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To cite this article: Nils Graber (2018) An alternative imaginary of community engagement: state, cancer biotechnology and the ethos of primary healthcare in Cuba, *Critical Public Health*, 28:3, 269-280, DOI: [10.1080/09581596.2018.1440071](https://doi.org/10.1080/09581596.2018.1440071)

To link to this article: <https://doi.org/10.1080/09581596.2018.1440071>



Published online: 19 Feb 2018.



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An alternative imaginary of community engagement: state, cancer biotechnology and the ethos of primary healthcare in Cuba

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ABSTRACT

This paper analyzes a form of community engagement that differs from the way it is usually conceived and practiced in the domain of global health. This story takes place in the Cuban context and more specifically in a recent programme of oncology clinical trials implemented in primary healthcare (PHC) centres. By considering both the genealogy of this program and local interactions between PHC professionals and patients and their close relatives, I show that, in the context of Cuban socialist biomedicine, community engagement emerges as an implicit practice that forms part of the PHC professional ethos. I explore the ways cancer biomedicine is adapted in order to address specific needs and demands related to public acceptance of cancer in the Cuban society, diagnostic communication and palliative care. I argue that the way community engagement is enacted within Cuban socialist biomedicine is alternative to the global health dominant paradigm since it does strengthen existing relations between citizenry, health professions and public health infrastructures. Finally, by questioning the specificity of such socialist approach to community engagement, I suggest it greatly contributes to global health literature, because it creates continuity within existing state infrastructures rather than bypasses them, and, furthermore, offers a unique vantage on the treatment of chronic disease.

ARTICLE HISTORY

Received 31 May 2017
Accepted 6 February 2018

KEYWORDS

Cuba; community engagement; clinical trials; primary healthcare; cancer biotechnology; Socialism

Introduction

In 2009, one of the main Cuban biotechnology centres – the Center of Molecular Immunology (CIM¹) – partnered with the Ministry of Public Health (Minsap) to launch a clinical trials pilot-programme. This programme was designed to test locally developed cancer immunotherapies – i.e. treatments that act upon the immune system to destroy tumour cells – in primary healthcare (PHC) centres called ‘poly-clinics’. The programme consisted of what local researchers term ‘pragmatic’ clinical trials designed to assess not only the effectiveness of the treatments but also whether cancer care could be integrated into the polyclinics, while oncology had previously been exclusively practiced in hospitals. The trials aimed to develop a strategy for implementing cancer immunotherapies in about one polyclinic per municipality (about 124 institutions) on the island. They would permit thousands of patients to access these cutting-edge drugs close to home. Furthermore, PHC practitioners, namely family doctors and nurses, who are trained to adapt their practices to people’s needs by living in community settings, would administer the treatment (Brotherton, 2012; Feinsilver, 1993).

I attempt to shed light on the form of ‘community engagement’ taking place through these PHC oncology trials in Cuba. I suggest that these engagements differ from the ways the term is usually conceived and practiced in global health research. There, community engagement usually takes place in the context of transnational research projects and humanitarian interventions marked by long histories of colonialism and exploitation (King, Kolopack, Merritt, & Lavery, 2014). In order to establish the legitimacy and efficiency of research projects, community engagement is intended to foster ‘dialogue’ with targeted communities, which is then (theoretically) fed back into the project design and implementation (MacQueen, Bhan, Frohlich, Holzer, & Sugarman, 2015). Although bioethical literature on community engagement attempts to avoid a reification of the notion of ‘community’ by considering a plurality of ‘stakeholders’ with different interests and values (King et al., 2014; Lavery et al., 2010), a feature of community engagement that is often overlooked is the way in which it often brackets off ‘the community’ from state institutions (Pfeiffer, 2003). This draws on a more general conceptualization of global health as a field of research and interventions that emerged in the late 1990s by replacing the old regime of ‘international health’ (Brown, Cueto, & Fee, 2006), and is now characterized by the dominant role of the World Bank, international NGOs, university lead programs, philanthropic organizations, and private firms (Birn, 2014; Lakoff, 2010). Even if global health interventions attempt to be responsive to communities’ needs and foster ‘civil society’ participation, ethnography-based scholarship has shown that such interventions usually take place within short-term programmes, where coordination with local health professionals and institutions is weak, producing a fragmented healthcare systems in many Southern countries (Crane, 2013; Pfeiffer, 2003). Furthermore, global health interventions tend to focus on ‘technology delivery’ with a poor understanding of people’s social life, temporalities and ‘local knowledge’ (Adams, Burke, & Whitmarsh, 2014; Biehl & Petryna, 2013). As part of a neoliberal agenda ushered in by ‘structural adjustment’ in the 1980s, global health interventions have favoured market-based reforms over state-run public programs (Pfeiffer & Chapman, 2010; Prince & Marsland, 2014).

