T05W22 / Promoting participation in health and social policy services and evaluation

Topic : T05 / Policy Design, Evaluation, other

Chair : Camille La Brooy (University of Melbourne)

Second Chair : Margaret Kelaher (University of Melbourne)

CALL FOR PAPERS

This panel seeks to provide a platform for the critical analysis of the role of participation in health and social policy-making and papers are invited on this theme. Consistent with the multidisciplinary nature of the concept of participation, contributions may come from a broad range of perspectives, including (but not restricted to) health policy, philosophy, political science/theory and sociology. The panel will explore both the theory and the practice of implementing participatory strategies in health and social policy. We are also interested in how policy-makers – in government and elsewhere – implement participatory agendas and the benefits and challenges of executing health and social policy with this goal in mind. Evaluative efforts that interrogate the use of participation in public policy are especially welcome. Moreover, this panel invites papers offering critical appraisals of health and social policy initiatives that enact and reinforce the participatory agendas, comparative case study approaches to participation, evaluations of participatory policies application of participatory frameworks to improve the impact of existing policies, and theoretical works that engage with key themes involving participation in health and social policy.

ABSTRACT

Since the Alma Ata Declaration in 1978, community participation has been recognized as vital to the delivery of primary health care and addressing health inequities, and it forms the basis of the WHO 'health for all' strategy. More recently, it has been promoted in the Ottawa Charter for Health Promotion as strengthening community action. Participation is understood to be a right that all citizens have, as outlined in Universal Declaration of Human Rights (Sharp 1992, Bracht and Tsouros 1990, Mahler 1981); governments in turn have the responsibility to provide communities with opportunities to engage in service planning and implementation. Community participation refers to the involvement of consumers of health services, such as patients or clients, families, friends, carers and the broader community at large. In incorporating the needs and aspirations of local communities, consumers and other stakeholders, a sense of ownership is bestowed that ultimately results in better uptake of programmes and more enduring implementations (Brach and Tsouros 1990). Participation has also been noted to promote greater awareness and assist in co-operation between different stakeholders (Brach and Tsouros 1990, Slocum and Thomas-Slayter 1995). In incorporating community and consumer values and skills, program planners gain access to previously inaccessible resources and knowledge that they can incorporate into the program plans (Tenbensel 2010) as well as developing the self-reliance of local community, contributing to that community's ability to undertake future projects (Bracht and Tsouros 1990). This panel explores the utilisation and incorporation of various participatory agendas in health and social policy making. The panel explores how participation:

1. promotes the legitimacy of collective decisions;
2. encourages public-spirited perspectives on public issues;
3. promotes mutually respectful processes of decision-making; and
4. provides an opportunity for advancing both individual and collective understanding and mitigate information asymmetries and disagreement (Gutmann 2004).

T05W22 / Promoting participation in health and social policy services and evaluation

Chair : Camille La Brooy (University of Melbourne)

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Session 1 Mechanisms for broadening participation in policy development

Tuesday, June 26th 10:15 to 12:15 (Posvar Hall - 3600)

Discussants

Margaret Kelaher (University of Melbourne)

Wise crowds and knowledgeable experts – exploring the proliferation of consensus statements and clinical guidelines in public health and the participation of consumers in their development.

Camille La Brooy (University of Melbourne)

Margaret Kelaher (University of Melbourne)

The existence of a significant increase in the number of consensus statements used to inform policy and guidelines in public health and medicine reflects an effort to restore greater public trust in expert knowledge. Consensus statements help inform practical actions in an environment of uncertainty. Consensus statements form part of what Keane (2009) describes as a rise in "monitory democracy"; whereby we are witnessing an increase in the level and quality of public scrutiny in all areas of public policy. In order to mitigate growing ambivalence and scepticism towards expertise more broadly, there is a growing requirement that policy and practice decisions are made in a way that is transparent and accountable. In addition, the propagation of consensus statements can be seen to correspond with a deficiency of comprehensive evidence that might otherwise allow for a more definitive statement to be made (U.S Department of Health and Human Services, 2014). This exponential increase in the number of stakeholders in health and medicine has also likely contributed to the increase in the number of agencies commissioning and interested in consensus statements.

