

Caring in the age of COVID-19: lessons from science and society

Cuidar em tempos da COVID-19: lições aprendidas entre a ciência e a sociedade

Cuidar en tiempos del COVID-19: lecciones aprendidas entre la ciencia y la sociedad

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Abstract

This paper focuses on our research and intervention in health promotion with patients and communities affected by various infectious diseases, in the project Knowledge-Sharing Platform. This project is developed at the National Institute of Infectious Diseases Evandro Chagas in the Oswaldo Cruz Foundation, Rio de Janeiro, Brazil, and promotes the continuing involvement of health researchers and professionals in the collaborative production of knowledge on health with patients and community groups and in their training as community health promoters. The new epidemic scenario created the demand for a space of dialogue and knowledge-sharing on the prevention of COVID-19 transmission. Due to the interruption of regular activities in the Knowledge-Sharing Platform, a strategy was launched to serve as a link between science and society and help overcome the social isolation imposed by the COVID-19 pandemic. The WhatsApp group allowed project members to participate by addressing questions (audio) on COVID-19 through mediation by community group leaders. The main questions by participants related to risk factors, transmission, immunity to the novel coronavirus, care related to prevention, symptoms, and treatment; and COVID-19 and influenza vaccine. The educational material Caring in the Age of COVID-19 was produced and shared with community leaders and distributed to the respective groups and was eventually shared in their communities as a response to a demand for knowledge that responds to the concerns of people already exposed to structural vulnerability.

Citizen Participation in Science and Technology; Health Promotion; Social Isolation; COVID-19

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Introduction

In keeping with international guidelines, the preventive measures recommended by the Brazilian Ministry of Health to minimize COVID-19 transmission in places with community transmission include social distancing^{1,2}.

Given the exposure to the risk of contagion and the incapacity to access preventive measures involving other health problems, which can thus be aggravated, situations of structural vulnerability³ may be expanded in the context of the COVID-19 pandemic. It is thus important to act on the links between scientific knowledge related to prevention of transmission in the more vulnerable communities and the continuity of promotion of their quality of life. Aspects involving health literacy and the difficulty in comprehending the guidelines published by health authorities, with precarious access to basic sanitation, running water, and healthcare in poor communities, thus require urgent attention, integrated into the promotion of relations between individual and community care to confront this epidemic's challenges.

The project *Knowledge-Sharing Platform: Community Involvement and Participation in Innovative Practices in Health Promotion and Knowledge Production* has been developed since 2012 by the Research Laboratory in Epidemiology and Social Determination of Health (LAP-EPIDSS) at the National Institute of Infectious Diseases Evandro Chagas, Oswaldo Cruz Foundation (INI/Fiocruz) in Rio de Janeiro in collaboration with the Center for Social Studies of the University of Coimbra, Portugal. The project seeks to build new practices in health promotion and forms of collaborative knowledge production involving epidemiologists, social scientists, infectious disease experts, other health professionals, patients, and members of community groups, developing public-interest health actions, allowing active participation by society, especially in the control of infectious diseases (e.g., HIV infection, Chagas disease, etc.), chronic and degenerative diseases (e.g., neoplasms), and other health and health-related problems that impact the population's quality of life. The principal activities involve educational talks on topics of interest to the participants, visits to scientific installations, income-generation workshops, and extension courses focused on relations between science and society in teaching, research, and clinical care settings.

The social partners of the *Knowledge-Sharing Platform* include the Association of Friends of the INI Struggling for Life (ALCA-INI), which provides support for patients receiving treatment for infectious diseases at the INI and their families, the "Amigas da Mama" Club (CAM), a group of women living with or who have lived with breast cancer and that encourages a support network for confronting the disease; and the Community Advisory Committee of the Clinical Research Center in HIV/AIDS of the Nova Iguaçu General Hospital (CCA-HGNI), which provides an interface between researchers and the community in HIV/AIDS prevention and treatment. These three groups participate actively in publicizing the project's activities.

The project's participants are already living in situations of structural vulnerability³, aggravated by social exclusion, difficulties in access to healthcare for surveillance and control of other health problems, and daily struggles against health inequalities and which the collective activities promoted by the project seek to support. Most of the participants see their vulnerability exacerbated by COVID-19, since they have other infectious diseases and/or chronic noncommunicable diseases.

Within the project's activities, the community groups demand access to scientific knowledge related to situations and processes that can seriously affect or contribute to the exacerbation of their health condition and that of the people living and in contact with them. This community action fosters involvement by the project's researchers with experiences pursuing better health conditions based on horizontal relations and focused on the community's concerns and problems related to health and quality of life. In this context, both the community groups and researchers informally grasp the role of "community health promoters".