I explore the distinctive form of community engagement at stake in contemporary Cuban biomedicine and its linkage with state socialism. Socialist and post-socialist health contexts have been widely overshadowed within global health literature. Perhaps this can be explained by Cold War representations that reified a binary opposition between ‘socialist’ and ‘capitalist’ societies (Geltzer, 2012; Vargha, 2014). Indeed, scholars have shown how in post-soviet countries global health programs were explicitly attempting to eradicate socialist state legacies envisioned as essentially authoritarian and repressive (Keshavjee, 2014), sometimes associated with ‘community participation’ models to ‘export democracy’ (Atlani-Duault, 2008; Koch, 2013). To that extent, Cuba, its so-called ‘medical internationalism,’ its local biotechnology industry giving priority to address national needs (Reid-Henry, 2010), and its commitment to a universal healthcare system based on PHC has a unique place within health globalization (Burke, 2013; Graber, 2013). In a Cuban context, communities are defined at the level of neighbourhood (*barrio*), which is not only an administrative unit, but a central place of social life where people share a common experience of the health system (Brotherton, 2012; Gibbon, 2013). Each neighbourhood includes a health office (*consultorio*) where a family doctor and nurse work, and frequently live. They are usually perceived as part of the community by local people (*ibid.*). While existing scholarship has shown how communities are deeply entangled within state health infrastructures, the way they are engaged remains unclear.

Following Kelly (2011), I consider the PHC cancer immunotherapy clinical trials as a ‘public experiment’ that transforms PHC infrastructures through the process of inserting and assessing oncology innovation. I will show how community engagement is enacted by PHC professionals in their attempt to constantly adapt cancer biomedicine to the communities’ needs. I argue that this form of community engagement represents an alternative imaginary to the one fostered in the global health context because it is building upon existing configurations of care, medical citizenship, health professions, and state infrastructures. By focusing on the ways PHC professionals adapt cancer biomedicine to local people’s needs, in a context of scarce resources, I follow Livingston’s (2012, p. 96) argument about the professional ethos of care that does not only reflect an ethical dimension, but also a political one that prolongs the ‘commitment of the state to care for its people.’ This article is organized in two parts. First,

by outlining the genealogy of the PHC oncology clinical trials, I show how this programme, which is enmeshed within the PHC professional ethos, implicitly integrates community engagement. Secondly, I present ethnographical material that sheds light on the ways family doctors and nurses set the conditions for the emergence of new individual and collective cancer experiences, in a context marked by both pervasive paternalism and cancer stigma (Gibbon, 2011, 2013). Moreover, I emphasize the PHC professionals' engagement with community to provide continuity between curative and palliative care. To conclude, I discuss the differences and overlap between the form of community engagement I have explored in the context of Cuban socialist biomedicine and the global health paradigm.

Methodology

This paper draws on research (between 2014 and 2016) conducted on the trajectory of cancer immunotherapy in Cuba. It is an ethnography of PHC clinical trial implementation. Hosted by the Cuban National Institute of Oncology (INOR), my research contributes to local efforts to understand the impact of this 'process,' by considering social aspects of institutional change, professional relations, and the experiences of PHC practitioners, patients and their families. I collaborated with the Health and Technology Assessment (HTA) team at the Centre of Molecular Immunology (CIM) that implemented social epidemiology approaches focusing mostly on assessing efficacy and ensuring product delivery. I conducted 58 interviews (33 recorded) related to the PHC clinical trials: 7 with oncologists, 8 with CIM researchers, 3 with public health and regulatory authorities, 22 with PHC practitioners (7 doctors, 7 nurses, 4 psychologists and 4 laboratory technicians) and 16 with patients (8 included at hospitals, 8 at the polyclinics). The PHC sites were selected according to direct relations I established with PHC practitioners during meetings and workshops about the trials. I was also able to undertake observations of consultations at both polyclinics and hospitals. Ethical clearance was obtained at both my host (INOR) and home institution (XXX). In an attempt to grasp territorial differentiation, about half of the data were collected in Havana and the remaining in the provinces of Villa Clara and Santiago de Cuba. The material was analyzed according to a biosocial medical anthropology perspective in order to understand how local practices within an on-going process are providing new accounts of wider politico-economical configurations of global health (Janes & Corbett, 2009).

