


Interview with Ana Paula Cupertino

Entrevista com Ana Paula Cupertino

Interview conducted by:

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Interviewee:

Ana Paula Cupertino

Bachelor of Arts from the Federal University of São João Del Rey, Master of Arts in Social Psychology from the University of Brasília, and Ph.D from the University of California, Davis, in the United States, where she currently resides. Continuing her career, she completed a postdoctoral degree program in the Department of Preventive Medicine and Public Health at the University of Kansas Medical Center. As a social and behavioral scientist, for the last 20 years Dr. Cupertino is funded by the National Institute of Health (NIH) to conduct research in the area of cancer prevention. She has more than 100 published scientific articles on the use of technology in cancer prevention, randomized clinical trials for smoking cessation in communities with low access and use of evidence-based treatment, primarily among Latinos, immigrants, and rural communities in the United States, Puerto Rico, Guatemala, Mexico, and Brazil. She is currently a University of Rochester Medical Center Professor of Public Health Sciences and Oncology. She holds the positions of deputy coordinator of the Diversity and Inclusion Program and scientific director of the Surgical Health Outcomes & Reaching for Equity (SHORE). At the Wilmot Cancer Institute, she is the founder and associate director of the Center for Community Engagement and Outreach with the following objectives: (1) to monitor the epidemiological burden of cancer in 27 counties in upstate New York; (2) to foster community participation in identifying, prioritizing, and addressing the cancer cases with the greatest impact on specific communities; (3) to understand and design actions on community priorities in basic, clinical, and population-based research and to facilitate the participation of underrepresented minority groups in clinical trials; and (4) to disseminate evidence-based programs to promote equity and address community priorities across the catchment area and beyond.

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Abstract

In this interview with the journal *Saúde e Sociedade*, Dr. Cupertino talks about her actions to reach people under challenging situations, such as the COVID-19 pandemic. The dialogue aimed to learn about successful experiences capable of erasing or reducing the perpetuation of health disparities. In her professional career, she worked at the Wilmot Cancer Institute (WIC), her current employer, always supported by important Brazilian references such as Paulo Freire. Her research work uses strategies that go beyond academic issues and bring the community to the forefront, enabling an accurate translation process. Finally, she considers the partnerships with Latin American countries as fundamental for developing health actions towards immigrants living in the United States, since the social relations variable is crucial for community health. Dr. Cupertino's testimony thus reveals a distinct look at distant realities, which can contribute to important reflections in a globalized world where exchanges are increasingly frequent.

Keywords: Minority groups; Community Health Services; Public Health; Cancer

Resumo

Nesta entrevista à revista *Saúde e Sociedade*, a Dra. Cupertino faz um relato do seu engajamento para alcançar pessoas em situações desafiadoras como a pandemia de covid-19. O diálogo buscou conhecer experiências exitosas capazes de interromper ou reduzir a perpetuação das disparidades em saúde. Em sua trajetória profissional, perpassou pelo Instituto de Câncer de Wilmot (WIC), onde atua no momento, sempre apoiada em referências brasileiras importantes como Paulo Freire. No seu trabalho, percebe-se a utilização de estratégias que ultrapassam questões acadêmicas e trazem a comunidade para o protagonismo da pesquisa, permitindo que o processo de translação ocorra apropriadamente. Por fim, define as parcerias com países da América Latina como fundamentais para o desenvolvimento de ações de saúde direcionadas a imigrantes que vivem nos Estados Unidos, uma vez que a variável relações sociais é determinante para a saúde de uma comunidade. A fala da Dra. Cupertino revela, assim, um olhar distinto sobre realidades distantes, mas que podem contribuir para reflexões importantes em um mundo globalizado, no qual intercâmbios são cada vez mais frequentes.

Palavras-chave: Grupos Minoritários; Serviços de Saúde Comunitária; Saúde Coletiva; Câncer.

Verônica Cortez Ginani: Recent world events, such as the COVID-19 pandemic, have highlighted important issues on public health care. The deficiencies of health care systems around the world were exposed and vulnerable populations, once again, were the most affected. However, this is not a new topic in your career. Considering your career trajectory, how do you see the inclusion of minorities, understanding their particularities, in research in the field of public health?

