PSICOLOGÍA COMUNITARIA INTERNACIONAL

APROXIMACIONES A LOS PROBLEMAS SOCIALES CONTEMPORÁNEOS VOLUMEN II

2

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DAVID PÉREZ-JIMÉNEZ
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PSICOLOGÍA COMUNITARIA INTERNACIONAL: APROXIMACIONES A LOS PROBLEMAS SOCIALES CONTEMPORÁNEOS VOL. II

INTERNATIONAL COMMUNITY PSYCHOLOGY: APPROACHES TO CONTEMPORARY SOCIAL PROBLEMS VOL. II

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ÍNDICE GENERAL

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de riesgo y, de forma específica, en la violencia en grupos juveniles desde la integración de métodos cualitativos y cuantitativos, desarrollando una extensa labor de formación y asesoría con organismos e instituciones en este ámbito. Recientemente se ha dedicado al desarrollo de experiencias de investigación-acción con agrupaciones juveniles de calle.

Judith Sixsmith is a Professor of Public Health Improvement and Implementation at the University of Northampton in the United Kingdom. Her expertise lies in qualitative research on issues of social marginalization, focusing particularly on participatory action research in the area of ageing and technology as well as access to services. Aiming to bridge divides between theory, policy and practice, her work often takes bottom up, experiential perspectives through which policy and practice are explored. Here, understanding the role of health and social care service provision and delivery has been particularly important, not just in terms of facilitating inter-professional working between commissioners, service providers, community residents and academics, but also in trying to make a difference to the everyday quality of life and well-being of people who are seldom heard.

Marion Terenzio is Vice President for Academic Affairs and Dean of Faculty, Bloomfield College in New Jersey. Her primary interest is on facilitating student transitions, particularly minority students, into and through their college experiences within the context of the heightened focus on globalization in higher education settings. Her research emphasizes the role of students and faculty engagement and the relationship between students and faculty.

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16 A PSYCHO-ONCOLOGICAL APPROACH TO ADDRESSING CANCER DISPARITIES IN NIGERIA[1]

David Lounsbury[2]
Chioma Asuzu, Adebola Adedimeji
Ime John, Kim Chung

ABSTRACT

We describe the formation of a specialized, international research partnership between two university communities: the University College Hospital (UCH), University of Ibadan, Nigeria, and the Albert Einstein College of Medicine (Einstein) of Yeshiva University, Bronx, New York, USA. Our partnership is focused on cancer. It seeks to establish a platform for a wide variety of prevention and control activities, including cancer surveillance, community outreach and education, screening and diagnosis, treatment and post-treatment (survivorship), as well as palliation. Our approach is grounded by principles of psycho-oncology, an emerging sub-discipline of research and clinical intervention in cancer, and uses psycho-social and behavioral research as a means to build 'collaborative capacity' and to prioritize and manage resources for patients, families and health care professionals.

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[2] The authors wish to thank Dr. Vic Sidel, Professor Emeritus of and founding member of the Department of Family and Social Medicine at the Albert Einstein College of Medicine; Dr. Jimmie Holland, Attending Psychiatrist, Department of Psychiatry and Behavioral Sciences, Memorial Sloan-Kettering Cancer Center, a pioneer of the field of psycho-oncology; as well as Prof. Michael Asuzu of the University College Hospital, Ibadan and Dr. Alyson Moadel, Albert Einstein College of Medicine, for their personal commitment and support in fostering our collaborative research in global cancer prevention and control.

Describimos la creación de una asociación internacional especializada entre dos instituciones de educación superior: University College Hospital (UCH), Universidad de Ibadan, Nigeria y el Colegio de Medicina Albert Einstein en la Universidad de Yeshiva, Nueva York, Estados Unidos. Nuestra asociación está enfocada en el estudio del cáncer. Buscamos establecer un foro desde el cual se realicen actividades de prevención, investigación, diagnóstico y educación a la comunidad, tratamiento y post-tratamiento (supervivencia) y cuidado paliativo. Nuestro método se distingue por la aplicación de aspectos psicológicos, sociales y conductuales como medio para diseñar e implementar iniciativas de fortalecimiento de las entidades colaboradoras. Estas iniciativas están fundamentadas en los principios de la psico-oncología, una sub-disciplina emergente de investigación e intervención clínica del cáncer.