The PHC oncology clinical trials: professional ethos and institutional framework

Community engagement in Cuba: from mass-mobilization to a community healthcare ethos

Since the Cuban revolution in 1959, community engagement has been a core component in the building of a national health system guided by socialist development vision that was grounded on the principles of health as a human right (WHO, 1975). Yet, community engagement has taken different forms. In the first two decades of the revolutionary era, health development politics were inspired by the Soviet health system and relied mainly on a mass-mobilization model (Feinsilver, 1993). First, the national health system was built through the training of a huge numbers of health professionals that were sent to rural areas to build basic medical infrastructures – often from scratch. Second, the whole Cuban population was mobilized through newly established revolutionary 'mass organizations'² to build health infrastructures and implement prevention campaigns like vaccination (Beldarraín, 2013; WHO, 1975). Under the mass-mobilization model collective efforts were limited to the efficient delivery of healthcare services on the island and were frequently expressed by military metaphors like 'the battle against dengue' or the creation of an 'army of white coats' (Feinsilver, 1993).

Community engagement took on another dimension in the 1980s with the creation of the 'family doctors and nurses' program' (*Médico y Enfermera de la Familia*, MEF). The MEF programme initiated the creation of *consultorios* or neighbourhood health offices, responsible for the health of an 'area' of about 120 households. This model relies on the *sectorialization* of the national health system: each consultorio is linked to a polyclinic, which is further linked to a hospital³. However, in the MEF model, 'community'

does not only refer to a target population of healthcare delivery. Rather it is defined above all as a singular group of people sharing a common experience in a territorial unit (Brotherton, 2012). Following the Alma-Ata Declaration's principles, the MEF programme builds on a holistic conception of health and a participatory approach to adapt healthcare to local communities' needs (Feinsilver, 1993; Reed, 2008). Formal participation was promoted by the inclusion of 'community representatives' within PHC advisory boards that organized health services planning and implementation. Board representatives were usually elected members of the 'Neighbourhood Popular Councils', instances created in 1976 as the local basis of political power (Feinsilver, 1993, p. 81).

Besides a formal participatory framework, the MEF program permitted the stabilization of the *PHC professional ethos*. Considered as a practical feature rather than an explicit set of rules, the professional ethos is acquired through training and everyday practice (Fassin, 2008). By initiating the specialty of 'Integral General Medicine' (MGI) as a mandatory diploma in medical training, which includes a residency at a consultorio, the MEF program made the doctor community-patient relationship a central feature of PHC (Brotherton, 2012). In daily practice, family doctors and nurses conduct at-home visits to carry out epidemiological surveillance and attend to the social environment of sick persons (by considering the family context, housing situation and socio-economic situation among others dimensions) (Batista Moliner & González Ochoa, 2000). As anthropologists pointed out (see Andaya, 2009; Brotherton, 2012; Gibbon, 2011, 2013), family doctors are frequently granted a status of local leader due to their prestige and knowledge of neighbourhood life. Thus, perceived as role model, they foster informal forms of participation to voice communities' concerns about medical and non-medical problems (such as housing, street cleanliness, delinquency, etc.). Another aspect of the PHC ethos is multidisciplinary practice: each community is followed by a 'basic work group' (*grupo basico de trabajo*) composed notably of a general practitioner, a nurse, a gynaecologist, a psychologist, a statistician and a social worker.

In the Post-Soviet era, marked by the 'Special Period' crisis of the 1990s (when the economy collapsed and the US reinforced its embargo), the whole public health system was threatened. Until today, there have been pervasive shortages and a surge of social inequalities that have affected the state's ability to meet local needs and demands considerably. Nevertheless, the public health infrastructures and PHC ethos have remained, which may explain why the main health indicators did not deteriorate (Spiegel & Yassi, 2004). Furthermore, my ethnography, which coincides with precedent anthropological work, indicates that the Cuban population still perceives family doctors and nurses as part of their community. As scholars suggest (Andaya, 2009; Brotherton, 2012), in the Post-Soviet context, the fact that relationships between doctors and communities were increasingly marked by an economy of 'favours and gifting', has perpetuated the PHC ecology rather than undermined it.

In the current context, formal community engagement frameworks, such as the mass mobilization one or the more participatory one linked to the Alma-Ata Declaration, are still at play in the Cuban health system. Yet, they are mainly taking place in infectious disease management, especially in the 'fight' against mosquito-borne diseases (Brotherton, 2012, pp. 125–127; Sanchez et al., 2009). However, in the case of chronic disease management, particularly cancer, I suggest that community engagement in Cuba finds its most powerful expression as an implicit practice forming part of the PHC professional ethos that is enacted in the direct relations between PHC practitioners, patients and their families.

