

Health Activism as a Resource of the Healthcare Systems

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Abstract— Public health activism is important, but often overlooked resource of the healthcare systems. The transition to participatory medicine, responsible self-treatment and self-help is considered by the World Health Organization as a vector for the development of public health systems worldwide. In this context, there is growing interest in how people organize health care practices; how they come together to jointly solve health problems; in what forms they express their disagreement with the organization of medical care or the distribution of health services; what actions are being taken to change the situation. Currently in the social science there is a lack of fundamental developments devoted to the study of health activism corresponding to the realities of modern society, especially in the context of new epidemic risks and the growing mediatization and digitalization of society. There is a need to develop a theory of health activism, taking into account the spread of new epidemic risks, changes in the forms and strategies of social activism, mediatization and digitalization. The aim of the research was to identify key theoretical approaches and gaps in existing research. We implemented a scoping review of literature available in the subject area of public health activism published in the last 10 years. Different forms of public health activism were identified in examined papers. A new vision of public health as a complex set of multi-level strategies and interventions requires the development of new theoretical approaches to the study of health activism. The research was supported by RSF (project No 22-18-00261).

Keywords— Public health, health activism, healthcare, collective action, sociology of health.

I. INTRODUCTION

The health problems in the modern world do not belong exclusively to the medicine, but exist in a social context in which the interests of different groups and communities are intertwined. As new epidemic risks (COVID-19, HIV/AIDS) emerge, public health issues are gaining in importance and go far beyond medical knowledge alone. Tackling health risks cannot be viewed as politically and morally neutral, as it is a central aspect of social well-being, and therefore social and political life. The transition to participatory medicine, responsible self-treatment and self-help is considered by the World Health Organization as a vector for the development of public health systems worldwide. It is expected that this transition will reduce the load on the state in improving public health and health care and redistribute responsibility in the field of health. In this context, there is growing interest in how people

organize health care practices; how they come together to jointly solve health problems; in what forms they express their disagreement with the organization of medical care or the distribution of health services; what actions are being taken to change the situation. An important, but often overlooked resource of the health care system is public health activism. Public health activism manifests itself both in the forms of public associations and movements formed around health issues, and in various forms of social self-organization in the field of health care. Public health activism refers to any bottom-up attempt to redistribute material, institutional, symbolic resources, power and responsibility in public health and health, using nongovernmental means to achieve its goals. On the one hand, health activism is a challenge to the existing health care order, which is seen as negatively affecting health or impending fair and equitable access to health services; on the other hand, social activism can be aimed at a joint solution of health problems and at filling gaps in the health care system.

Research on social health activism is important for understanding the complex and multilevel nature of interactions in public health and health care, the role of social factors in changing health behavior, and public potential for solving health problems. Until recently, in the scientific literature, public health activism was limited only to the activities of organized social movements of vulnerable groups and their allies, aimed at the redistribution of health care resources that promote the health of these groups, public recognition of their problems, gaining better access to health resources or greater control over health and well-being. New epidemic risks are changing the nature of social health activism, not limiting it to certain vulnerable groups and spreading it to the widest segments of the population.

Contemporary research on health activism relies heavily on classical methodological tools, placing activism within the conceptual framework of social movement theories. However, in modern society, the redistribution of power, resources and responsibility is carried out in a less obvious way than it was assumed in the classical concepts of social movements. At present, the interpretation of the process of social change as a planned linear strategy is not enough; this process is much less straightforward and predictable than traditional approaches of social movements suggest. The controversial point also concerns what should be considered a successful result of such activism and evidence of a redistribution of material, institutional or symbolic power.

Currently in the social science there is a lack of fundamental developments devoted to the study of health activism corresponding to the realities of modern society, especially in the context of new epidemic risks and the growing mediatization and digitalization of society. These changes require a transformation of the understanding of health activism, consideration of health activism not as a political movement for the redistribution of medical power, but as self-organization and unification of people and communities in order to jointly solve health problems that go beyond conventional or routine procedures and have an explicit purpose, which is usually to empower people and communities in the field of health. There is a need to develop a theory of health activism, taking into account the spread of new epidemic risks, changes in the forms and strategies of social activism, mediatization and digitalization.

II. MATERIALS AND METHODS

We implemented a scoping review of literature available in the subject area of public health activism published in the last 10 years. The aim of scoping review was to identify key theoretical approaches and gaps in existing research. We searched English-language journals using the electronic databases PubMed and Google Scholar. We made a matrix of found papers that met the specified criteria to help us organize the data for analysis of the literature. We used a narrative approach to analyze the selected papers.

