

The transformative potential of health as a commons

O potencial transformador do comum em saúde

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ABSTRACT Italy was a participating country in the People's Health Movement multi-centred action-research project (Civil Society Engagement for Health for All). The Italian team, a collective named Grup-pa, undertook several participatory action-research activities including, in a first phase, a mapping of groups active in fields linked to the social determination of health and health promotion, through individual and collective interviews. In a second phase, three public workshops, structured around the exchange of practices, focused on key themes emerged from phase one. A major construct originated from this work, centred around the co-construction of experiential knowledge on health as a commons, has been named 'health commons practices'. The focus on practices is not merely strategic (producing synergies and alliances), but inherently political (conceiving participation as a value) and connected to health and staying healthy (as individuals; as a community). The construct of 'health commons practices' is meant to make visible an area of ongoing transformations in new spaces created by movements and in more traditional actions in defence of existing public services, addressing health as a socio-political issue. In this essay, we sketch the reflection around six keywords that are central to it: commons, care, technology, efficacy, sustainability, institution.

KEYWORDS Health promotion. Social change. Equity. Social participation.

RESUMO A Itália foi um dos países participantes do projeto de pesquisa-ação multicêntrica do Movimento pela Saúde dos Povos (Peoples's Health Movement), chamado 'Engajamento da Sociedade Civil para a Saúde para Todos' (Civil Society Engagement for Health for All). A equipe italiana, um coletivo chamado Grup-pa, realizou várias atividades participativas de pesquisa-ação, incluindo, em uma primeira fase, um mapeamento de grupos ativos em áreas ligadas à determinação social da saúde e à promoção da saúde, através de entrevistas individuais e coletivas. Em uma segunda fase, três oficinas públicas, estruturadas em torno do intercâmbio de práticas, focalizaram-se em temas-chave surgidos durante a primeira fase. Um importante construto originado deste trabalho, centrado em torno da co-construção do conhecimento experiential do comum em saúde, foi denominado 'práticas do comum em saúde'. O foco nas práticas não é meramente estratégico (produzir sinergias e alianças), mas inerentemente político (conceber a participação como um valor) e ligado à saúde e à manutenção da saúde (dos indivíduos; da comunidade). O conceito de 'práticas do comum em saúde' pretende tornar visível uma área de transformações contínuas em novos espaços criados pelos movimentos sociais e em ações mais tradicionais em defesa dos serviços públicos existentes, abordando a saúde como uma questão sociopolítica. Neste ensaio, esboça-se uma reflexão em torno de seis palavras-chave que lhe são centrais: comum, cuidado, tecnologia, eficácia, sustentabilidade, instituição.

PALAVRAS-CHAVE Promoção da saúde. Mudança social. Equidade. Participação social.

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Introduction

Between 2014 and 2018 the People's Health Movement (PHM) undertook a large multi-centre participatory action-research project exploring social movement activism in the struggle for 'health for all', including action on the social determinants of health and access to affordable, high quality health care. The aim of the research was to better understand five domains of civil society engagement around health (movement building; campaigning and advocacy; capacity building; knowledge generation, access and use; and engaging with governance), with the goal of improving activist practice.

Italy was one of the six countries that participated in the project, which was undertaken by a collective named Grup-pa (acronym for 'permanently open group'). The collective was created in order to carry out the project, and was formed from a loose network of people – mostly from a health background – that had previously collaborated in advocating for a change in medical education, with a greater focus on the social determination of health and the relationship between globalization processes and health inequality^{1,2}. The network had also promoted self-organised training activities in different Italian universities and at the national level, and contributed to the creation of the Italian Network for Global Health Education (RIISG)³.

Grup-pa's main objective in joining the larger action-research project was to contribute to the creation and strengthening of a health movement in Italy. This was based on two assumptions: 1) the belief – grounded in history and in experience – that change can happen when the people who are mostly concerned by some issues organise themselves and take an active role in trying to address them⁴⁻⁶; 2) the high fragmentation between social movements in Italy and the absence of a health movement (despite a rich history that led to the creation of a universal healthcare system in 1978, together with the approval of progressive laws on reproductive and mental

health). The methodology of participatory action-research was in this sense very well placed to act both at the level of knowledge generation, and at the level of action and practice, since a pre-condition for the engagement of the collective was the intention to make a change in the direction of a more just, equal and healthy society⁷.

Along with the main project framework, the Italian action-research developed in two phases. In a first phase, Grup-pa undertook a mapping of groups active in Italy in fields linked to the social determination of health and health promotion, through individual and collective interviews. In a second phase, the collective organised and facilitated three public workshops, structured around the exchange of practices through inclusive and participatory methodologies, focused on key thematic axes emerged from the analysis of the data collected in phase one: social movements and welfare; building healthy spaces and communities through collective reappropriation and self-organization; new forms of community and sustainability through the commons⁸.