The most recent community demand has been for knowledge on COVID-19, given the participants' concern over the circulation of fake news. To respond to this demand, we organized a chat circle entitled *Contributions by Community Health Promoters to the Prevention and Control of COVID-19*, scheduled for March 19, 2020, with participation by epidemiologists, infectious disease experts, and specialists in hospital infection, aimed at involving the community in the shared construction of knowledge on the pandemic.

The confirmation of local SARS-CoV-2 transmission by health authorities in Rio de Janeiro and the implementation of measures during the public health emergency of international concern resulting from COVID-19, including social isolation in the state of Rio de Janeiro as a way of decreasing community transmission⁴, made cancellation of the event unavoidable due to the concern with distancing and isolation of the project's participants.

The project's focus on individuals that are already vulnerable due to the undervaluation of their experiences and knowledge led us to create a space for action and response to situations of illness and vulnerability and demands for various forms of care during the epidemic⁵. Given the social isolation, the relations of trust and care built through health promotion activities motivated us to adopt WhatsApp as a communications tool for collectively dealing with the challenges, keeping the project's activities alive, now in a virtual environment.

The current paper aims to share and present the building of this space for dialogue and exchange of experiences for building knowledge on COVID-19 in a virtual environment already familiar to the participants in the project's scope and/or in their personal relations.

Methodology

The paper reports on the experience with a health activity based on the collective construction of an educational tool to contribute to the prevention and management of COVID-19.

We have attempted to value the shared questions, responding with the group to the new challenges. We adopted WhatsApp as the platform for participatory construction, aimed at promoting individual empowerment, collective participation by the project's stakeholders, and community engagement based on the use of participatory methodologies^{6,7,8}.

The WhatsApp group called *Caring to Avoid COVID-19* aimed to develop the activity with the LAP-EPIDSS team and 3 community groups (ALCA-INI, CAM, and CCA-HGNI) as mediators between the project and the groups' members. We chose this app since it is the virtual media most widely used by these social groups to communicate with their members.

We defined leaders as people that participate in and are dedicated to their community groups, inspiring trust and offering individualized attention and care and seeking solutions with their community members. A proposal was thus presented to the 4 community leaders (LGC in portuguese) project participants to collectively develop educational materials on COVID-19, with WhatsApp as the platform. Since the community groups represented by their LGC have a WhatsApp group, the proposal was for them to share the following question with their groups' participants: "What information on the new coronavirus do you consider important to share with the community?"

The survey ran from March 23 to 26, 2020. We included in the WhatsApp group a message with the proposal's underlying question and an audio to explain the activity's proposal to the LGC participants in the *Knowledge-Sharing Platform*, as a way to promote access and understanding for everyone involved.

The project was approved by the Institutional Review Board of INI/Fiocruz (CAAE n. 88434218.6.0000.5262).

Results

The WhatsApp group *Caring to Avoid COVID-19* was created on March 23, 2020. It consists of 5 members from the *Knowledge-Sharing Platform* team and 4 LGC from community groups that participate directly in the project's activities. Two leaders from ALCA-INI also participated. Everyone agreed to participate and confirmed that the initiative was a way to feel that they belonged and were valued in the process of producing and sharing knowledge on COVID-19.

The participants' main questions involved risk factors, transmission, immunity to the new virus, care related to prevention, symptoms, and treatment, and COVID-19 and influenza vaccine.

After compiling the questions raised by each group's participants, the team prepared the answers based on the websites of the World Health Organization, U.S. Centers for Disease Control and Prevention, Brazilian Society of Infectious Diseases, and Ministry of Health.

Since it was urgent to provide feedback, the consolidation and layout of the material *Caring in the Age of COVID-19* were shared with the LGC from the participating community groups. Following revision and evaluation by the LGC, especially concerning the content, language, and display, the material was approved and distributed by the leaders to their respective community groups, totaling approximately 100 people who had access to it. Some LGC also shared the material in other states of Brazil (Pernambuco, Bahia, Espírito Santo, and São Paulo). Members of the project team also asked to share the material in their work groups (health and teaching institutions), in addition to groups of friends.

We believe that the material reached more people than initially estimated, which has been a common experience in the project. The material was deposited in the Institutional Repository of the Fiocruz (Arca; <https://www.arca.fiocruz.br/handle/icict/41236>).

Discussion

The *Knowledge-Sharing Platform* has a long track record of action-based research focused on collaborative knowledge production in clinical, epidemiological, and social research in infectious diseases and in the creation of innovative health promotion. The platform is also a space to join and build relations of trust and care through health promotion activities.