The ability of consensus fora to restore public faith in the scientific projects is highly contingent on the quality of consensus statements being produced. Consensus statements have been frequently criticised in the literature in terms of the process of their development, the nature of the consensus they achieve, and their impact on public and policy perceptions of the role of science. First, expertise, ideological and/or financial interests are often strongly linked. Second, consensus statements are seen as inefficient largely because they are required to elicit agreement from researchers who are inexperienced in communicating outside their specific disciplines and whose fundamental training is not directed towards generating consensus (Sarewitz, 2011). This can result in processes that generate a form of consensus that, although hard won, does not go beyond well-accepted facts and does not facilitate evidence-based change in practice (Sarewitz, 2011). This paper explores the use of consumers and patient groups in consensus processes in order to ascertain whether their inclusion facilitates better quality consensus statements and a greater level of expert accountability. In order to do this, a criteria for evaluating the quality of methods for developing consensus-based recommendations is borrowed from James Surowiecki's (2004) thesis on the 'wisdom of crowds' (Lorenz 2011; Kattan 2016; Baumeister 2016). Surowiecki (2004) suggests four conditions necessary for a group to make good decisions namely: 1. Diversity of expertise. 2. Independence. 3. Decentralization and, 4. Aggregation.

Using this typology, data from 40 qualitative interviews undertaken with participants from the US, Australia and the UK in four consensus areas (medical imaging, genetic testing, depression, and obesity) are analysed to explore the utility of consumers in consensus generation and health policy more broadly as well as to consider the quality of consensus statements and clinical guidelines being produced. Interviewees were from peak national agencies/commissioning agencies and fell into the categories of stakeholder: policy makers/practitioners/consumers. Interviews were approximately thirty minutes to one hour long. The

methodological approach was iterative within and between participants. Data was coded and entered using N-Vivo software to ensure data integrity and enhance analysis, and all transcriptions cross-checked to ensure validity.

It is argued that involving consumers ensures that scientific democratisation becomes a clear objective for scientists and policy makers alike, ensuring greater trust in experts via transparency and accountability. However, the ability of consumers to deliberate on an equal footing with experts is not guaranteed and, as such, the quality of consensus statements being produced generally suffer.

Consumer engagement to maximise the impact of public reporting of hospital performance data in Australia

Khic-Houy Prang (University of Melbourne)

Abstract

Consumer engagement to maximise the impact of public reporting of hospital performance data in Australia

Khic-Houy Prang1, Rachel Canaway1, Marie Bismark1, David Dunt1 and Margaret Kelaher1

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Background

Public performance reporting (PPR) of hospitals has been proposed as a mechanism for improving quality of care by providing transparency and accountability, increasing hospital quality and safety and informing consumer choice (1). In Australia, national mandatory PPR for public hospitals, including measures of cancer waiting times, was introduced in 2011. All public hospitals are now required to provide data to the Australian Institute of Health and Welfare which is then reported on the MyHospitals website (2). Public performance reporting is not mandatory for private hospitals, although some participate on a voluntary basis.

Prior research indicates that PPR has limited impact on consumers' healthcare decision-making (3,4). This may be due to the content, design and implementation of PPR which are not explicitly tailored to meet the needs and demands of consumers (5). Engaging with consumers to address these issues could lead to greater impact and utility of PPR.

Aims

The aims of this study were to assess whether PPR of hospital data was used by patients with breast, bowel or lung cancer to inform hospital choice; factors that influence their hospital choice; the level of demands for PPR; barriers to using PPR; and how PPR could be improved to meet their information needs.

Methods

A national cross-sectional questionnaire was conducted among 243 patients with breast, bowel and lung cancer who attended a public or private hospital as a private patient for elective surgery between 1st January and 31st December 2016. Patients were recruited via the Australian Government Department of Human Services using Medicare Benefits Schedules codes. Descriptive and conventional qualitative content analyses were conducted.

