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Embodying 'health citizenship' in health knowledge to fight health inequalities

Incorporando 'cidadania em saúde' ao conhecimento de saúde para combater as desigualdades na saúde

Incorporando 'ciudadanía en salud' en el conocimiento de salud para luchar contra las desigualdades en salud

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ABSTRACT

This paper wishes to contribute to the debate around citizen participation in health system decision-making that has been present internationally for the last 30 years. I argue that if we aim to change health inequalities, health professionals and planners need to understand the illness and health service experience of citizens. The concept of 'health citizenship' introduced here refers to health knowledge that integrates the lay knowledge of patients and that this integration is translated into health actions such as clinical communication and the planning of health care, programs, and policy. We illustrate our argument with the two cases: health literacy and the promotion of breastfeeding in a Canadian population living in context of poverty. This paper then concludes by addressing the leadership role, Brazilian graduate nursing schools can play in promoting 'health citizenship' and by doing so, contribute to fight health inequalities.

Key words: Health citizenship; Health literacy; Breastfeeding; Nursing; Illness meaning.

RESUMO

Este trabalho pretende contribuir para o debate em torno da participação do cidadão na tomada de decisão do sistema de saúde que está presente no âmbito internacional nos últimos trinta anos. Defende-se que, se pretendem mudar as desigualdades na saúde, os profissionais e planejadores da saúde precisam compreender a experiência dos cidadãos com a doença e os serviços de saúde. O conceito de "cidadania em saúde", aqui introduzido, se refere ao conhecimento em saúde que integra o conhecimento leigo de pacientes e que essa integração se traduz em ações de saúde, como comunicação clínica e planejamento de cuidados, programas e políticas de saúde. O argumento é ilustrado com dois casos: o letramento em saúde e a promoção da amamentação materna em uma população canadense que vivem em contexto de pobreza. Em seguida, conclui-se, abordando o papel de liderança que os cursos de pós-graduação em enfermagem no Brasil podem desempenhar na promoção da "cidadania em saúde" e, assim fazendo, contribuir para combater as desigualdades na saúde.

Descritores: Cidadania em saúde; Letramento em saúde; Amamentação; Enfermagem; Significado da doença.

RESUMEN

Este trabajo pretende contribuir al debate en torno a la participación ciudadana en la toma de decisiones del sistema de salud que ha estado presente a nivel internacional durante los últimos 30 años. Sostenga-se que, si queremos cambiar las desigualdades en salud, profesionales y planificadores de la salud deben comprender la experiencia de los ciudadanos con la enfermedad y los servicios de salud. El concepto de "ciudadanía en salud", aquí introducido, se refiere al conocimiento de la salud que integra el conocimiento laico de los pacientes y que esta integración se traduce en acciones de salud, tales como la comunicación clínica y la planificación del cuidado, programas y políticas de salud. El argumento es ilustrado con dos casos: la educación para la salud y la promoción de la lactancia materna en una población de Canadá que vive en el contexto de la pobreza. Se concluye tratando el papel de liderazgo que los cursos de postgrado en enfermería de Brasil pueden desempeñar en la promoción de la "ciudadanía en salud" y, al hacerlo, contribuir a luchar contra las desigualdades en salud.

Palabras clave: Ciudadanía de la Salud, alfabetización para la salud, lactancia, enfermería, significado de enfermedad.

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At the beginning of nineteenth century, the French politician, sociologist, and philosopher, Alexis de Tocqueville, visited North America and returned to France so impressed by the progress of this society toward equality that he wrote the book *De la Démocratie en Amérique* (1835), an essay since considered a precursor of democracy in much of Europe. His famous labeling of modern society as democratic refers, as he explained, to the political power civilians hold in exercising their citizenship through the expression of majority opinion. While majority opinion often changes in democracy, de Tocqueville argued that the political influence and power of the latter is that which remains permanent and most legitimate. Today, the notion of citizenship rights is more encompassing, in particular, following Marshall's seminal book⁽¹⁾, which proposes to include legal, political, and socioeconomic rights as integral aspects of citizenship. According to the latter, legal or civic rights are what "enable the individual to participate freely in the life of the community, such as property and contractual rights, rights to freedom of speech, of thought and of religious practice, as well as right to assemblies and association." Political rights, on the other hand, are what entitle citizens to participate in the government of the community, such as for example, the right to vote. Finally, social and economic rights are those that enable the individual to participate in the general wellbeing of the community. They include rights to health care, education, and welfare. However, if these rights are not formally inscribed in the constitution, their access is subjected to the discretion of the gatekeepers of health services⁽²⁾. Moreover, Marshall argued that without these three rights being guaranteed by the state, gross inequalities of wealth, education, and status are to be expected and thus, in turn, threaten the equality of civil and political rights⁽³⁾. Based on the same logic, Kickbush⁽⁴⁾ proposed that in modern democracies, equal access to health should be considered *de facto* a right for all citizens.