In this article we describe the formation of a specialized, international partnership between two university communities: the University College Hospital (UCH), University of Ibadan, Nigeria, and the Albert Einstein College of Medicine (Einstein) of Yeshiva University, Bronx, New York, USA. This partnership tests a novel approach to improving health care delivery in places like Nigeria, a low income country, as defined by the World Bank's estimates of gross national income (GNI) of US $995 per capita, or less. Substantively, our partnership seeks to create a model for implementation of comprehensive cancer prevention and control research activities – including cancer surveillance, community outreach and education, screening and diagnosis, treatment and post-treatment (survivorship), as well as palliation.

Community psychology, which embraces an ideology of social action, can aid in understanding how to intervene to address the complexities of cancer disparities in diverse, resource-constrained settings. Hersch (1972), a founder of the field of community psychology, referred to social action as a third frame of reference, building upon the clinical and the public health perspectives that underpin the science and practice of psychology in the United States.

The clinical framework stems from the medical model. People are patients, and their individual wellbeing is the fundamental, or key, object of focus. The clinical aim of intervention is to treat the individual so that his or her condition is cured or so that its consequences are minimized. Effective clinical treatment requires specialized infrastructure and well-trained, skilled professionals, such as physicians, psychiatrists, and psychologists. The public health frame of reference shifts focus from the individual to the population as a whole. The goal of a public health intervention is to reduce the impact of a disease and, in particular,

to reduce its incidence, if not to find a way of preventing it altogether. The social action frame of reference, as defined by community psychologists, views the individual as embedded within a particular ecology comprised of multiple, dynamic, interactive forces. In the context of the emerging relationship between the UCH and Einstein, social action takes the form of on-going, collaborative partnership.

While we are by no means the first to develop a partnership addressing cancer disparities in resource-constrained settings, we believe our approach is distinguished in that it is grounded in principles of psycho-oncology (Holland et al., 2010) and strives to leverage these principles as a means to build collaborative capacity (Foster-Fishman, Berkowitz, Lounsbury, Jacobson & Allen, 2001). In other words, we intend to use psycho-social and behavior research findings to help partners at UCH and Einstein prioritize the design, development and management of new cancer resources for patients, families and health care professionals in Nigeria.

Need for Alternative Way to Address Global Cancer Disparities

Psycho-oncology is an emerging sub-discipline of research and clinical intervention in cancer. The Institute of Medicine describes psycho-oncology as an intervention science that enables cancer patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioral and social aspects of cancer, cancer treatment, and its consequences so as to promote better health and improved quality of life (Adler & Page, 2008). Psycho-oncology is concerned with two categories of inquiry and intervention: a) psychosocial: the psychological and social response of the patient at all stages of disease and of their families, and b) psychobiological: the psychological, social and behavioral issues that impact or influence morbidity and mortality (Holland, et al., 2010). The overarching principle of psycho-oncology is that recognition that complete care includes both medical and psychosocial intervention. As such psycho-oncology seeks to identify and address psychosocial needs as they unfold, for patients, their providers, and their families (Adler & Page, 2008).

Collaborative capacity refers explicitly to the conditions that facilitate effective working relationships and sustainable organizational and community change. It is defined by four critical levels, namely: a) member capacity – the skill/knowledge and motivational sets that stakeholders require to collaborate effectively; b) relational capacity – the development and sustainability of social relationships directed at attaining desired goals; c) organizational capacity – the ability to develop effective leadership, administrative procedures, resource management,

and open communication channels; and d) programmatic capacity – conditions needed to either develop, implement or disseminate new research and programs to patients, providers, and families served by the UCH. Foster-Fishman et al. (2001) affirm that there is no one best way to design or foster partnerships for change, as organizations like the UCH and communities like Ibadan, Nigeria are complex and dynamic.