Results

Ninety-four percent of patients attended a private hospital for elective surgery. Almost half of the patients chose their preferred hospital. Choice of hospital was primarily influenced by the patient's specialist (89%) and not PPR data (92% unaware). Although patients considered PPR to be important (70%), they did not want to see the information. They preferred their general practitioners to tell them about it (40%). Barriers to patients' use of PPR included lack of awareness (74%) and relevance (11%). Patients considered cost of surgery (59%), complications (58%) and success rates (57%) important information to be reported. They preferred the data to be reported at the individual doctor level (48%). Four themes were identified from the open-ended questions: 1) decision-making factors; 2) data credibility; 3) unmet information needs; and 4) unintended consequences.

Discussion

Our findings suggest that PPR of hospital data had limited impact on patients' choice of hospital. Greater dissemination of PPR is required to increase awareness. Furthermore, many patients expressed interest in

using PPR to support their healthcare decision-making, however current content and format of PPR do not meet their information needs. PPR information must be patient-centred with an emphasis on making the data meaningful, interpretable and relevant. To maximise value in PPR and minimise unintended consequences, ongoing guidance from consumers are necessary.

References

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'WhatsApp-ing' Citizens' Frustrations; Influencing Governance Policy through Expressive and Connective Digital Platforms

Amos Kibet (University of Salford, Manchester)

Citizen's frustrated and dissatisfied with poor policies and bad governance have formed WhatsApp groups for deliberation, agitation and mobilisation in some Kenyan counties. The growth and penetration of the internet in Africa, coupled with the popularity and ubiquity of smart phones have positioned Social Networking Platform (SNSs) platforms in a strategic role in governance. SNSs including WhatsApp are the new spaces through which citizens in developing countries organize, coordinate and imagine both governance discourse and action. However, scholarly discussions as to whether SNSs platforms potentially influences governance discourse and policy directions within government frameworks has failed to yield tangible results or conclusive deliberations. This paper argues that three critical elements make the use of SNSs platforms like WhatsApp very critical as vehicles of participatory governance in developing countries and more specifically in devolved systems of government achieved in countries like Kenya. First, they provide access to a broader range of opinions and discussion on issues compared to traditional media, and this access is nearly instantaneous. This has consequently transformed how individual's express governance decisions, policy opinions and collective petitions through group formations. Secondly, they have translated loose, amorphous groupings hence creating stronger connectivity between users. Such connected grouping often yields stronger voices and more reforms in terms of governance compared to an individual's minimal actions. Thirdly, they have restructured inter-personal and group connectivity therefore revamping the nature, level and structure of policy discussion within the governance architecture. Uniquely, the combination of WhatsApp instant messaging features together with its other unique SNSs characteristics makes it doubly strategic in influencing governance discussions as have been witnessed in some Kenyan counties. WhatsApp affordances include its ability to carry text, picture and video at very low costs, and the ability of the platform to convene groups for 'talk' on critical issues. Using technological determinism theory, this paper looks at the role of WhatsApp in establishing expressive and connective platforms and whether/how such resultant formations have influenced governance policies in Kenyan counties. I specifically examined 15 WhatsApp groups (with an average of 250 members each) where I classify them as official and non-official (top-down and bottom up approach). Using a sample size of 263 respondents obtained from the 15 groups, I administered an online questionnaire through WhatsApp platform. The questionnaire sort to establish the profiles of the sampled WhatsApp groups and how discussions in such groups have influenced knowledge and efficacy towards governance issues at the county level. Has mobilisation been achieved through such forums? The paper also sought to establish tangible and empirical examples of instances where WhatsApp group discussions have translated to petitions on policy and change in governance. Being part of my wider PhD theses (ongoing), preliminary results indicate a wider adoption and strategic utility of WhatsApp by both citizens and county officials for governance discourse. This paper aims to contribute to a more structured discourse on how citizens in developing countries can tap into existing smartphone potentials to agitate and deliberate on good governance practices within their areas of jurisdiction.