A main result of this work, centred around the co-construction of experiential knowledge on health as a commons, goes under the name of 'health commons practices'. This concept was elaborated in several rounds of collective action, reflection and discussion, based on the data generated through the two phases of the action-research project. In this essay, we present the key-words around which the construct is articulated (commons, care, technology, efficacy, sustainability, institution), illustrating both the practices that are linked to it, and why they are central for a transformation towards a more just, equal and healthy society.

Health commons practices

In the current political and economic context, in which privatization is promoted as the solution to 'unsustainable' public services, protecting health and equity implies supporting

universal, solidarity-based, publicly funded and quality healthcare systems^{9,10}. On the other hand, in many countries – including Italy – the healthcare system is built around an individualising and medicalising vision of ill-health, with very little understanding of its social determination. As a reflection of this, despite recent efforts towards people-centred and integrated approaches, health systems remain highly fragmented and working in silos, particularly at the (blurred) boundary between health and social issues. Still centred around hospitals and the treatment of disease, with little or no proactive community approaches and health promotion programs, traditional healthcare systems tend to neglect the needs of those who cannot access (for economic, juridical, geographic, cultural or other reasons), and of those who can formally access but do not see their needs taken into account and met (for example, minorities including the LGBTQI communities). They also lack the resources, both in terms of competence and organization, to address the complex needs produced by conditions of increasing social, political and economic precariousness.

This tension, between the need to defend the Italian National Health Service (SSN) from dismantling and privatization, and the struggle for a different approach to health and healthcare that is more inclusive, accessible and just, and oriented at the social as well as the individual determinants of health, was perceived by Grup-pa as a central axis of fragmentation among Italian movements that – more or less directly – deal with health issues. On the one hand, there are traditional organizations and networks, with strong historic legacy with the political parties and social movements that backed the Italian healthcare reform in 1978, that engage in advocacy against cuts to the public health expenditure, and the introduction of private health insurance, and for a strengthening of public financing and provision of health services. On the other hand, there are new social movements that set up innovative, self-organised spaces to address

emerging health needs, for example popular clinics (for those who cannot access the SSN, including undocumented migrants, but also those who are progressively left out due to longer waiting lists, closing services, etc.) and queer ‘consultorie’, set up by trans-feminists and LGBTQI communities to address needs that are undetected and unmet in the SSN. These movements denounce the marketization of health and privatization of healthcare for limiting the possibility to act for a transformation of public services from within, and argue for the need to establish radically alternative practices in non-institutional spaces.

The questions addressed by Grup-pa through the action-research were centred around the challenge to imagine a healthcare system that deals with health and not only with disease, taking into account and addressing the social and structural determinants of ill-health. This should include addressing the power dynamics also within the healthcare system, that are responsible for reproducing unequal relationships between professionals and between professionals and patients, accepting as ‘natural’ the social determination of health.

The vision, that was named ‘health commons practices’, involves linking the theory of the social determination of health with the knowledge and practices generated in the field of the commons, referring not to the collective possession of something but the collective action of commoning as a political principle of transformation¹¹. The focus on practices is not merely strategic (for the production of synergies and alliances), but inherently political (conceiving participation as a value) and connected to health and staying healthy (as individuals; as a community).

The construct of ‘health commons practices’ is meant to make visible an area of collective agency and ongoing transformation both in the new self-organised health spaces created by movements, and in the more traditional actions in defence of existing public services, provided that they address health as a socio-political issue. The challenge is to go

beyond the practice and the rhetoric of defending public healthcare, while standing strongly against its dismantling and privatization, and to experiment with new forms, practices and approaches to health within and outside existing institutions.

Rethinking care

The concept of 'care' encompasses different and possibly conflicting meanings. Within the dominant biomedical paradigm, 'care' is often perceived as a unidirectional action that a professional operates towards a patient, who is a passive receiver (subject) of the therapeutic act. This approach has been criticised also within mainstream medicine, and today many try to move from a disease-centred approach (to cure), to an approach that takes into account not only the biological dimensions but also the perceptions of the patient and the implications of disease on his/her psychological wellbeing and feelings (to care). However, this shift from 'cure' to 'care' is only one of the challenges/tensions involved in enacting different models of care. The idea of person-centred care, where a patient is not only a person with symptoms or a disease, implies also addressing the asymmetry in the care relationship, that is particularly relevant in health and can lead to objectification, infantilization and structural violence.

In this light, it is important to recognise how some social movements struggle to counter the idea that care entirely depends on the technical knowledge of an expert/professional, while the knowledge and experience of the person/the community is discredited. However, overcoming the hierarchy between technical and scientific knowledge, perceived as true and official/institutional, and any other kind of experiential knowledge, is particularly difficult and the dominant paradigm continues to operate also upon/within the movements that struggle to emancipate themselves from it.

