaucratic traditions and logics to build knowledge. This method was key in issues related to the reliability of the documents that we intended to use as a corpus to analyze how health centers monitored the health of the population. By combining this ethnographic analysis of documents with non-directive interviews with the health personnel, the analysis of the audiovisual material on these documents (registration forms, social histories, etc.) raised the problem of who registered [within the health centre], why they did so, and in which ways. Since some of the staff also worked as internal investigators it was easy for them to identify the issue of a general sense of distrust the personnel in charge of the registries had, because they did not trust who really benefited from this type of data generated by systematic registries of the institution. Nurses basically were the ones in charge, with only one health centre having administrative staff in charge. In these narratives it emerged that data were changed according to purposes; for example, because of external pressure as it would not be politically appropriate for that community that this information was known (such as high rates of a certain infectious disease, cases of low weight, etc.). In addition, through the analysis of the internal researchers' narrative I was found that data were frequently used as exchange goods and were only completed when they had to go to the provincial Ministry of Health when supplies were needed (e.g. gynecological consultation sheets for specula), therefore the registries were filled in a time when they were not always sure of the precise information and, although not very often, the staff have had to invent the information. There were also different criteria required for registering the same indicator. Therefore, working on these documents and registries but strictly monitoring the conditions in which they were produced 'from the internal researchers' examination, prevented us from including statistics that had such a low degree of reliability for the next cycles required.

Conclusion

The selected methodologies revisited in this essay tried above all, to respect and account for the particularities of the contexts, generating situated knowledge rooted in the realities for which this knowledge is intended, avoiding the fact that the population and their health needs would be defined from policymakers' desks. People should be a part of these processes of local knowledge generation through the use of horizontal methodologies [23], such as collaborative research. Although action research includes the understanding from the perspective of social actors, identifying from this constructivist lens the multiple possible realities, this type of research goes a step further on issues such as power, social hierarchies and the possibilities of transforming these into realities.

One of the central conclusions of these years is that no matter what methodological expertise external researchers have, nothing can guarantee what will work for the specific goals of research in such contexts, because the unpredictability inherent in the very flow of life in these scenarios is added to the delicate balance in which they take place. Therefore, there is no certainty about what will happen with such research goals, especially when indicators of extreme vulnerability are combined with respect to the environment, epidemiological profiles and socio-economic conditions of these populations.

In a previous article I discussed the need for the inclusion of these epistemologies in order to better understand why the inequalities in cancer care and cancer prevention occur and how they could be better reversed. Two years later I maintain that yes, it is generally the best option to focus on the investigation into the inequalities in cancer, but that is not always the case. There are occasions when, due to the complexity of the scenarios, the focus on cancer is lost, vanishes, or does not appear, perhaps, ever. The extreme fragility of each intervention we carry out as researchers, the contingencies that arise and the structural weakness of these places, transform them into 'minefields' in which the flutter of a butterfly wings can cause a tornado in other part of the world, as is often said in the theory of complex systems.

This delicate balance can be affected suddenly by a police raid, a wave of violent deaths, the literal collapse of infrastructure, a sudden epidemic by some vector out of control that adds to the deteriorated health conditions, among others. Therefore, can we continue to inquire about access to cancer-prevention programs when the health centers and the places where people live are suddenly threatened by an imminent collapse caused by a geological crack in which the political corruption, the lack of predictability and other factors were responsible for not having anticipated it (as is currently the case in one of the zones)? Is it possible to continue doing fieldwork in neighborhoods during periods of extreme turmoil which, in native terms, are transformed into a 'powder keg' in which the 'settling of accounts' arises between enemy families linked to drug trafficking, tightening their grip before the arrival of new 'dealers' to the area - threats, as happened two years ago in another of the communities involved in our research? In these circumstances it is hardly relevant to these communities to continue asking questions about cancer.

The main value of these methodologies is that they allow researchers to act according to the needs of the communities. By choosing them, at one point, it implies a belief in them, and this also includes their limits. The basis for this selection then is not only epistemological; it is mainly ethical and political. They are chosen principally because they respect the needs of such communities with structural inequality conditions. They are chosen because this type of knowledge protects participants from being used and discharged as happens in some methodologies in which 'researchers come, take our data and leave'.

Longer research times, specific topics of interest lost, relevant data and informants excluded due to certain non-academic strict purposes (such as avoiding internal researchers being identified), are only some of the methodological limitations. However, politically engaged researchers interested in issues of social justice an imperative when working within this scenarios need to take a step beyond simply adhering to a 'do not harm' ethical demand, and that is to advance the search for how to contribute to a society with greater equity, something that collaborative research has a long tradition of doing.

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