T05W22 / Promoting participation in health and social policy services and evaluation

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Session 2Exploring solutions to health and social policy problems

Tuesday, June 26th 13:45 to 17:00 (Posvar Hall - 3600)

Discussants

Angeline Ferdinand (University of Melbourne)

Epistemological solutions for leveraging diversity of organizational sensemaking in the case of Wicked Problems

Christie Satti (Massey University)

Purpose: This presentation will discuss the lessons learned from developing sensemaking workshops to support participatory action research in a current study using Q methods. The study seeks to uncover the diversity of thinking about student wellbeing within a university context. The researcher identified 45 subjective perspectives from thematic analysis of interviews, anonymous submissions, and focus groups with over 100 university students, teaching and professional staff. By-person factor analysis was then used to identify 4 inter-subjective statistically generated perspectives.

Wicked problems are defined as epistemological problems that reflect a deficiency of sensemaking within the social and political context. In this case, the management perspective as reflected within the organizational evaluation framework, flattens and constrains the diversity of perspectives into dominant organizational managerial narratives, which constrain sensemaking. Here student wellbeing is presented as lacking the requisite variety of inter-subjective sensemaking to be considered representative and is hindered by dominant values and beliefs at the management level. The sensemaking workshops were designed to involve participants in analysis of the four inter-subjective perspectives, in order to develop an evaluative judgement framework for each perspective. Participants are provided opportunities to role play[1] with evaluation logic models, values and beliefs, while engaging with current university data. Workshop activities include spaces for reflection and community-building through sharing lived experiences.

The research question is how can a playful workshop environment leverage the findings of participatory analysis of Q method data to diversify organizational sensemaking, as reflected by evaluation practice? Participants will be encouraged to use techniques such as role play. The epistemological potential of methods using play and laughter[2], work by exposing the supposed naturalness of dominant narratives as artificial, increasing the diversity of acceptable narratives which make sense.

The implications of the work for policy making are the development of tools for continuous dialogue rather than for consensus, which constrains sensemaking by masking and reinforcing monologism at the inter-subjective level. This work contributes to methods that are consistent with constructivist understandings of wicked problems. Within public health discourse, this research contributes to empowerment approaches that see self-determination as pivotal to individual agency, by engaging individuals in activities that encourage the development of their own subjectivity and perspective through performance and social critique.

[1] See Alkin and Christie's (2002) The use of role-play in teaching evaluation. AMERICAN JOURNAL OF EVALUATION, 23(2).

[2] See Bakhtin, M. M.'s (1968) The Role of Games in Rabelais. Yale French Studies.

Does the Minimum Wage Law Mandate Bite Harder: The Effects of the Home Care Rule on Home Care Workers and the Cost of Home Care Services

Ngoc Dao (University of Wisconsin-Madison)

Today more than 2 millions home care workers across the country provide personal assistance and healthcare support to elderly and/or disabled people in the home and community-based settings (PHI, 2015). Approximately 90% of the home care workforce is female with the median age of 45 years old. Although the size of direct care workforce has doubled over the past decade because the delivery of the service has dramatically shifted from institutional settings like the nursing home to home and community-based settings, home care workers nowadays still receive low wages.

The 1974 amended Fair Labor Standards Act (FLSA) enlarged the coverage to all workers employed in "domestic service" but provided the "companionship services" exemption. This exemption basically excluded workers providing companionship services to the elderly and disabled from the federal minimum wage and overtime protection. More specifically, in 1975, the Department of Labor interpreted the "companionship exemption" as including all direct care workers in the home; even those employed by third parties such as home care agencies (PHI, 2013). However, a number of states have extended state minimum wage and overtime protections laws to some or all-home care workers. And in six more states and the District of Columbia, workers have been protected under minimum wage but not overtime protection. In October 2013, the Department of Labor (DOL) redefined and narrowed the exemption known as the Home Care Rule by allowing certain types of home care services to be protected by federal minimum wage and overtime.

This paper examines the 2013 Home Care Rule regulated by the Department of Labor, which now covers home care workers under the Federal Minimum Wage Mandate. Optimizing the variation in changes in state minimum wage mandates under the new Rule, I test the hypothesis that under the new Home Care Rule home care workers experience higher wage while employment rate is likely to be little affected. I also examine the effect on the cost of home care service among those who experience homecare services.