'Bringing cancer biotechnology to the street corner': an implicit form of community engagement

Launched in 2009, the PHC oncology clinical trials sprang from a new Comprehensive National Cancer Control Program (PICC) implemented in 2004 to strengthen, among other things, the integration of the national biopharmaceutical industry with the whole health system, including at the PHC level (Romero, 2009). This strategy addresses problems of access to cancer care in a context dramatically marked by transport difficulties and a lack of imported technology inherited from the Special Period crisis. While the PHC level had already been involved in cancer prevention and screening, the PICC's novelty is treatments within polyclinics.

The PHC oncology clinical trials programme was designed by the CIM in coordination with Minsap as an innovative public health experiment attempting to transform advanced cancer into chronic disease manageable at the level of PHC (Lage & Crombet, 2011). It is grounded in cancer immunotherapies, a field the Cuban biotechnology industry has investigated since the 1980s (Lage, 2008; Reid-Henry, 2010). Currently, CIM produces both ‘therapeutic vaccines’ – generating cancer antigen-specific immune reactions – and monoclonal antibodies targeting tumour biomarkers. Until today, three PHC cancer protocols have been carried out; all test locally developed biopharmaceuticals for advanced (metastatic) non-small cells lung cancer (NSCLC). This choice was mainly informed by public health objectives, because lung cancers account for about 20% of the overall mortality by cancer in Cuba (Minsap, 2014). Considering the lack of accessible treatments for NSCLC, especially in developing countries, this focus is also informed by CIM’s exportation strategy. This programme highlights the ‘socialist’ dimension of the Cuban biotechnology industry, which relies on the articulation between market-driven exporting strategies and public health programmes at the national level and through South–South agreements (Reid-Henry, 2010). Regarding the PHC oncology clinical trials, a CIM’s executive expresses its political mandate in the following terms:

A [private] firm is not interested in evaluating the effect of its drug in an open-population. Furthermore, I have always said that the difference between CIM and a pharmaceutical firm is that...stock exchange restricts to approve a drug and then sell it, it does not care about *coverage* and or *social benefit* [my emphasis] neither do they care about reducing mortality. No. Our goal is really that in Cuba people will die less from lung cancer, knowing it is the first cause of death ... (...) We need to reach to make compatible chronic treatment with quality of life and considering the insertion of the patient in its work, social, and familiar life. Then it’s why we need to bring it to the street corner with a very safe drug ...

The CIM executive emphasizes the industry engagements necessary to conduct phase IV clinical trials, which are post-approval protocols designed to assess the impact of a drug in the ‘real-life’ settings as opposed to the standardized procedure of classical randomized clinical trials (RCT). For trials in an ‘open-population’, there is no predefined sample’s size limit and inclusion criteria are expanded to include elderly patients suffering from co-morbidities who are usually excluded from RCT. Such trials are rarely conducted by private firms, since they usually do not provide economic value (Davis & Abraham, 2011), but are used in global health programs (Montgomery, 2017). In the interview, the executive expresses CIM’s political mandate through a commitment to ensure ‘population coverage’ and to ‘bring’ the product within patients’ social environments. Furthermore, the excerpt emphasizes the importance of developing drugs that are very safe and can be delivered in the health system, including PHC. This shows how the industry is concerned with the products’ quality and delivery. The team of social epidemiologists at CIM, with which I collaborated as a social scientist, is dedicated to evaluate the drugs’ impact in terms of effectiveness and coverage. These researchers, who conceived the protocols in collaboration with oncologists and Minsap’s experts, do not promote community engagement as an explicit feature. Rather, community engagement is envisioned as an implicit practice enacted by ‘bringing’ therapeutic innovations to PHC professionals.

A professional demand to ‘treat cancer patients in the community’

A key component of the new PICC, one that was pivotal for building capacity for the PHC oncology clinical trials, was the creation of a Certificate of oncology for PHC professionals (*Diplomado Básico Nacional de Control del Cáncer*). The certificate began as a pilot program in 2007 in Havana and centred on prevention, screening and palliative care. From 2009 it expanded to include clinical trials and basic oncology. Health authorities sent a call for application in every polyclinic selected for the trials to establish a ‘PHC research team’ composed of a family doctor, a nurse, a psychologist, a pharmacist and a laboratory technician. Hundreds of PHC professionals applied to the certificate program, which highlighted the demand for learning more about cancer care. Thus, a family doctor involved in the trial explained:

In the medical training there is nothing, no specific program on the cancer theme. Then, really every doctor, when you graduate, when you are in the *consultorio*, you begin to see patients who really have cancer. They are in their household, at home. This is why it was a demand of knowledge as such from family doctors, to know something related to cancer in order to treat these patients that you have in the community.