That being said, whether or not rights to health care are inscribed in the constitution, citizens can nevertheless participate in the governance of health services to maximize their accessibility to appropriate health services. The debate around citizen participation in health system decision-making has actually been present internationally for the last 30 years or so⁽⁵⁾. However, many have argued that citizens involved in health promotion, health governance, and other public health administration and planning activities are not typical of the larger community⁽⁶⁾. In fact, they are usually considered to belong to the privileged strata of society, thus suggesting that only the empowered participate in the governance of health services. Following this position, others have found that the "role of communities in influencing decisions and selecting priorities is in reality, considerably less than the level hoped by sustained political rhetoric favoring citizen participation in the governance of health services"⁽⁶⁾. One study, however, has illustrated that even though participation represents a challenge for most vulnerable groups, it is still possible⁽²⁾. In the above mentioned study of a mental health patient association, the authors found that these patients were able to participate actively in the governance of mental health services. By

doing so, they ensured the respect of their rights, enhanced the accountability of health services, and widened their participation in society as "active citizens." This participation constitutes an important step for mental health patients who face daily social exclusion because of the stigma attached to their type of illness. The study, however, seems to be an exception in the body of literature related to participation in governance of health services, suggesting that participation is not a pervasive phenomenon, but remains a challenge for vulnerable or marginalized groups. Furthermore, beyond the issue of citizen participation in health service governance, the participation of these groups in the area of health policy itself has been markedly neglected, a situation that some explain by the strong hierarchy known to exist between physicians, other health professionals, and with patients⁽⁴⁾.

Whether they pertain to policy orientation or health care delivery, debates on the relevance of citizen participation in health governance also recognize that participation relies on the capacity of citizens to make sound health-system decisions⁽⁵⁾. In this perspective, it is often argued that health professionals are those who are best positioned to provide scientific knowledge of "what constitutes good health care and health services"⁽⁷⁾. In this context, lay citizens are considered capable of assisting in the formulation of sound public and medical policies only, if they have a good understanding of this complex type of knowledge. On the other hand, Prior proposed a convincing counter-argument by stating that lay participation in health governance is an entitlement by virtue of the experiential knowledge citizens have of their own needs and experiences—what is referred to in the literature as "experiential participation"⁽⁸⁾.

I argue in this essay that if we aim to change health inequalities that still prevail in most democracies⁽⁹⁾, not only do citizens participating in health governance need to understand the issues at stake, but health professionals also need to understand the illness and health service experience of citizens. In other words, decision makers and health professionals need to access and use health knowledge that integrates the knowledge citizens have of their illness and health service experiences. *Health citizenship*, the concept I present here, involves that health knowledge embodies the illness meaning and experience of patients from the inception of health knowledge to its translation into actions pertaining to clinical communication, health care delivery, as well as public health programs and policy. The proposal of this argument is based on the belief that integrating illness meaning and experience in health knowledge production and action can contribute to resolve four predicaments known to contribute to health inequalities affecting vulnerable groups.

The first predicament is linked to the famous victim-blaming phenomenon. Indeed, many health or social services designed to help disadvantaged persons have unintentional iatrogenic effects⁽¹⁰⁾. Culpitt has discussed, for example, the long-term psychological effects of using social services, such as creating low-self esteem and reducing one's involvement in the decision-making process⁽¹¹⁾. Conversely, it is widely known that many health promotion programs fail to change

the health behaviors of the vulnerable groups they target, and consequently, the latter are often blamed for not adopting the healthy practices they are being taught to adopt⁽¹²⁾.

The second predicament refers to the fact that three civil rights – legal, political, and socioeconomic – while being intrinsically inter-dependant, also requires that members of society are equal⁽³⁾. So social inequality, in itself, infringes on other rights of citizens. Equal social worth requires that a minimum level of resources be availability to everyone, as well as a safety net ensuring a minimum of income, education, health, and housing, so that all individuals are able to enter the mainstream of society and fully exercise the totality of their rights. We know that these types of equalities are hard to find. The third issue, is the social stigma experienced by many vulnerable groups (i.e. mental health patients, the unemployed, the low income segment of society, immigrants, etc.) that are affected by inequalities of health. Stigma is known to affect negatively access to health and health care. A known way to counteract stigma is to have a sense of community belonging, in contrast to the sense of being marginalized or considered a second class citizen⁽¹³⁾.