This is the first study using Difference-in-Difference to estimate the federal new minimum wage rule as an exogenous experience to see how the outcome variables change between affected states and unaffected states related to home care services in both supply and demand side. And therefore the contribution of the paper is significant in understanding how government policy could interact and influence the consumption of home care services, which is a big question to be answered.

Models for Long Term Care Policy: A Global Perspective

James Anderson (Purdue University)

Aging populations pose major health policy issues worldwide. Projections indicate that by 2050 22 percent of the world's population will be 60 years of age or over. In developed countries, the elderly population will soar to 32 percent. Even in developing countries one out of five will be 60 and over. At the same time, the number of workers per retiree is projected to shrink to 2.3 in the U.S., 1.5 in Japan and 0.7 in Italy by 2050. The different ways that countries confront the issue of providing care for their aging populations will be addressed in this paper. The methodology used is comparative. Long-term care policies in countries such as Denmark, Germany, France, Switzerland, Australia, Japan, Israel, Turkey and Mexico will be compared to the U.S.

The U.S. is only one of three OECD countries that do not provide long-term care coverage. Elderly needing institutional long-term care must rely largely on out-of-pocket expenditures (28%), Medicaid (31%), Medicare (22%) and Private Health Insurance (9%). Seventy percent of all nursing home residents rely on Medicaid to pay for their care. The share of the older population receiving government subsidized care in most of the OECD countries is much larger.

Denmark is a leader in providing long-term care. Fully 27 percent of the elderly population receive government supported care. In Denmark, no new nursing homes have been established since 1987 because of an integrated homecare system. The Home Prevention Act mandates twice a year home visits to

assess the needs of elderly citizens. This policy has resulted in a leveling off of long-term care expenditure and a drop in the percentage of the GDP devoted to long-term care.

Germany provides three levels of assistance depending upon the required hours of assistance per day. Disabilities in activities of daily living are assessed. Subsequently, the elderly can arrange their own services within a fixed budget. Similarly, in France under the Alliance for Personal Autonomy (APA) Act of 2002, individuals purchase long-term care insurance. Policyholders receive a payout in the event of dependency. In Sweden, reform of the government long-term care policy in 1992 that decentralized care resulted in a 50 percent reduction in the ratio of hospital beds to older adults. The cost is borne by local municipalities (85%), national grants (12%), and out-of-pocket expenditures (4%). Care managers assess individual needs and create a home health care plan. There is a monthly cap of $193 on long-term care costs for users.

There is much greater variation in long-term care policies in Asian countries. Japan has traditionally relied on families to provide care for elderly relatives. With its burgeoning elderly population (projected to be 26% by 2020), longer life expectancy, and more women entering the work force, the need for long-term care in-home services has increased by 109%. As a result, Japan adopted a Long Term Care Insurance (LTCI) Policy in 2000. Municipal Long Term Care Councils classify the elderly needing care into care groups. Both institutional and home care are funded by the LTCI.

In China traditionally, family members cared for the elderly. While care for the elderly is still largely provided by family, migration from rural to urban areas and the one-child policy has resulted in not enough family to care for the elderly. Currently China is piloting several LTC programs. In Qingdao city, pooling of insurance is in effect. About 90 percent of the elderly needing services receive care at home or in residential locations.

The elderly in South Korea are covered under the Long Term Care Insurance policy enacted in 2008. Older adults requiring care are assessed at home by health care professionals. They are then classified into a category for services. Users pay 15 percent of in-house services and 20% of residential services.

Turkey has the lowest coverage for institutionalized long-term care compared to European countries and major Asian nations. There are no long-term care insurance plans and there is a severe lack of facilities for elderly needing care. There is still a strong tradition of family care for the elderly in Turkey.

These and other models of long-term care policies will be discussed and compared. Elements of those policies will be selected for potential application to the United States.