Ana Paula Cupertino: The Wilmot Cancer Institute (WCI), like the rest of the country, faced unprecedented challenges during the COVID-19 pandemic. This public health crisis occurred when I was hired to develop WCI's Community Outreach and Engagement Program. At that time, we were in the stage of mobilizing and integrating communities to establish priorities in research, participation in randomized clinical trials, education and program promotion actions, as well as in the implementation of research with community participation. While the community was focused on surviving COVID-19, we were concerned about the growing disparities found in the epidemiological study of cancer in our area compared with the state and country. For example, we knew that tobacco use and the incidence of tobacco-related cancer and mortality were high in racial and ethnic minorities, rural communities, and residents in areas with high rates of deprivation.

Another concerning aspect was the abandonment of cancer prevention achieved with studies on mammography, colonoscopy, and cervical cancer. As a consequence, cancer would be detected late and the consequences would be disastrous. We couldn't stop preventing cancer and we needed to understand the implications of COVID-19 on cancer care! Despite the limitations imposed by the pandemic, our efforts grew exponentially, since we had the partnership with community leaders, citizens and agencies united with the same goal. Following the true principles of community-based participatory research, in which community and academic priorities occupy a similar space, we expanded from 26 to 54 community members gathered entirely remotely. In partnership with community efforts for testing and vaccination, we collected data on

barriers and facilitators of cancer treatment during the COVID-19 pandemic. The sample included 200 community members with diverse backgrounds (19% LGBTQIA+ communities, 20% rural workers, 12.5% rural, 47.5% mainly Spanish-speaking Latinos, 21.5% Black). The survey results indicated that specific communities (e.g., African American and LGBTQIA+) were facing challenges in following Centers for Disease Control and Prevention (CDC) guidelines regarding COVID-19 prevention and highlighted the negative implications of social isolation and financial burdens.

The ability to adapt with agility and undertake virtual engagement activities demonstrates the readiness of communities to join academia in dealing with COVID-19 and cancer, even during a public health crisis. We learned that dissemination, research, and community engagement activities were less expensive but highly effective using virtual modes (Facebook Live, Zoom). In summary, we learned that by maintaining the community engagement principles of trust, transparency, and robust two-way partnership, it is possible to achieve high community participation across the research outreach area. As vaccination rates increased, during COVID-19, our team participated in more than 200 in-person community health events (e.g., dissemination of educational materials, street walks, soccer league participation, and community participation) and 50 neighborhood walks with members and organizations of the Wilmot Community Cancer Action Council (CCAC) to connect underserved communities with cancer prevention, research, clinical trial, and education programs.

Verônica Cortez Ginani: Scientific knowledge can be understood as the result of the convergence between the researcher and a social and historical context. In the field of public health, this finding begins in the 1940s, as criticism of a specialized and fragmented medical model, present in the United States, which did not serve the interests of the community and increased the costs of treatment. The initial reflection of this movement was preventivism (preventive medicine), with curricular changes in medical programs in the 1950s, in the same country, and with

worldwide repercussions. The idea was, at that time, to broaden the view on the individual, understanding them comprehensively. The development of this movement, also in the United States, was the rise of community medicine in the 1960s, as a result of popular and intellectual mobilization around social issues (Osimo; Schraiber, 2015). All these movements evolved from the understanding that the knowledge expressed by the community is essential for directing actions in the health area. However, it was perceived that it is also challenging. First, because it requires a delicate and insightful movement for learning about it, since access to this information requires joint work based on a need recognized by both the community and the researcher. In this sense, how is it possible to integrate research and community?

Ana Paula Cupertino: As researchers, it is imperative that our research with communities reflect the evidence of the models developed by Paulo Freire. In this sense, our work on cancer prevention in several communities achieved important results following the principles of community-based participatory research that is consistent with the “theory of the oppressed,” a model advocated by Paulo Freire. The research model based on community participation follows the following assumptions: (1) community with researchers identify and define the problem to be studied; (2) community participates in leadership with the power to guide decisions with health professionals, researchers and leaders; (3) community participates in all stages of research including the definition of content and means for implementation of interventions; (4) community guides recruitment following principles of diversity, inclusion and equality in research; and (5) community informs the interpretation of data and dissemination of results in the community and in scientific circles.