Finally, the fourth issue, is that health actions and services are too often conceptualized and implemented while assuming that groups being aimed at, share compatible or replaceable constructs of health and illness while having the power to change their behaviors. Such a naïve position, often leads to the failure of public health actions and services while resulting too frequently in the above mentioned victim-blaming phenomenon known to undermine the health rights of vulnerable groups.

The case of health literacy is the first example I will present here to discuss the ways in which these type of predicaments can operate and affect the health knowledge being produced in relation to vulnerable groups. Health literacy, as defined by WHO is considered to be defined as the cognitive and social skills as well as the abilities of an individual to gain access, understand and use health information in ways that promote and maintain good health⁽¹⁴⁾. The health literacy movement is basically about improving health and reducing inequities by empowering both individual and communities to make informed and ethical decisions about their health⁽⁴⁾. Recently, empirically based research in the United States has concluded that people with poor health literacy are more likely to use emergency services, be hospitalized, be non-compliant to medication, and being more unlikely to use preventive services, with the effect that individuals with low health literacy incur higher health care costs. Following the production of this type of research, the health-related "incompetency" of these populations could rapidly be seen as problematic for society as a whole. As an example, Kickbush and Maag have emphasized that low health literacy may cost the US economy up to \$73 billion per year⁽⁴⁾. Notwithstanding its noble objective of reducing inequalities, the construct of "health literacy" is mainly portrayed as a competency problem of certain segment of the population. It also reflects the adoption of a top-down approach that focuses on the knowledge and

skills that incompetent strata of the population must acquire in order to optimize their use of health services.

The problem with this type of approach for resolving the problem of health inequalities is that it disregards the importance of illness meaning and experience as well as cultural knowledge and practices relative to health and illness that people refer to when they build their "competencies"⁽¹⁵⁾. Indeed a wealth of empirical research has underscored that "when processing new information or in making decisions, individuals actively construct knowledge along the lines of schemas informed by past experience rather than passive recall of isolated bits of information"⁽¹⁶⁾. Moreover, people with shared experiences and social contexts tend to have some degree of overlap among their themes, metaphors, and constructs—what is referred to as "cultural models"⁽¹⁶⁾. Others have shown for a while that these cultural models are in fact organized into shared explanatory models⁽¹⁷⁾ and prototypical illness experiences⁽¹⁸⁾ that constitute parts of popular theories of health and illness⁽¹⁹⁾ shared between members of specific cultural groups. In this regard, not recognizing the importance and value of this type of cultural knowledge and the need for groups to make sense of medical knowledge in relation to their own pre-existing lay systems of knowledge has much to do with the power of science and, in particular of medical science.

Foucault's revolutionary statement in his famous book *Discipline and Punish*⁽²⁰⁾, according to which power and knowledge are intrinsically inseparable, has particular resonance with regard to the issues of citizenship and the health inequalities faced by vulnerable populations. Foucault explores in his book the "micro-powers" that control all areas of society beyond the action of political agents and governments. He argues that knowledge and power are not only inseparable but actually complement each other in the governing of social relations within institutions such as prisons, schools, work, and of course, medical institutions. In the context of clinical communication. For example, doctors are too often considered the sole knowledgeable experts, while patients are considered lay neophytes in relation to their health problems. In this context, patient knowledge is often seen as incomplete or invalid. Patient narratives tend to be investigated by medical doctors mainly for identifying diagnostic categories, the first step in clinical work. Consequently, patient lay knowledge is disregarded in the clinical interview, while clinician knowledge is considered the expert knowledge driving the interview. In turn, medical expertise relies largely on the knowledge produced by evidence-based medicine and positivist science. The hegemony of medical knowledge in the clinical context stems, of course, from the power of medical institutions but also from the power positivist science holds in society. This hegemony all too often translates into patriarchal relations, which are expressed in clinical communications with patients but also between health professionals of different disciplines.

Recognizing that power and knowledge are inseparable, I thus argue that producing health knowledge that is

socio-culturally informed by participating citizens can actually allow for shifts of power in the clinical encounter but also in public health actions. Indeed, when cultural knowledge held by citizens is recognized as valid and useful in partnerships between health service “providers” and participants, it can stimulate the participants’ sense of ownership and power in decisions relating to their own health. In my experience, integrating participants’ social and cultural sources of knowledge alters traditional routes of knowledge production and translation while challenging traditional power structures and dynamics. These important issues can be explored through different forms of participatory research that aim to translate knowledge into social and health related actions.