Our review of the literature on the topic of capacity building in global cancer prevention and control indicated that, to date, it has been informed almost exclusively by clinical and public health frames of reference (e.g., epidemiological, medical, and public health). In general, the model described emphasized the following aims: a) install systems for on-going surveillance (i.e., to understand need and make smart investments in treatment resources), b) foster primary prevention (e.g., minimize tobacco use), c) foster secondary prevention (i.e., screening services, e.g., mammography), and then d) expand and maintain facilities for diagnosis, treatment and palliation (CanTreat International, 2010; Farmer et al., 2010; Krown, 2011; Mellstedt, 2006; Shulman, Willett, Sievers & Knaul, 2010). In addition, the current literature discusses how to foster cost-effectiveness (Groot, Baltussen, Uyl-de Groot, Anderson & Hortobágyi, 2006; Kerr & Midgley, 2010), how to 'scale-up' (CanTreat International, 2010), who should fund 'scale-up' projects (Magrath, Bey, Shad & Sutcliffe, 2010), and how such investments can be mutually beneficial to all partners (Anderson, 2010).

Although what is called for in the current literature is practical, strategic, and arguably ethical, most of these works did not so much as mention the unmet psychosocial or psychobiological needs of patients, or the ability of providers to treat these needs. One recent article, the consensus statement from the Breast Health Global Initiative (Harford, Otero, Anderson & et al., 2010), listed psychosocial services as a 'basic resource' for cancer patients in all low and middle sources countries (LMCs}. Otherwise, in the literature we found authors ignore the psycho-oncology principle of holistic care, blending both medical and psychosocial interventions (Adler & Page, 2008).

Cancer Morbidity and Mortality in Nigeria

Global surveillance reports show that cancer is now a leading cause of death worldwide, surpassing mortality attributed to AIDS, tuberculosis, and malaria combined (CanTreat International, 2010; Farmer, et al., 2010). The number of cancer cases is expected to double over the next 15 years, with up to 70% of the 20 million of the expect new cases of cancer to originate in LMCs (Mellstedt, 2006).

Nigeria, like the majority of countries in Africa, reports approximately 101,800 new cases annually (IARC, 2010). This rate will be compounded by continued rapid increase in population growth (Library of Congress, 2008; WHO, 2005), adoption of western lifestyles (smoking, high fat, calorie-dense foods; lack of physical exercise), and increased exposure to toxic environments (Farmer, et al., 2010; Lingwood et al., 2008; Porter, 2008). This, augmented by inadequate access to preventive education, screening, and quality cancer treatment, as well as *high levels of cancer-related stigma serve to keep survival rates in these countries* distressingly low (Mellstedt, 2006; Ngoma, 2006). These dynamics explain how Nigeria, the most populous country in Africa (148 million), is currently reporting less than a 40% five-year survival rate, which is among the lowest rates of survivorship worldwide (García et al., 2007; Mohammed, Edino, Ochicha, Gwarzo & Samaila, 2008).

The majority of cancers among Nigerians, in excess of 70%, are diagnosed at an advanced stage of disease, leading the lowest 5-year survival rates in the world. Moreover, data indicate that age of diagnosis in Nigeria is much younger, approximately ten years earlier, than in high income countries (Anyanwu, Egwuonwu & Ihekwoaba, 2010; Ogunbiyi & Shittu, 1999).

Contemporary Challenges to Health and Health Care Delivery in Nigeria

There are many contemporary challenges to health care delivery in Nigeria. Barriers exist at multiple levels, operating within the context of particular social, cultural, and economic circumstances. It is generally agreed that poverty poses the greatest challenge to overcoming cancer health disparities (Freeman & Chu, 2005). In Nigeria it is estimated that 70% of the population currently live below the poverty line, with many Nigerians earning less than one US dollar per day (Anyanwu, et al., 2010). Although a former health care policy provided low or no-cost care to patients treated at Nigerian Government hospitals for cancer or other serious diseases, as well as to those who sought care a teaching hospitals like the UCH, economic difficulties have forced elimination of these benefits. Consequently, most Nigerians do not have the personal or familial resources to cover the costs of treatment, which often compels patients' to forego necessary care (Anyanwu, et al., 2010).