This excerpt emphasizes the demand by PHC practitioners for specific knowledge and tools to care for cancer patients whom they follow at *consultorio* and polyclinics. The doctor points to the paucity of cancer care training in the general medical education. Until very recently while the general practitioner specialty (MGI) emphasized community healthcare it did not prepare practitioners to manage cancer patients. Cancer was exclusively envisioned as a set of diseases requiring complex technology and invasive treatments circumscribed to the spaces of specialized services at hospitals or research institutes. PHC practitioners frequently expressed a prevailing ‘fear’ of cancer patients, which points to the wider ‘cultural stigma of cancer’ in Cuban society that Gibbon explores (2013, p. 13) in her ethnography about community genetics of breast cancer on the island. In my hospital ethnography, I also found a strong ‘paternalism’ in Cuban oncology: patients are often not informed when diagnostics reveal malignancy. Oncologists frequently justified this non-communication of the diagnosis (or at least euphemization) with reference to the common belief among patients that ‘cancer equals death’. Informing patients about a serious condition could lead to a trauma, depression or even suicide. At the same time, however, oncologists systematically inform patients’ family members about the diagnosis (and usually prognosis). As it has been showed elsewhere in the Global South (Sariola & Simpson, 2011), ‘medical paternalism’ and ‘family-centredness’ reveal other conceptions of the human subject often at odds with Western biomedicine’s ‘autonomous agent’.

In Cuban socialist biomedicine, paternalism could seem a normal and desired feature, as the state emphasizes its responsibility to preserve and better the health of its citizens. My ethnography in polyclinics sheds light on a more complex picture: the PHC professionals are enacting community engagement with the intent build new individual and collective experiences of cancer that transcends cancer stigma and challenges paternalism.

Local practices of community engagement: integrating cancer chronic treatment within the PHC

The vaccine form: normalizing the figure of the cancer patient through technology adaptation

In the main corridor of a polyclinic in Old Havana, I am waiting for Dr María,⁴ the family doctor in charge of a cancer clinical trial who offered me the opportunity to be present at her consultation. She proposed that I sit next to the vaccination room (*vacunatorio*), the place where she will attend the patient, who is a bit late today. I am surrounded by young children accompanied by their mothers, waiting to be vaccinated against infectious diseases. The nurse at the *vacunatorio* calls them one at a time, which generally provokes the shouts of the toddlers. Suddenly, Dr María comes back, accompanied by an old lady, who is having trouble walking. She is giving one arm to the doctor, the other to a man, probably her son. They slowly enter the *vacunatorio* and María invites me to follow them. I begin to talk with the patient and her son while the nurse is preparing the intravenous infusion of the monoclonal antibody Nimotuzumab. While she is being injected with what is termed a ‘serum’ (*suero*), Josefina, the old lady, explained to me how her life was shattered when she was diagnosed with ‘such a disease’ two years ago at a hospital. The interview is interspersed by the children shouting as the nurse continues to vaccinate next to us. (*Fieldnotes, Havana, January 2016*)

At first glance, this observation seems to show that cancer immunotherapy is administered in a way that echoes the prophylactic vaccination model – long-standing PHC interventions familiar to the Cuban population.⁵ The treatment is administered in the *vacunatorio*; the nurse who administers the cancer biological to the elderly woman is also the one who vaccinates children. The substance administered was not really a cancer ‘therapeutic vaccine’ (see Lage, 2008), which is injected intramuscularly like a prophylactic vaccine, but an intravenous infused monoclonal antibody. Yet, its effect was also referred to as an ‘immunization’. In spite of these several analogies, the way cancer immunotherapy is administered

to Josefina substantially differs from the way the young children surrounding her are immunized. While the toddlers are the passive targets of a mass vaccination campaign, the woman is an active actor of her treatment who can negotiate its meaning and its modes of administration.