In order to address this asymmetry in

practice, some groups, especially from trans-feminists and LGBTQI communities, adopt an approach based on a 'caring communities/collectives', where the action of mutual care is shared within a group bound by political visions and practices. In this perspective, care becomes a 'middle space', something that benefits the persons within the group and at the same time represents a political action or statement aimed at transforming the very idea and practice of care. In other words, it acts as a means of (political) subjectivation. It is important to add that, for such spaces to become means of collective liberation, they have to be based on the disclosure and self-reflectivity of each person on him/herself and his or her own privileges.

Which technology for which health paradigm?

In the dominant medicalising and capitalist vision of health, an improvement in health conditions is represented as a consequence of building more hospitals, developing more technology, doing more research on drugs, implementing personalized approaches to medical care¹². However, this paradigm further shifts the attention and the investments away from the upstream conditions that influence a large proportion of our chances of a healthy life (the social determinants of health), that are strictly related to how a society is organised and, therefore, to the issues of equity and social justice¹³.

Moreover, technological development is closely related to the capitalist mode of production, that is responsible for an unsustainable burden of externalities towards the environment, and connected to growing inequality and exclusion from access to care. This happens, not only in low and middle income countries (for example, lack of access to cancer treatment for most of the world's population), but increasingly also in high income ones (for example, the restriction

in access to new hepatitis C drugs, imposed by the Italian government due to their high cost¹⁴). Finally, the dependency on the private sector for bringing to market essential drugs generates dangerous conflicts of interest (e.g. in research investment priorities and pricing). More care does not necessarily mean more health, but almost always means more profit¹⁵.

Another set of considerations around technology and health relates to people's perceptions, ideas and experiences, that are central to the therapeutic relation. First, because the use of technology is closely related to the issue of expert or technical knowledge addressed earlier. Secondly, because health technologies are closely connected to the health paradigm in use and shape the experiences and ideas around disease and care. If the disease is something confined to the biological body, only a technology that is capable of exploring the body and its organs will give reliable answers; conversely, the very existence of that technology contributes to reinforcing the exclusion of other variables, that it is not able to explore. Medical anthropology suggests not to separate ideas and experiences (the mind) from the body that lives them. In this sense, our dependency from technology is a fact, independent from any consideration on the validity of technology. Technology can never be neutral because it enters into the modes in which we organise, represent and (re)produce reality¹⁶.

If, as stated above, the aim is to work towards a transformation in our approach to health, both within healthcare services and through the new self-organised health practices of social movements, there are three open questions to address:

1. Is it possible to separate (medical) technology from the capitalist mode of production that is responsible of perpetuating inequality and devastating the planet?
2. While criticizing the embodied vision that sees technology and hyper specialization as

the approach to ill-health (which may translate into an oppressive system of control), are we aiming to exclude technology from care practices, despite the proven benefit of tools such as essential medicines?

3. Who can assess which technologies are beneficial and which are not - and how and in which democratic spaces? Is it possible to imagine a collective management of health technologies, from research to production? And, again, what are the criteria to label a technology as 'beneficial'?

Widening the concept of efficacy

This last question, about what can be said to be 'beneficial', implies asking ourselves how we may evaluate a health outcome, not as an abstract question but as a tool to orient our collective health practices. Starting from the mainstream discourse around efficacy, there are considerations to be made that can shift or expand its meaning to encompass more dimensions of health.

Within public institutions, the focus is mainly on the concepts of efficiency, cost-effectiveness and appropriateness. These concepts, and the relevant indicators, have been appropriated into a managerial approach to health and healthcare, which is widespread also within public health services.

Alongside these criteria, there is a large use of the concept of 'technical efficacy', which is the capacity to produce an outcome that is measurable in terms of recovery from a disease or increase in life expectancy. This approach selects some parameters and indicators, those related to aspects that are measurable and considered as objective (for example, the rate of survival), reproducing a binary vision of health and disease that is far from the lived experience of people and may reinforce dynamics of exclusion or control. Moreover, considering only the

biological aspects of ill-health may lead to their essentialization, concealing the symbolic dimensions as well as the structural factors that shape the distribution of health and disease among the population.

While imagining new health practices, it is important to imagine also new ways to look at the outcomes of the (health) processes that are generated. In this sense, we may try to redefine the concept of efficacy, in order to include qualitative, subjective and socio-political dimensions. The debate on how to name such a concept is still open, we may however use an example to illustrate the different elements involved. From a biomedical perspective, the efficacy of an intervention on a person suffering from tuberculosis may coincide with the efficacy of the pharmacological treatment, despite the fact that this does not intervene on the contextual causes that contributed to the development of the disease. In order to define the impact of a health practice that acts both on the individual condition and awareness, and on its social determinants, we propose to speak of 'biopolitical efficacy', to highlight the potential to promote subjectivation and overall transformation.