Poverty has also been shown to impact the number and quality of care settings as well as the qualifications of the providers who staff them (e.g., fewer board-certified physicians) (Bach, Pham, Schrag et al., 2005). Like other resource-constrained settings, efforts in Nigeria to develop cancer prevention and control programs have been hampered by lack of investment in health care infrastructure

and multiple other competing health priorities. Although a network of teaching hospitals has been established in Nigeria, it is not adequate to meet the demand. Consequently, at sites like the UCH, it is not uncommon to find that cancer patients have traveled great distances to receive care, and that they must wait for days or weeks to receive treatment.

Culture is also a major contributor to poor cancer outcomes in Nigeria. For example, in Nigeria research studies have documented that patients often favor treatment by a traditional healer or other non-orthodox medical professional. Such preferences or choices are found to have delayed access to medical services by six months or more post-initial symptom. At the UCH, more than 70% of all cancer patients who present for treatment are diagnosed with last stage disease (Solanke & Adebamowo, 1996). Culture can affect how information is processed about cancer prevention, treatment and care. Trust in medical providers is also an issue. In one study, investigators reported that a high proportion of patients believed that hospital-based care of cancer leads to worse outcomes, and consequently avoided presenting to a hospital (Ukwenya, Yusufu, Nmadu, Garba & Ahmed, 2008).

Psycho-Oncological Intervention Science as a Capacity Building Strategy

So, how can these needs be met? We hypothesize that by placing a psycho-oncological 'lens' on our capacity building efforts, we will more easily see ways to prioritize and problem-solve meeting short-term and long-term needs of patients, their families and their providers, while simultaneously managing the complex contingencies facing resource poor environments. Step-by-step, project-by-project, we expect that this approach will grow and sustain sufficient collaborative capacity to achieve the long-term objective of our partnership, namely establishing the UCH as a cancer center of excellence in research, training and clinical services for Nigeria.

Progress will occur over time, via a three-component developmental process, as outlined below:

1. Managing immediate, psychosocial needs of current cancer patients, their providers and their families, intervening to manage the stressors of cancer and cancer treatment in an under-resourced environment;
2. Prioritizing efforts to enhance or expand existing programs, services, and infrastructure through on-going dialogue with patients, their family members, and their care providers; and

3. Fostering culturally appropriate dissemination and implementation of evidence-based practices, made available by the global cancer community, including new cancer therapies in medical and surgical oncology, community-based screening and epidemiology, survivorship, palliation, and other support services.

Figure 1 depicts the iterative nature of the capacity building process. Success depends upon engaging the right mix of stakeholders (member capacity) in meaningful work (relational capacity), such that needed resources (programmatic capacity) are effectively developed, managed and sustained (organizational capacity). This cycle of building collaborative capacity may involve implementation of multiple, simultaneous new projects, of varying sizes and objectives. Efforts can start at any point in the loop, although they should always be centered on meeting immediate, or pressing, psycho-social needs of patients, families and providers. Over time, these efforts yield experience that grows the level of collaborative capacity and improves the UCH's ability to more fully manage these needs. As demand ebbs and flows, so too will the need for each level of collaborative capacity. Similarly, the robustness of the UCH-Einstein partnership will impact how quickly and effectively new practices are implemented. Foster-Fishman et al. (2001) affirm that there is no one best way to design or foster effective partnerships for change, the objective is to foster social action with the affirmation that organizational partnerships and communities alike are complex and dynamic.