The first step, well before starting a research program, aims to form a coalition between community and researchers. In this sense, at Wilmot, we convened the CCAC, which became the cornerstone of all community-academia partnerships carried out by our researchers of basic science, programs for clinical and behavioral research. The CCAC

determined its own mission: “To work together today to reduce the burden of cancer tomorrow.” In addition, it defined as objectives: (1) to establish goals to identify high-priority research, dissemination and education initiatives; (2) to foster participation in clinical trials; (3) to increase the performance of participatory research that responds to community aspirations; and (4) to promote equity. As a result, 104 community members have participated in the CCAC since its establishment, and 54 members have attended more than 50% of the meetings. CCAC members include community health educators, cancer survivors, patient advocates, and the team composed of representatives from 46 community organizations that span the entire coverage area of the cancer center. These organizations have partnered on community events, including health fairs and educational forums, to expand the reach and responses of Wilmot researches across the region. CCAC members voted on four priorities for action and organized themselves into working groups: “Primary prevention,” “Survivor support care and care,” “Rural integration,” and “Community research.” Each group, in collaboration with researchers, receives a pilot resource to implement initiatives in relation to the identified priorities. The results of these activities carried out by community representatives together with researchers direct new research projects, always respecting methodologies and approaches that aim to reduce disparities in cancer. The individual CCAC working groups meet up to two times a month to work on priority research projects and implement components of the logical model. Thus, they empower the voice of the community at the WCI. In addition, CCAC leaders meet with the Cancer Center director monthly and participate as leaders in different committees, such as the “clinical trials office,” “training and education curriculum” etc.

Verônica Cortez Ginani: All health actions, including cancer prevention and treatment, depend on the possibility of making medical protocols a reality for communities. This translation process is based on well-planned strategies that involve, among others, contacting the community leader and recruiting the community to participate in the actions. According

to your experience, what investments are needed in this regard for community intervention research to be successful?

Ana Paula Cupertino: The major resource needed to implement community-based research is human resources committed to the CBPR model. CBPR is truly built with researchers and community representatives together. This is not an easy process and requires time in the developmental stage. In the developmental process, there is the establishment of the pillar, the foundation, the integration of academic knowledge with community knowledge as a whole. Thus, everyone is committed to a common goal: understanding health disparities. By understanding the roots and factors influencing disparities, we begin to develop actions and interventions that enable us to reach the scientific evidence that can later be disseminated at populational levels. However, once this partnership is established, the results are quite positive.

Financial resources are also important. The results are in the long term and high investments are required. I have a work of more than 15 years to understand why Latinos in the United States, Mexico, Puerto Rico, and Brazil smoke. We also want to know how interventions using technology to inform behavior change combined with medication prove highly effective compared to a control group receiving only educational material. In the United States, it is possible to identify financial resources in government entities, research funding centers or resources destined to community organizations. In short, resources are often abundant, but they fail to achieve the goals necessary for positive change in a health reality because they lack commitment to scientific models built with the community. This leads us to reflect on how, in countries such as Brazil, actions with scarce funds have a much more significant impact on the community. Possibly it is a response to the presence of true empowered and motivated researchers and community leaders in health promotion. It reflects the use of principles of work based on Freire: respect, transparency, honesty, sustainability and responsibility.

Verônica Cortez Ginani: Your reality of action provides a context of great gender, cultural, ethnic, and racial diversity. Simultaneously, it is common the dissemination of research that reveals a certain distance between minority populations and social support systems, such as with the medical community (Amarasekera et al., 2019). These situations end up contributing to the perpetuation of health disparities. In this sense, some strategies can be explored to mitigate the evident disparities in cancer incidence and mortality rates among racial and ethnic minorities, in the American context. One of them is the enrollment of these populations in randomized clinical trials for research addressing cancer. The first step in this direction would be the cultural and linguistic adaptations of educational materials. This is followed by the use of patient navigators, who are people trained to assist patients in the processing through the health care system, and, finally, the construction of continuous community partnerships (Vuong et al., 2019). Could you share any of these experiments with us? How do you envision these actions occurring in Latin American countries, including Brazil?

Ana Paula Cupertino: This is certainly a strategy. With regard to the “patient navigator” or community health agent (CHA), we can speak with great pride that these are models originating in Latin American countries. The CHAs, or health promoters, specifically, are Primary Health Care (PHC) agents that consist in a collective health model developed in Brazil and other Latin American countries, such as Mexico, based on Paulo Freire, and are part of the culture of this population.

Here in the United States, we still have great difficulty implementing this figure, which is not seen as part of the health care system. What exists here is the “patient navigator” within the hospital. All strategies aimed at supporting patients in facing barriers, such as caregivers and other different levels of partnership with the individual, are within the hospital. In this sense, Latin America differs and is a benchmark whenever one thinks of this person who is within the community and is associated with it, not as part of the research team or within the hospital.