Social distancing and isolation are necessary measures, but they concern us because isolation and social exclusion are a central part of the structural vulnerability³ affecting the participants (and their communities). Based on dialogue and exchange of experiences in a virtual setting, we thus built this strategy to overcome the distancing between the project's participants and support the demands for knowledge on dealing with COVID-19.

The initiative had not been planned initially in the activities of the *Knowledge-Sharing Platform*, but it emerged as a response to the need for an immediate intervention due to the characteristics of COVID-19.

The WhatsApp group *Caring to Avoid COVID-19* served as a space for dialogue and knowledge-sharing in COVID-19 prevention, mobilizing all the stakeholders in this participatory process. As we hoped, the individual reports shared through the project's solidarity network have allowed attenuating the social isolation experienced by many participants and have continued to strengthen the relations as a form of care. The *Knowledge-Sharing Platform* views caring as kind of relationship and an ethnical stance in research and intervention that highlight the relevance of attitudes and moral values, affective relations, and our responsibility to involvement, understanding, and respect for vulnerable individuals and communities^{9,10}.

The new view of care problematizes and seeks to contribute to social transformation of health professionals' role¹¹ and all the participants' relations through new experiences with caring for other under exceptional conditions.

Dialogue, creativity, and attentive listening to participants' demands for promoting this form of care, which expresses the way health is viewed by the project, is inherent to planning the proposed activities. This experience reconfirms our view that health promotion requires mutual promotion of caring with empowerment and well-being. The production of such care contributes to the survival and flourishing of caregivers and those receiving the care and to the acknowledgement of interdependence as a condition for life with dignity.

Given the urgent need for new forms of intervention in the COVID-19 epidemic, we believe that this experience can expand the scope of future public health measures based on scientific commitment to the struggles for health by these communities and the communities' strengthening that results from this involvement. This strength is expressed in the solidarity of the community health promoters, working to control transmission of the disease in their communities, but also as a lesson and a process in the production of new forms of knowledge and skills, expanded in their experience and dialogue with health researchers and professionals^{12,13}.

We conclude that the complex social and political dimensions of the COVID-19 pandemic must be addressed as part of this expanded construction of health promotion and public health.

We intend to continue this experience as a space for dialogue and construction of knowledge and care, based on prevention and health promotion, since it represents our ethical position and commitment to those experiencing this epidemic.

This brief paper also serves to reflect on a view of the new processes of social determination of health and the production of new knowledge resulting from the interface between scientific knowledge and knowledge born from experience during a health emergency.

Contributors

C. T. V. Souza, C. S. Santana, and P. Ferreira contributed to the study's conception and design, data collection, analysis, and interpretation, drafting and relevant critical revision of the intellectual content, and approval of the final version, guaranteeing its accuracy and integrity. J. A. Nunes, M. L. B. Teixeira, and M. I. F. S. Gouvêa contributed to the data collection, analysis, and interpretation, drafting and relevant critical revision of the intellectual content, and approval of the final version, guaranteeing its accuracy and integrity.

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References

1. Secretaria de Atenção Primária à Saúde, Ministério da Saúde. Protocolo de manejo clínico do coronavírus (COVID-19) na atenção primária à saúde; março de 2020. <https://coronavirus.saude.gov.br/manejo-clinico-e-tratamento> (accessed on 29/Apr/2020).
2. World Health Organization. Coronavirus disease (COVID-19) pandemic. <https://www.who.int/emergencies/diseases/novel-coronavirus-2019> (accessed on 29/Apr/2020).
3. Bourgois P, Holmes SM, Sue K, Quesada J. Structural vulnerability: operationalizing the concept to address health disparities in clinical care. *Acad Med* 2017; 3:299-307.
4. Rio de Janeiro. Decreto nº 46.973, de 16 de março de 2020. Reconhece a situação de emergência na saúde pública do Estado do Rio de Janeiro em razão do contágio e adota medidas de enfrentamento da propagação decorrente do novo coronavírus (COVID-19); e dá outras providências. *Diário Oficial do Estado do Rio de Janeiro* 2020; 17 mar.
5. Ferreira P, Souza CTV, Santana CS, Nunes JA. Caring in times of COVID-19. *Somatosphere: Science, Medicine, and Anthropology* 2020; <http://somatosphere.net/2020/caring-in-times-of-covid-19.html/> (accessed on 17/Apr/2020).
6. Lima ICV, Galvão MTG, Pedrosa SC, Cunha GH, Costa AKB. Uso do aplicativo Whatsapp no acompanhamento em saúde de pessoas com HIV: uma análise temática. *Esc Anna Nery Rev Enferm* 2018; 22:e20170429.
7. Silva RC. Metodologias participativas para trabalhos de promoção de saúde e cidadania. São Paulo: Vetor; 2002.
8. Queiroz AG, Couto ACP. Metodologia participativa, subjetividade individual e social: facilitação de reuniões de moradores em Residências Terapêuticas. *Pesqui Prát Psicossociais* 2015; 10:171-8.
9. Waldow VR. Cuidar: expressão humanizadora da enfermagem. 6ª Ed. Petrópolis: Editora Vozes; 2012.
10. Waldow VR. Enfermagem: a prática do cuidado sob o ponto de vista filosófico. *Investigación en Enfermería: Imagen y Desarrollo* 2015; 17:13-25.
11. Barros S, Oliveira MAF, Silva ALA. Práticas inovadoras para o cuidado em saúde. *Rev Esc Enferm USP* 2007; 41(Esp):815-9.
12. Lima FA, Galimberti PA. Sentidos da participação social na saúde para lideranças comunitárias e profissionais da Estratégia Saúde da Família do território de Vila União, em Sobral – CE. *Physis (Rio J.)* 2016; 26:157-75.
13. Santos BS. O fim do império cognitivo. Belo Horizonte: Autêntica Editora; 2019.