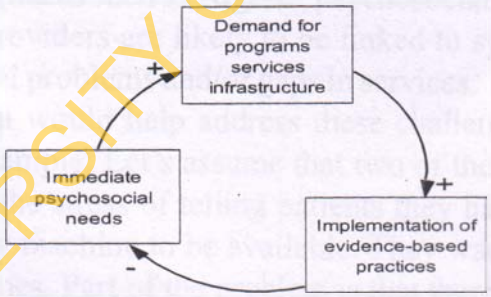

Figure 1 - Building collaborative capacity by meeting psycho-social and behavioral needs of patients, families, and providers

Managing Immediate Psychosocial Need

Decades of psychological and health services research has generated a wide range of evidence-based practices that can be employed by providers in most cancer care settings, including most LMCs, to address or prevent psychosocial

needs of cancer patients and family members. These include ensuring effective doctor-patient communication, access to psychotherapy and counseling services, psychopharmacological treatments for depression and anxiety, self-management interventions (i.e., diabetes, cardiovascular disease), behavior change programs (e.g., smoking cessation), and interventions for family caregivers (Epstein & Street, 2007).

To effectively offer these services to patients, their families, and to engage providers in basic communication skills training, efforts should be made to establish a clinical setting for psycho-oncology services, as both the UCH and Einstein have done. At the UCH there is the *LoLo Marinho Psycho-Oncology Centre*, founded in 1992 by Professor Jude Ohaeri, MD (Psychiatry) and Professor Adedapo Campbell MD (Oncologist). Dr. Asuzu and her colleagues are well positioned to help facilitate these types of research and services. Currently she is the Director of the Lola Marinho Psycho-Oncotherapy Centre, a clinical setting for cancer patients receiving radiotherapy for solid tumors. The clinic was named in memory of Lola, wife of Dr. Tony Marinho, an obsterician and gyneacologist and health advocate based in Ibadan. To our knowledge, the Centre is the first of its kind in Nigeria. Similarly, at Einstein, Dr. Alyson Moadel is Director of the *Psycho-Oncology Translational Research Clinic*, which offers cancer patients and families affected by cancer counseling and education services, as well as a variety of programs in stress management, smoking cessation, yoga, diet and exercise. The Clinic was founded by Dr. Moadel in 1995.

However, in places such as Nigeria, psychosocial needs of patients, their families and their providers are likely to be linked to systemic problems, involving either procedural problems and/or gaps in services. To illustrate how our psycho-oncology model would help address these challenges, we offer the following hypothetical example. Let's assume that two of the radiotherapists at UCH can no longer bear the stress of telling patients they have to wait day after day for the radiotherapy machine to be available. They want to come up with a plan to manage wait times. Part of the problem is that there were two such machines in operation a month ago, but one of them was taken out of commission by a major power surge in the electric line, one afternoon. The desired goal may be to reduce patient wait time to no more than one day, and to ensure that all treatment sessions occur as scheduled by the radiotherapist.

Many issues would need to be considered, such as the backlog of more than four weeks of patient visits (say, approximately 48 patients), the fact that some patients' conditions are more critical than others, whether or not the broken radiotherapy machine can be fixed, and at what cost. To decide what to do, radiotherapists, engineers, nursing staff, as well as some patients (member capacity), may be called upon to collectively choose a program to streamline wait

times (organizational capacity). The quality of their interaction allows them to decided about which program they believe will be most effective, given current resources within Radiotherapy (relational capacity), then facilitates the speed and effectiveness with which the program is implemented (programmatic capacity). Ultimately, a decision is made to integrate enhanced stress reduction programming for patients and family members, conducted in the waiting room by one of the nurses. In addition, efforts to arrange to refer patients to a cancer treatment hospital in Abuja are also pursued. On top of this, Einstein partners propose to develop an updated patient tracking system, using laptop computers equipped with cellular access to Nigerian internet services. Over time, these interventions are mounted, some more smoothly than others. Any number of examples of how our psycho-oncological model of capacity building can be applied could be generated. The process would always include moving through the cycle of needs identification, deciding whether or not to act (prioritizing), and then implementing a plan of action to effectively address the need.