In the United States, the idea is that individuals, after receiving their service in secondary and/or tertiary health care, return to their routine and have to deal with a series of medical recommendations such as physiotherapy, use of medicines and nutritional guidelines, which are often obstacles to the implementation of the prepared health care plan. All these difficulties interfere with the implementation of the health care plan and the maintenance of this individual in a health trajectory. Therefore, there is a very important indicator, rehospitalization, which highlights the work of “patient navigators.” This figure can support individuals at the time they leave the hospital, following a cancer or surgical treatment, for example. However, the gap within the community must be filled, unlike Brazil and Mexico, which despite their limitations already have this individual, who is the CHA or health promoter. It would be the equivalent of the health referral and counter-referral system in Brazil. That is, there must be a place within the community to overcome the social determinants of health that are the root of the factors that worsen health outcomes.

It is considering this model that our cancer center is working. For example, although screening tests, such as mammograms, colonoscopies, among others, are common and indicated procedures, they are still below what is desired in needy communities. In order to change this situation, the presence of “patient navigators” is essential to assist in enabling these procedures. Today, in the United States, health care systems provide a very detailed assessment of the social determinants of health, which are available in the medical record. Thus, this enables “patient navigators” to trace the barriers to accessing screening tests, such as language, transportation, domestic violence, etc., and seek solutions to overcome them. Then, individuals are able to complete the screening tests or undergo the necessary medical examination. However, what is still missing is the follow-up, when they are in the community and may still need to undergo a biopsy or receive an exam result. As there is no guidance and continuity in the contact, patients often does not return. When they return, they are already in a more advanced stage of cancer, which could have been avoided if this community model existed.

Verônica Cortez Ginani: World agreements are being jointly designed to advance global health. The United States has a globally respected tradition of funding global health programs, primarily related to low- and middle-income countries. What would be the prospects of possible partnerships entered into at the University of Rochester and Brazilian universities for health research? What are the projects in which you are involved in other Latin American countries besides Brazil?

Ana Paula Cupertino: Unfortunately, American investment in research with international partnerships has been decreasing over the years, compared to 10-15 years ago. This collaboration was greatly compromised by the pandemic and will probably take a long time to recover. Resources are quite scarce at the level of the National Institutes of Health or even the FDA (Food and Drug Administration) or CDC. The fact is unfortunate for the role that the United States has always had in global health, in the academic sphere. However, this is the current reality of the country and will, possibly, result in negative consequences for Latin America. Regardless of this limitation of federal government resources in global health, I think that in the case of partnerships, of researchers like me, it remains a priority. Always, when we carry out activities in Latin American countries, it is possible to learn a lot. When we returned, we were able to implement more effective actions with Latino immigrants.

Approximately nearly 20% of the American population today is Latino. Hence, in my research program, this partnership continues and will grow after COVID-19. These partnerships can happen in educational terms and through the exchange of knowledge between research groups. I am always very interested in the groups that are working with community research. Another aspect is the assessment of differences between countries and the United States. So today I have some important partnerships. With Mexico, there has been a very solid relationship for 20 years or more. Especially since most immigrants here in the US are Mexican.

Accordingly, several studies were carried out as a result of this partnership. For example, there is evidence on

the comparison of efficacy between interventions with Mexican smokers in the United States and Mexico. It is fabulous to understand that, despite social barriers, financial challenges, and limits on access to health care programs, smokers in Mexico have a much better outcome than in the United States. The outcomes can be attributed to some variables, such as social discrimination and lack of a sense of community. Within the United States, there is a lack of social assistance and support, among other variables, which can compromise health. Therefore, Mexicans who stay in Mexico have a much better health profile than those who come here. Another important work is that carried out with Guatemala. We carry out a work of great effect in Guatemala in Indigenous communities in the prevention of pelvic cancer. There are several barriers to reaching this community, such as access to them, which are located around the Santa Catarina Palopó lake. However, in general, it is a partnership that also involves a lot of emotion and affection. With Brazil, there is a partnership with the Federal University of Juiz de Fora and the intention to expand to other institutions in the coming years.

Verônica Cortez Ginani: I hope that it will really be possible to strengthen these partnerships to expand

the impacts generated by research of excellence. Thank you very much for your availability and I think we were able to meet the main objective of the interview.

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