Producing scientific knowledge that embodies health citizenship thus requires – from its inception to its translation into health care and public health action – integrating the voice of citizens. After all, it is citizens, by virtue of their civil rights and regardless of their social, economic, or health status, who benefit from health care and public health programs. This is why I have chosen, at this national conference of research in nursing, to talk about the importance of producing health knowledge that embodies health citizenship, and I strongly believe that graduate nursing schools in Brazil are especially well positioned to take leadership in this regard.

To support this position, in the following sections, I will first examine the international leadership that graduate nursing schools in Brazil have historically taken in the Americas. Secondly, I will underline the pervasive desire in nursing, as a health discipline, to maintain a distance from doctors, who hold hegemony over the medical profession. I will then explain how the dominance of positivist science and evidence-based medicine represents, in fact, an opportunity for graduate nursing schools in Brazil to further assert and develop their leadership in Latin America and the rest of the world by producing health knowledge that purposefully embodies health citizenship. This strategic choice would not only contribute to combating the health inequalities faced by vulnerable populations, but would, also contribute to enhancing the identity of nursing as a health discipline.

LEADERSHIP OF BRAZILIAN NURSING SCHOOLS

The first doctoral program of Nursing in the Americas was initiated in the United States at Colombia University in 1933 and at New York University through the latter’s doctorate of education program⁽²¹⁾. Brazil expressed its leadership by developing a doctoral program in nursing in 1981, thus much earlier than Canada and other Latin American countries. For example, in Canada, the first doctoral program was offered in 1991 at the University of Alberta. Venezuela’s first nursing PhD program was created in 1998, a full 17 years after Brazil’s. In 2001, some 20 years after the first PhD program was created in Brazil, nine PhD programs were offered by five Brazilian universities. Brazilian universities with mature doctoral programs also expressed their leadership internationally by assisting other countries outside Latin America to

develop their own doctoral programs⁽²¹⁾. The Brazilian PhD curriculum is similar to that of the United States, but with a stronger emphasis on epistemology, philosophy of science, and research methods. The expectations of the Brazilian programs are for PhD graduates to express their leadership in the health domain, contribute to the development of nursing knowledge, and improve the quality of nursing practice, education, and health care⁽²¹⁾. The purpose of doctoral studies is to prepare leaders in nursing and health care, with an emphasis on knowledge development. Its aim is also to produce experts as well as active citizen-scientists who shape health and social policy⁽²¹⁾. Following the Pan American Health Organization’s recent overview of the nursing work force in Latin America, some of the main challenges faced by the discipline of nursing include introducing nursing knowledge that demedicalizes training programs, promotes critical thinking and citizen awareness within a perspective of social justice for health, overcoming inequality and exclusion, and guaranteeing qualified health care for all⁽²²⁾.

One of the main purposes of a doctoral nursing program is therefore to produce knowledge that helps understand health inequality within context. Nurse scientists, however, in accomplishing their mission, are faced, as are other scientists, with the known limits of positivist science and evidence-based medicine, which are ill-equipped to address the complexity of context and inter-subjectivity involved in the inequalities of health^(12,23). Because of their realist ontology and objective epistemology⁽²⁴⁾, positivist research methodologies are unable to produce knowledge that integrates the voice and cultural knowledge of patient and communities that health services target.

Nevertheless, I do consider that the hegemony of evidence-based medicine, as well as its inherent limit for addressing contextual determinants, represents a real opportunity for nursing graduate schools. Indeed, graduate nursing schools could take leadership in adopting a different research paradigm, one that embodies an ontology, epistemology, and methodology that are better suited to address the socio-cultural determinants involved in the inequalities of health. In this sense, the constructivist paradigm, because of its relativist ontology, subjectivist epistemology, and related qualitative methodologies, is better suited to understand the role played by contextual determinants of health and the negotiations required to integrate cultural knowledge into health knowledge production. It follows then that the use of qualitative methods is better suited to understand the socio-cultural context of patient health behaviors and illness experiences, as well as patient-clinician interactions.