Resumo

Esta comunicação é centrada na nossa pesquisa e intervenção em promoção da saúde com pacientes e comunidades afetadas por diversas doenças infecciosas, no projeto Plataforma de Saberes. Esse projeto é desenvolvido no Instituto Nacional de Infectologia Evandro Chagas, Fundação Oswaldo Cruz, no Rio de Janeiro, Brasil, e promove o envolvimento continuado de pesquisadores e profissionais de saúde na produção colaborativa de conhecimento sobre saúde com pacientes e grupos comunitários, e na sua capacitação como promotores de saúde comunitária. Face ao novo cenário epidêmico, surgiu a demanda de um espaço de diálogo e partilha de conhecimento sobre prevenção da transmissão da COVID-19. Devido à interrupção das atividades regulares do Plataforma de Saberes, foi promovida uma estratégia que servisse de elo integrador entre ciência e sociedade e ajudasse a superar o isolamento social imposto pela pandemia da COVID-19. O grupo de WhatsApp possibilitou aos integrantes do projeto participarem por meio de formulação de perguntas (áudio) sobre a COVID-19, por intermédio da mediação dos líderes de grupos comunitários. Os principais questionamentos dos participantes estão relacionados com fatores de risco; formas de transmissão; imunidade ao novo vírus; cuidados relacionados à prevenção, sintomas e tratamento; COVID-19 e vacina da influenza. O material educativo Cuidar em tempos da COVID-19 foi produzido e compartilhado com os líderes comunitários e disponibilizado aos respectivos grupos, e veio a ser disseminado nas suas comunidades como resposta a uma demanda de conhecimento que responde às preocupações vividas pelos que já se encontram em situação de vulnerabilidade estrutural.

Participação Cidadã em Ciência e Tecnologia; Promoção da Saúde; Isolamento Social; COVID-19

Resumen

Esta comunicación se centra en nuestra investigación e intervención en la promoción de la salud con pacientes y comunidades afectadas por diversas enfermedades infecciosas, en el proyecto Plataforma de Saberes. Este proyecto está desarrollado en el Instituto Nacional de Infectología Evandro Chagas/Fundación Oswaldo Cruz, en Río de Janeiro, Brasil, y promueve la implicación continuada de investigadores y profesionales de salud en la producción colaborativa de conocimiento sobre salud con pacientes y grupos comunitarios, y en su capacitación como promotores de salud comunitaria. Frente al nuevo escenario epidémico, surgió la demanda de un espacio de diálogo e intercambio de conocimiento sobre la prevención de la transmisión de la COVID-19. Debido a la interrupción de las actividades regulares de la Plataforma de Saberes, se promovió una estrategia que sirviese de vínculo integrador entre ciencia y sociedad y ayudase a superar el aislamiento social impuesto por la pandemia de la COVID-19. El grupo de WhatsApp posibilitó a los integrantes del proyecto, que participaran mediante la formulación de preguntas (audio) sobre la COVID-19, a través de la mediación de los líderes de grupos comunitarios. Los principales cuestionamientos de los participantes se relacionaron con factores de riesgo; formas de transmisión; inmunidad ante el nuevo virus; cuidados relacionados con la prevención, síntomas y tratamiento; COVID-19 y vacuna de la gripe. El material educativo Cuidar em tempos da COVID-19 se produjo y se compartió con los líderes comunitarios y fue puesto a disposición de los respectivos grupos, así como difundido en sus comunidades, en respuesta a una demanda de conocimiento que responde a las preocupaciones vividas por los que ya se encuentran en situación de vulnerabilidad estructural.

Participación Ciudadana en Ciencia y Tecnología; Promoción de la Salud; Aislamiento Social; COVID-19

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