Prioritizing Efforts to Enhance or Expand Existing Programs, Services, and Infrastructure

Resource constrained settings often need to make tough choices about what problem or issue to address first. During the early years of our partnership, enhancement or expansion of UCH cancer services will come in the form of extramural grants, for research as well as for patient programs or services. There are, in fact, two active pilot research grants currently awarded.

Briefly, the first pilot study was awarded to Dr. Chioma Asuzu (PI) and her colleagues at the UCH and Einstein. This study is funded by the African Organization of Research and Training in Cancer (AORTIC) and the National Cancer Institute (NCI). Semi-structured interviews and follow-up focus groups will be used to elicit information about patients' (N=400) treatment history before coming to the UCH. Patients who report having been treated by a traditional healer are asked for permission to recruit the traditional healer (N=8) to an interview, which will document healers' knowledge about cancer symptoms and their willingness to refer patients whom they suspect may have cancer to the UCH.

The second pilot grant was awarded to Drs. Ilir Agallui and David Lounsbury (Co-PIs), and to their colleagues at Einstein and the UCH. This study was funded by the Einstein Global Health Program. It provides funds for one year of research on prostate cancer in Nigerian men. It will use case-control design (n=50 incident cases and n=50 controls) of prostate cancer among male patients aged 40 to 79 years who are admitted to UCH and will inform the following assessments:

a) knowledge, attitudes and beliefs about participating in clinical research and genetic studies; b) recruitment and participation rates of prostate cancer patients and controls; c) the feasibility of collecting, storing and analyzing biospecimens (i.e., blood and/or mouthwash samples) at UCH; and d) preliminary estimates of prevalence of various potential risk factors for prostate cancer.

Fostering Culturally Appropriate Dissemination and Implementation of Evidence-Based Practices

The final component of our psycho-oncological model concerns active exchange of people, knowledge, and resources between the UCH and Einstein. This is dependent upon creating and sustaining sufficient organizational and relational capacity. The fundamental objective of the UCH-Einstein partnership is to work in a complementary manner to support each other and, where appropriate, leverage each others' resources in mutually beneficial, sustainable ways. In order to effectively reduce the personal and societal impact of cancer and other chronic diseases, in Nigeria as well as in the US, we must learn how to put evidence-based health promotion interventions into widespread practice. The US National Cancer Institute has called attention to the need for research designs that explicitly examine dissemination and implementation strategies, focusing on external and internal validity, motivational and contextual factors at the local level, as well as change at the population and systems levels.

The UCH-Einstein partnership is well-suited to foster active exchange of the growing compendium of research on the efficacy of behavioral interventions recognized by the global cancer community to be effective in reducing inequities and improving health outcomes in underserved communities. Both institutions offer comprehensive cancer treatment services. The UCH, founded in 1957, has 56 services and clinical departments and runs 96 consultative outpatient clinics a week in 50 specialty and sub-specialty disciplines. Einstein, founded in 1955, has approximately 2,000 faculty members, 750 M.D. students, 350 Ph.D. students, and 380 postdoctoral investigators. To effectively manage an active exchange of information, research, and other programmatic resources, monthly video conferencing, e-mail, and a designated website for data capture and exchange has been established, fostering extensive organizational capacity, as well as a venue for linking in new members from both institutions (member capacity).

Conclusion

Nigeria, like the majority of countries in Africa, currently suffers a great burden of cancer, with less than 40% of persons diagnosed with this disease surviving more than five years, the lowest rate of survivorship worldwide. This is despite being a vibrant, diverse society with vast human and natural resources that could be effectively leveraged for sustainable development and improved health of communities. To help achieve this potential, we are applying a psycho-oncological model to build capacity building in cancer prevention, treatment and care for the UCH. The test of our approach will be time and our ability to ultimately help transform UCH into a 'cancer center of excellence' for Nigeria, which can foster dissemination of evidence-based prevention, treatment and care throughout the nation.

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