Josefina is aware that the vaccine is a *therapeutic* one, which is treating but not preventing cancer. As we initially talked in an elusive way about her 'disease', she explained to me that she never smoked but that her husband did, and added: 'I am part of the passive smokers who get lung cancer.' Using the term 'cancer' in this consultation, next to young mothers and children, she is making the disease and her illness publicly visible and meaningful, which overtakes the cultural stigma of cancer as a disease equating death. The vaccine form, which makes the treatment familiar and understandable by echoing prophylactic vaccination, contributes to instilling a new representation of cancer as a disease that can be 'controlled' through repeated 'immunizations'; Dr Maria proudly indicated to me that Josefina is getting her 'number 12', which means she has been included in the protocol now for about 24 weeks.

This excerpt also shows how acts of 'tinkering' (Mol, Moser, & Pols, 2010) are used to integrate cancer immunotherapy within the socio-spatial dynamics of polyclinics, which facilitates the normalization of the figure of the (lung) cancer patient within the community (including young mothers and their children). In such settings, patients' demands are more likely to be met than in the highly structured space of a hospital's oncology service. Thus, as Dr María explained to me later, she usually tries to conduct oncological consultations at another room in the basement of the polyclinic, behind closed doors, in order to get more privacy. But given that Josefina prefers the *vacunatorio*, because it is more easily accessible and of its public dimension, Dr Maria was willing to respect her wish.

Therapeutic vaccination, then, is not implemented as part of a vertical program designed to target a specific disease, as is common in mass-vaccination campaigns (Wailoo, Livingston, Epstein, & Aronowitz, 2010), but as a negotiated intervention, shaped by both past interactions between PHC professionals, cancer patients and the wider community of people at the polyclinic. As an implicit practice embedded within care interactions, community engagement is going beyond the national industry's political mandate to delivering efficient and safe drugs. Dr Maria is adapting biomedicine to make cancer an understandable and accepted disease within the community that is bound to her polyclinic.

Dr Flora's huequito: fostering the emergence of a community experience of cancer

At a polyclinic situated in a working-class suburb in Eastern Havana, I met Dr Flora and two of her patients included in the PHC clinical trial. Dr Flora has been a family doctor here for more than twenty years and still works at a *consultorio* located in the same neighbourhood where she lives. She and her patients call the place where the clinical trial take place their 'small corner' (*el huequito nuestro*). Because there was no consultation room available in the polyclinic, Dr Flora managed to set up a specific consultation in two small abandoned administrative offices in the polyclinic's backyard. She moved some old benches onto the patio to make a waiting room. One office is designed for vaccinations and the storage of medical records and protocols. The other is not only set up as an oncology consultation room (where walls are covered by cancer prevention messages and posters), but as a more intimate place with Flora's souvenirs and family photos on the shelves, and a Cuban coffee maker. Dr Flora's *huequito* highlights local initiatives by PHC professionals designed to re-arrange often-scarce clinical resources and spaces to produce a community experience of cancer. It is a semi-open place, suited to patients and their relatives, but also to other people from the neighbourhood who are worried about having a cancer (Flora usually receives them before the clinical trial's consultation).

The following excerpt of fieldwork's notes sheds light on how the cancer patients' voices are expressed and promoted at the *huequito*:

Jorge, a former technician, is 58 years old and has received the therapeutic vaccine Cimavax-EGF for 6 years. He is one of the oldest survivors of the clinical trials. Rogelio, a thin old man who still works as a carpenter, has been included for two years in another protocol (a phase III non-inferiority trial), in which he has been randomly allocated to the arm receiving a monoclonal antibody.

The two patients are talking together with me about the conflicting situations with their family regarding diagnostic communication and therapeutic decisions. Rogelio really learnt that he had lung cancer when he was asked to participate in the clinical trial by his oncologist. His family did not want to include him, thinking that the chemotherapy and radiotherapy cycles he had previously received were enough. He decided to include himself despite his family's reticence. He signed the consent form protocol and asked a neighbour to sign it (as it is required to get a witness signature). After having started the treatment at the polyclinics, Dr Flora asked to meet his family members in order to explain to them the aims and process of this clinical trial. But even if they understand better, they still do not accompany Rogelio to the consultations.