In this last part of my address, I will briefly discuss my second example that aims to illustrate how research projects can integrate the voice and knowledge of citizens into knowledge production and how this integration can be accomplished through a participatory approach we used in a study on breastfeeding determinants of a low-income group in Québec, Canada. In response to the World Health Organization’s⁽²⁵⁾ call to promote breastfeeding worldwide, the province of Québec (Canada) adopted a health policy in

which breastfeeding was one of five public health priorities⁽²⁶⁾. This was followed by the release of provincial breastfeeding policy guidelines, "L'Allaitement maternel au Québec: Lignes directrices (LD)" whose purpose was to further develop the policy and guide its implementation. Over the past decade, Québec has made remarkable progress in its goal to increase breastfeeding rates and regain a culture of breastfeeding throughout the province. Since 1997, the rate of breastfeeding initiation in Quebec has climbed dramatically from one of the lowest rates in Canada (60%), to one of the highest (85%)⁽²⁷⁾. These statistics no doubt reflect the contribution of the concerted public health action to promote breastfeeding that has occurred in the province since the release of the LD. However, compared to non-exclusive rates, the 2007 objectives set by the LD for exclusive breastfeeding were far from being met, with rates of exclusive breastfeeding at 52% at hospital discharge and 35% at two months, 20 % at four months, and 3% at six months post-discharge, thus remaining well below WHO recommendations^(28,29). Moreover, province-wide, women from vulnerable groups such as those living with high levels of distress, living in poverty, or having low birth weight babies were identified as breastfeeding less frequently and for shorter periods of time. In such circumstances, nurses working in community clinics (CLSCs) were facing difficulties promoting breastfeeding to low-income French-Canadian mothers, who, incidentally, also tend to have more low-birth-weight babies and suffer more often from psychological distress⁽²⁷⁾. Subsequently, the nurses expressed a need for producing health knowledge that would help reveal the determinants of low-breastfeeding rates among low-income French Canadians in Québec. The underlying objective of their request was that new knowledge be produced that would help them tailor their promotional and support efforts to the needs of this group of mothers, who by not breastfeeding, were contributing to reproducing, in their babies, the sharp health inequalities they themselves faced.

Consequently, I, along with several colleagues, developed a research project to study this predicament using qualitative methodologies and a cultural and participatory approach. In our project, low income French Canadian mothers participated in an ethnographic study on the cultural determinants of breastfeeding^(12, 26). During the last stage of the project, the mothers participated in focus groups to validate the ethnographic results of the study and to produce specific recommendations that would help guide breastfeeding promotion and services in the province of Québec⁽¹²⁾. Ten recommendations to guide policy, regional programs, and professional training were produced by mothers and then presented to a group of sixty participants composed of nurses, medical doctors, community workers, and regional health planners. After the presentation of these recommendations, the latter were invited to participate in additional focus groups to evaluate the acceptability and feasibility of each of the mothers' recommendations. The key stakeholders participating in these groups considered that eight out of the ten recommendations produced by the mothers were acceptable and feasible for

integrating into their breastfeeding promotion interventions. The project succeeded in integrating the participation of a vulnerable group (low-income mothers) into the production of new health knowledge (guiding of health policy and public health programming) and thus supported our goal of integrating cultural knowledge into health knowledge production, translation, and action. The process also suggests that by integrating the voice of even the most vulnerable citizens into the production of health knowledge, we can address some of the root causes of health inequalities that some groups face on a daily basis in their use of health services. Furthermore, health professionals confronted by the capacity of mothers to integrate their cultural knowledge to help guide policy, programs, and health care delivery, were exposed to their own "incompetency" in terms of lay knowledge and to the imperative of negotiating an approach to care that integrates both types of knowledge—cultural and biomedical.

CONCLUSION

The notion of citizenship introduced by de Tocqueville has expanded from the political arena to include the rights of access to health care, education, and minimal revenue that guarantee the expression of the totality of civil rights. Citizen participation in the governance of health care and policy is important in the fight against inequalities of health that still pervades in health care. However, participation remains a challenge for citizens belonging to known vulnerable groups of society. *Health citizenship* is a concept that refers to the importance of incorporating citizen's participation in the process of health knowledge production, translation, and action to better understand and manage contextual determinants governing health inequalities.

Producing health knowledge that addresses sociocultural determinants of health is important for vulnerable populations because such populations experience exclusion, social stigma, and inequalities regarding health. In light of the international leadership shown by Brazilian graduate nursing schools and their mission to address the inequalities of health and promoting citizenship, such programs are especially well positioned to integrate the participation of citizens into the production of health knowledge from inception to translation into care, services, and policies. By espousing this objective, the graduate nursing schools of Brazil can *de facto* promote the exercise of "health citizenship" of vulnerable populations and thus contribute to address the social determinants of health that affect these populations. By moving forward in this direction, the graduate nursing schools of Brazil can expand their role as leaders and as citizen-scientists who can contribute significantly to shaping health, health care, and health policy on a national and international level.

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