III. RESULTS

The predominant theoretical approach to the study of social activism in health is the sociology of social movements [1]. Within the framework of this approach, health activism is interpreted as a public collective activity of vulnerable groups and their allies aimed at reallocating resources and public recognition of problems. Social movements, including health movements, are informal networks based on shared beliefs and solidarity that mobilize around conflict issues through frequent use of various forms of protest. Typically, social movements operate outside of the main institutional channels of governance, putting pressure on the government because it is the purpose of their actions (or not), through either a symbolic challenge to its legitimacy or under duress [2]. Social movements of health were interpreted as the so-called new social movements. Their emergence was theorized as resistance to the colonization of the life-world by the state and the economy in terms of the supervision and regulation of behavior. The most striking example of such a movement is the antipsychiatric movement, which sought to oppose the power of psychiatrists as state agents to define normality and deny the freedom of those deemed “mentally ill”. However, the distinction made between “new” and “old” movements is a matter of debate. In addition, many of the problems associated with “old” social movements, including health issues, have re-emerged in the context of the “global justice movement”, whose international protests at the beginning of the 21st century reshaped the politics of social movements, focusing on global level. A shift in the dominant paradigm of viewing social movements from conceptualizing social movements as an irrational crowd response to structural tension on the part of previously atomized people to the paradigm of rationality of activism with an emphasis on the

integration of activists into social networks, and on the influence of the availability of resources and political opportunities on mobilization represents the main paradigm shift of the last decades in the field of study [3]. However, at present, this paradigm itself is criticized for its assumptions about rational choice and ignoring aspects such as identities and cultural practices.

An important feature of contemporary research on social health movements is the emphasis on advocating lay knowledge and patient perspectives in relation to medical knowledge, overcoming the medical monopoly, and advancing the perspectives of health care recipients. Within the framework of this line of research, through the approval of the experience of the patient as a legitimate source of knowledge about both the definition of disease and the measurement of treatment efficacy challenges the monopoly and authority that the medical profession enjoys on these issues. In some cases, this approach coincides with a shift towards the ethics of consumerism in health, influenced by neoliberal health reforms, but it is recognized that criticism of public health activists is more fundamental than criticism of the consumer-oriented program of neoliberalism, and the language of consumerism is in many cases alien to them [4].

Despite significant advances in research on health activism from the perspective of a social movement approach, many authors now point to their limitations and inadequacy to describe the current situation [5]. It is noted that modern social health activism takes on more latent and diffuse forms than it can be described from the perspective of the sociology of social movements [6]. Researchers pay attention to the shortcomings of a universal approach to the study of social activism of health, which ignores the diversity of its modern forms. Separate studies are emerging looking at the transformation of health activism in modern society [7].

Currently, there has been a transition to a radical expansion of views on the essence and content of health activism, taking into account new, as well as already existing, but previously unrecognized forms of activism. Here are examples of some recent research looking at new forms of social health activism. In [8] activism is seen not as opposing the existing system, but as using the existing system and the logic of the market for radical changes in relation to access to medicines, thereby undermining the understanding of activism as an opposition to neoliberalism. The recognition of non-public acts of collective participation in health structures is helping to move away from the view of activism as an organized resistance to achieve visible social change. The very care and assistance within the framework of formal health care structures is in some cases regarded as radical political acts. For example, in the study [9] on the example of stigmatized and often marginalized recipients of diamorphine in heroin substitution therapy, it is shown how caring for vulnerable groups becomes a political act, as activists promote ways of helping excluded people in their relationships with health professionals, thereby challenging the dominant medical model and regime of rationality. A study [10] describes how health-care workers move beyond their formal care functions. According to the authors, such actions can be interpreted as activism, since they are a component of social change, promoting public health.

Knowledge activism is a relatively new approach that views activism as a means of advancing research findings into policy and governance decision making. At the same time, this approach was practically not considered in relation to public health problems. In the context of the coronavirus pandemic, for example, knowledge activism takes the form of individual blogs dedicated to detecting distortions in statistics that are allowed in official information. In the scientific literature, as a rule, knowledge activism is examined from the point of view of the relationship between research and policy. Traditional knowledge transfer and knowledge exchange approaches are seen as ineffective compared to the knowledge activism approach as a means by which research data can be used in the context of policy action. The risk to academic integrity and objectivity of such overtly political behavior is recognized, but it is argued that excluding research from the political sphere leads to less or no impact of research on practice. In a study [11] a survey of health and safety professionals was used to find out the amount of time respondents spent on various types of representational activities. Representatives who were defined as knowledge activism were more likely to participate in complex interventions and reported better results from their activities. Medical authority is viewed from a fundamentally new perspective by examining situations in which doctors themselves are viewed as representatives of activist movements involved in so-called “clinician-led evidence-based activism”. The redirection of medical power in an alliance with vulnerable groups is interpreted as an example of redirecting medical authority. Researchers note such a feature of modern health activism as the rejection of emancipatory aspirations and the rhetoric of liberating social change in favour of the rhetoric of collective action in the service of “responsibilized citizenship”.

Participation in collective action focuses on the individual benefits of access to information and social support from peers. For example, the study of the Internet usage in online patient communities revealed stigmatization of leftist ideas and self-identification of participants not as activists, but as “advocates” [12].