Rogelio said to Jorge: 'They could not, they had to accept what I said. This is normal. This is me struggling for life. You cannot let me die!' Jorge answered him in a more nuanced way about patient autonomy. He says: 'In some cases it can be negative, in others positive. It depends on the person's conscience. Do you understand? It depends of how you are prepared, of your psychology, your constitution!' Jorge explains that he was himself 'not prepared to know' he had cancer when he was at the hospital receiving chemotherapy. He could really accept the diagnostic when he came to Flora's consultation. (*Fieldnotes, Havana's Eastern suburb, May 2016*)

Flora's *huequito* showcases how a form of community cancer care is established through PHC practitioners' local initiatives to arrange new social clinical spaces. The conversation between Rogelio and Jorge draws attention to the different perceptions of notions such as 'autonomy' or 'collective ethics' among Cuban patients. In Rogelio's case, the informed consent, as a device centred on autonomy principles as opposed to 'family-centeredness' ethics (Sariola and Simpson, 2011), represented an opportunity for self-affirmation against his family's will. Conversely, Jorge considers it unethical to reveal the cancer diagnosis to a sick person who is not 'psychologically' prepared. In his case, informed consent was not of any help; he could only accept the disease through a spiritual practice (meditation) but also through the interactions at Flora's *huequito*, with both his her family doctor and other patients.

Despite their contrasting views on medical paternalism, Jorge and Rogelio value Dr Flora as a mediating figure. In both cases, Dr Flora plays a crucial role by engaging intra-familial tensions and personal trauma caused by cancer diagnosis and treatments. By exploring each situation's medical and social components, she helps patients become actors beyond the formal informed consent. It is important to stress that the enactment of the PHC professional ethos is facilitated by structural factors. For example, family doctors were allocated a specific time slot, about one day per week, for clinical research and they usually have more time per patient than hospital oncologists. This invites us to consider medical paternalism in a more nuanced way, particularly in the context of severe diseases such as cancer, as intrinsic to the asymmetry that defines any relation of care (Livingston, 2012, 164–166). Thus, the way Dr Flora performs community engagement is not neutralizing the asymmetry of care, but is clearly challenging the paternalism that prevails in Cuban oncology by adapting care to each situation and facilitating interactions between cancer patients and the wider community.

From 'chronic' to palliative treatments: engaging to ensure continuity of cancer care

Chronic diseases affect people throughout their life through periods of stability, acute crisis and slow deterioration, which requires constant adjustments of treatments and relations with their social worlds (Strauss, 1975). In the context of cancer, a usually lethal disease, Baszanger (2012) shows how chronicity is shaped by multiple, uncertain and often invasive interventions that constantly redefine the frontier between curative and palliative care. In the recent trend towards chronic disease management in global health, Whitmarsh (2013) argues that compliance is a central feature, which consists in disciplining patients in order to adapt to new therapeutic regimens. In the context of the Cuban PHC clinical trial, I show how PHC practitioners are enacting community engagement to adapt biomedicine to people's needs, and, by doing so, ensure continuity of care from chronic treatment to palliative care.

My ethnography shows how PHC professionals are adjusting or even bypassing the clinical trial's protocol to address specific demands linked to a chronic cancer management. When the patient could not come to the consultation, because of his/her deteriorating state or because his close relatives were temporarily unable to transport him/her, the family doctors agree to delay the treatment. Furthermore, in the interviews, many family doctors and nurses mentioned that they 'vaccinated' patients' at the

consultorio, or even at their home. Other types of adjustments were related to the reduction of the frequency of immunizations because of chronic pain in the injection sites. Reported to clinical trial manager as ‘small protocol deviations’ since they were planned by the trial, such adaptations were usually coordinated with the hospital oncologist. These practices highlight how PHC professionals adapt care to the specificities of chronic disease temporalities. Thus, they conduct activities that are typical to their professional ethos, such as at-home visits and educational activity.

Lisa, a nurse in an Eastern province, decided to set up ‘educative speeches’ (*charlas educativas*) at the polyclinic for patients, their relatives, and neighbours interested in the themes of the talks. She told me that for her: ‘the clinical trial is not just about the vaccine but is also a community activity’. The main goal of the educative speeches is to inform patients and their relatives about the risk to which chronic lung cancer patients are particularly vulnerable at home: dust, and smoking (that can exacerbate respiratory failure), but also diseases transmitted by mosquitoes (that can easily kill immune-deficient persons). While these educative sessions coincide with both the mass-mobilization and the current global health framework of educational health designed to discipline behaviours of chronic patients (Feinsilver, 1993; Whitmarsh, 2013), they also create a space where lung cancer patients can interact with other members of the community. In effect, some sessions are dedicated to lung cancer, and patients are invited to provide testimonies of their disease experiences. Furthermore, Lisa joyfully mentioned me that the local PHC research team organizes ‘vaccination birthday parties’ at the polyclinic, when patients reached one year of survival in the clinical trial.