The crux of sustainability

Sustainability represents a challenge both for the new self-organised health practices developed by social movements, and for those who act to change the healthcare system from within.

In relation to the welfare state, the ambiguous concept of sustainability is a slippery slope. In fact, it is in the name of the contested discourse on their claimed 'un-sustainability' that governments of any colour justify the dismantling of public healthcare services. In this sense, the concept is used in its economic meaning, focusing only on healthcare expenditure. Any other dimension outside the economic one disappears from consideration.

At the same time, also the new self-organised health practices within social movements struggle with their own sustainability, yet on different bases. They speak of sustainability referring to accessibility and inclusiveness, impact, and possibility to survive in a capitalist system, reflecting both material and immaterial aspects, on a personal and a collective level. We propose to speak of the sustainability of health commons practices highlighting three dimensions: material, emotional/relational and political.

From a material point of view, which resources can these groups and activities rely on? Is it possible to imagine personal and collective means of survival that enable stability and continuity? Many activist groups reached through the action-research create forms of direct or indirect income, reflect on how to build economic sustainability placing activism at the centre of one's life, create practices of redistribution, alternative economy and/or mutualism. Which is the impact that these new forms of sustainability can have, and what are their limits in terms of accessibility and equity?

In addition to these considerations, there is an ongoing reflection on what we named 'emotional/relational sustainability' of the groups and persons involved in these processes. This second dimension of the concept of sustainability is linked to the practices put in place in order to manage the decision-making power and processes, the division of tasks and responsibilities, and the level of personal and relational engagement. In many groups reached through the action-research, one may witness forms of self-exploitation that generate discomfort and frustration, derived from the organizational practices that have been adopted. To move from hierarchical models towards others that focus on co-responsibility requires a shift, also at the personal level, and a great attention to the care of relationships, in order to develop new organizational forms that keep together

needs, expectations, desires and functioning.

There is yet another implication of sustainability, that we propose to call ‘political sustainability’. Many groups reached through the action-research try to keep together the action on micro-contexts, starting from the needs and desires of those involved and/or the surrounding communities, with a transformative action on the broader political context. In this tension there is a double risk: to reduce the collective experience to the needs and desires of those who are (already) part of it, or, on the contrary, to create spaces and activities that are far and detached from those who inhabit them.

Is it possible to build experiences that, starting from the individual, are open to new and different needs, practising an intersectional approach¹⁷⁻¹⁹ to the different forms of oppression? What tools may we use to evaluate the impact of these experiences on the territory and local communities, besides the impact they have on the lives of those who cross them? With what strategies may we multiply and strengthen these struggles, escaping from the geographical boundaries and the paradigms of identitarian belonging? How may we concretely plan and organise solidarity networks and alliances between experiences?

Imaginaries and instituting processes

To imagine new health practices means also to imagine new institutions for health and health care. For many social movements, the concept of institution is associated with discipline, social control, standardization of bodies and needs. However, it is also associated with the concept of ‘instituting process’, the autonomous process of production of an institution²⁰.

Processes of collective knowledge generation, bottom-up welfare networks, self-care pathways that are built together indicate a way of thinking about institutions as living, open and participated processes, in which the practices are ongoing dynamic negotiations and

not something that is given once and for all.

In this sense, we may speak of instituting movements, considering instituting as the power to create new imaginaries in opposition to the static nature of current institutions. It is in relation to this line of thought that we formulate the proposal to speak about the new self-organised health experiences within social movements not (only) as self-care practices, but as health commons practices. This allows to highlight their instituting potential, varied according to the extent to which they attribute political value to new imaginaries, while at the same time escaping from forms of neoliberal capture and dispossession.

Conclusions

In this essay, we have summarised some of the reflections originated from an action-research conducted ‘from within’, as the research collective (Grup-pa) is part of the broader social movement which was subject of the investigation. The discourse around the six keywords – commons, care, technology, efficacy, sustainability, institution – is at times more developed, at times less, based on the depth of the analysis and exchange both within Grup-pa, and between the collective and other groups involved in experimenting new self-organised spaces around health and its determinants.

The naming of ‘health commons practices’ is meant to overcome the fragmentation between those who defend existing public health systems and those who create new spaces where more (political) dimensions of health can be addressed, and open a field of discussion, experimentation and collective agency towards a more just, equal and healthy society. By definition, an action-research generates more questions than answers and is meant to accompany a practice of transformation. In this sense, the best way to test the validity of the construct is to continue to practice it.

Collaborators

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