Social networks are radically changing the strategies of social activism, the terms such as “slactivism”, “clicktivism”, “clickocracy” appear. This issue is actively studied in social sciences [13], but poorly studied in relation to health activism. Another poorly understood form of social health activism is performative activism. This concept was developed in relation to activism in other spheres [14], but the analysis of performative activism in public health requires deeper research.

IV. DISCUSSION

Modern health activism includes not only social movements, but also such forms as networks of mutual assistance, exchange of resources and information, online health communities, peer-to-peer education, advocacy groups for patients and doctors, etc. Under the influence of digitalization and mediatization of public relations, the strategies of health activism are changing, a significant part of social activity is transferred to the digital space. Social activism in public health is becoming diffuse, latent, and more difficult to identify and investigate. The spectrum of activist actions is quite wide, from conventional

indirect to unconventional direct methods of action. The transition on this scale shows the potential for mobilization. Public health activism generally aims to create a healthier social environment. At the same time, the understanding of what is “good” can differ significantly for different agents. For example, anti-vaccine movements pursue their own understanding of “good” that runs counter to public health interests. In the context of the spread of new epidemic risks, social activism is often accompanied by the politicization of health problems - a process in which certain social agents construct public health problems as political ones, making them a stake in the political game. This is the other side of health activism, which requires study from the point of view of detection and assessment of the potential to mobilize such forms of social activism. An important aspect of the research problem is to identify the connection between social activism of health and the politicization of the discourse that represents public health problems, health threats, risks and practical measures aimed at risk management.

V. CONCLUSION

Currently health activism is not limited to the activities of organized social movements, but is included in various practices of social agents, is not limited to vulnerable groups, but in one form or another has the potential to spread to the entire population, more opportunities for association, diffuse and latent nature of such associations, greater potential for social mobilization. A new vision of public health as a complex set of multi-level strategies and interventions requires the development of new approaches to the study of social health activism. Modern changes require a radical expansion of views on social activism in public health, which would take into account both new and previously existing, but unrecognized forms of social activism in the field of health, a change in the strategies of interaction of agents of social health activism with the state and society. A new look is needed at the social processes that take place in the public health and health care system as a complex set of multi-level strategies, undertaken by different agents, and aimed at solving public health problems in different ways. It is necessary to expand the understanding of social activism in the field of health from the point of view of supplementing it with aspects of self-organization and self-help, since it is these forms of activity that are latent and diffuse forms of redistribution of resources, power and responsibility in the public health system in modern society.

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REFERENCES

- [1] P. Brown, S. Zavestoski, *Social Movements in Health*, Oxford: Blackwell, UK, 2005.
- [2] G. Jonathan, F. Lee., *Key Concepts in Medical Sociology*, SAGE, 2013.
- [3] N. Crossley, *Making Sense of Social Movements*, Buckinghamshire: Open University Press, UK, 2002.
- [4] T. Brown, E. Fee, *Social Movements in Health*, *Annual Review of Public Health*, vol. 35, pp. 385-398, 2014

- [5] C. Campbell., F. Cornish., Public health activism in changing times: re-locating collective agency, *Critical Public Health*, vol. 31(2), pp. 125-133, 2021.
- [6] H. Cowan, Taking the national (ism) out of the national health service: Re-locating agency to amongst ourselves, *Critical Public Health*, vol. 31 (2), pp. 134–143, 2021.
- [7] F. Cornish, 'Grenfell changes everything?' Activism beyond hope and despair, *Critical Public Health*, vol. 31 (3), pp. 292-304, 2021.
- [8] A. Martinez-Lacabe, The PrEP response in England: Enabling collective action through public health and PrEP commodity activism, *Critical Public Health*, vol., 31 (2), pp. 225-233, 2021.
- [9] F. Dennis, Advocating for diamorphine: Cosmopolitical care and collective action in the ruins of the 'old British system', *Critical Public Health*, vol. 31 (2), pp. 144-155, 2021.
- [10] J.M.Mulligan, A. Garriga-Lupez. Forging compromise after the storm: Activism as ethics of care among health care workers in Puerto Rico, *Critical Public Health*, vol. 31 (2), pp. 213-224, 2021.
- [11] A. Hall, J. Oudyk, A. King, S. Naqvi, W. Lewchuk. Identifying knowledge activism in worker health and safety representation: A cluster analysis, *American Journal of Industrial Medicine*, vol. 59, pp. 42-56, 2016.
- [12] A.C. Schermuly, A. Petersen, A. Anderson. 'I'm not an activist!': Digital self-advocacy in online patient communities, *Critical Public Health*, vol. 31 (2), pp. 203-212, 2021.
- [13] P.P. Dogaev., Slaktivism as a form of social and political participation in the era of "post-truth", *Politics and Society*, vol. 8, pp. 1-9, 2017.
- [14] T. Shefer, Activist performance and performative activism towards intersectional gender and sexual justice in contemporary South Africa. *International Sociology*, vol.34, pp 418- 434, 2019.