Lisa’s case shows how the form of community engagement that PHC practitioners perform through activities goes beyond the clinical trial’s implementation to meet chronic cancer patients’ needs. They also pursue engagement when patients are withdrawn from the protocol due to deteriorating health status. Most family doctors and nurses I interviewed told me that when the patient is withdrawn from the protocol, they accompany him or her until their final days, even if it is not part of the task of the PHC research team. As it is planned by the health system, it should be the *consultorio*’s team that should provide palliative care to the cancer patient with some support provided by polyclinics’ and hospitals’ specialists (Figueredo Villa, 2011). Yet, as the *consultorio* team is generally not trained to follow terminal cancer patients, and overwhelmed by other activities, patients must go to the hospitals, where there is no specific structure for palliative care. Thus, by accompanying patients beyond the protocol, the PHC professionals involved in the clinical trial create a continuity of care from chronic treatment to palliative care through engagement.

Conclusion

In this paper, I have attempted to capture the forms of community engagement in a PHC oncology clinical trials taking place in contemporary Cuba’s socialist biomedicine. Although community engagement is not a formal component of the clinical research programme, I have shown how it is performed as part of the PHC professional ethos as an implicit practice enacted by family doctors and nurses through local initiatives at the polyclinic level. By engaging communities in the course of the trial, PHC practitioners build an emerging form of community cancer care in a context of prevailing paternalism within Cuban oncology that provides both moral and political dimensions of care (Livingston, 2012). Thus, my findings extends Gibbon’s argument (2013), that PHC professionals are conferring another meaning to Cuban state socialism, as a biopolitical regime not only based on paternalism and egalitarian delivery of social goods (as in the mass mobilization model), but also on individual and communities’ capacities to reshape and transform health politics.

To some extent, the form of community engagement I have explored overlaps with existing practices within global health research projects. As historians of scientific and medical relations during the Cold War era argued (Geltzer, 2012; Vargha, 2014), it is crucial to avoid reproducing essentialized oppositions between socialist and capitalist societies. As showcased in Dr Flora ‘small corner’, the family doctor is attempting to reconcile the biomedical autonomous subject with more collective forms of personhood, a stake described in other Global Health contexts (Sariola & Simpson, 2011). Bioethical approaches on

informed consent attempt to take into account these local conceptions of individual and collective ethics (Lavery et al., 2010). Lisa's 'educative speeches' can also be related to 'community activities' designed to provide 'information' promoted by global health projects (*ibid.*). However, I have argued that the form of community engagement taking place in Cuban socialist biomedicine is alternative to global health's dominant paradigm because it builds upon and strengthens existing infrastructures of public health. It is not undertaken as a bounded set of activities disarticulated from local health research and local public service delivery as is frequent in global health interventions (Biehl & Petryna, 2013; Crane, 2013; Pfeiffer, 2003). When PHC practitioners practice community engagement to promote patients' self-affirmation, they reproduce the state idea that family doctors and nurses are among the actors most entitled to represent communities' interests. When Dr Maria is making the cancer treatment understandable to patients by echoing prophylactic vaccination, she is creating continuity between state dedication to eradicate infectious diseases and its commitment to offer innovative cancer treatment at the level of PHC. Even if Dr Flora built her *huequito* in the polyclinic's backyard because there was no adapted consultation room available in her polyclinic, she created a cancer consultation place open to other people in the neighbourhood. While global health research projects frequently produce 'material artefacts' that will not last after the intervention (Kelly, 2011; Montgomery, 2017), PHC professionals are performing community engagement to integrate oncology innovation to the PHC infrastructures and the local ethos of care. Thus, they are contributing to building a new form of cancer ambulatory treatment that integrates chronic treatment and palliative care. Given the still emerging trend toward chronic diseases in global health (Livingston, 2012; Whitmarsh, 2013), the Cuban experience in PHC cancer clinical trials offers a novel perspective on community engagement in the field of oncology, one that constantly attempts to adapt the biomedical machinery to both existing public health infrastructures and people's needs.

Notes

1. All acronyms for Cuban institutions are in Spanish.
2. Among others, this includes the Committees for the Defence of the Revolution (CDR), the labour syndicates or the Federation of Cuban women.
3. In 2014, there were 11'550 *consultorios*, 451 polyclinics and 152 hospitals on the island (Minsap, 2014).
4. All the names are pseudonyms, yet reflecting gender.
5. Cuba has one of the largest vaccination programs in the world, covering against 13 diseases (see Lage, 2008).

Disclosure statement

The author reports no conflicts of interest.

Funding

This work was supported by the Institut Francilien Recherche Innovation Société (IFRIS) [Mobility grant]; Institut National Du Cancer (INCa) [PhD scholarship]

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