T05W22 / Promoting participation in health and social policy services and evaluation

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Session 3Case Studies: Exploring participation and evaluation in Indigenous and developing country contexts

Wednesday, June 27th 09:00 to 12:15 (Posvar Hall - 3600)

Discussants

Camille La Brooy (University of Melbourne)

Participation in health policy making for persons with mental illness in Timor-Leste: the current situation and where to from here?

Teresa Hall (University of Melbourne)

Background: Over the past 40 years, persons with mental illness and their family members have been increasingly more involved in health policy planning and decision-making to rectify their historical lack of meaningful participation. Mental health consumer organisations are a way for persons with mental ill-heath to participate in governance processes. Nonetheless, the pervasive societal belief that persons with mental ill-health are not capable of making reasonable decisions can make participation tokenistic, obstruct it entirely or limit it to health promotion activities without any direct involvement in policy making.

Timor-Leste is a half-island country in the Asia Pacific that is in the process of developing its mental health system. Mental health remains a low priority in the landscape of communicable disease-related mortality and morbidity, human resource and capacity shortages in general health and low public expenditure for basic infrastructure. There is no mental health consumer organisation, but there is one community-based organisation that works with people with mental illness. In a context where most people with mental illness are refined exclusively to home and have limited social and community engagement, how might Timor-Leste foster an environment conducive to participation in health policy making by persons with mental illness?

Aim: This paper explores the challenges and opportunities for participation in Timor-Leste when people with mental illness are approached from a disability perspective, from a traditional and cultural perspective and through a biomedical perspective.

Methods: Seventy-three individual (n = 60) and group (n = 13) qualitative interviews were conducted with 82 actors in contact with the mental health system in Timor-Leste over a five-month period from September 2017 to January 2018. To capture the diversity of experience and roles, actors were recruited from the national (Dili), municipality (Baucau) and administrative post (Venilale) levels from the following five groups: (1) people with mental illness and their families; (2) mental health or social support service providers; (3) government decision makers; (4) civil society; and (5) other community members or organisations such as multilateral organisations and international development partners.

Results: Preliminary results suggest that persons with mental illness in Timor-Leste are restricted from public life because they are deemed to be dangerous, shameful or 'lost causes. Treatment for mental illness in Timor-Leste is biomedical and so the side effects of the old age psychiatric medications available in the country (i.e drowsiness, motor deficits, memory loss) complicate social participation. In addition, the collectivist cultural norms mean that decision making is made as a family unit rather than an individual unit. Consequently, the idea that people with mental illness would be involved in decision making at a high level was unacceptable to most participants. Nonetheless, the strong focus on human rights within civil society in Timor-Leste, particularly by organisations within the disability sector, can be seen to set the mindset for participatory action by the beneficiaries of social policy. For example, persons with disabilities are mobilised in peer-support groups and other disability organisations, and undertake intensive advocacy about the rights

of persons with disabilities (including psychosocial disability/mental illness).

Improving indigenous health care from a comparative critical perspective: Lessons from Brazil, Chile, Australia and New Zealand.

Leo Pedrana (Instituto de Saúde Coletiva, Federal University of Bahia)

Angeline Ferdinand (University of Melbourne)

Margaret Kelaher (University of Melbourne)

Leny Trad (Federal University of Bahia)

Many countries with Indigenous populations have developed strategies to improve the accessibility and appropriateness of health care services for their Indigenous peoples based on principles espoused by the Alma Ata Declaration. These strategies have included changes to policy and practice designed to facilitate the inclusion and participation of Indigenous communities as well as the articulation of Indigenous and occidental healthcare knowledge and practices. Nevertheless, global Indigenous health analysis shows a persistent gap existing between Indigenous and non-Indigenous populations in various national contexts (I. Anderson et al., 2016). Due to similar patterns of Indigenous health across borders, there have been calls for greater global collaboration in this field (Stephens C et al., 2006). However, while Latin American countries have demonstrated considerable innovation in developing strategies to improve Indigenous health (Montenegro RA, Stephens C. The Lancet 2006), these approaches have rarely considered outside the region. Rather, within the global literature on Indigenous health policy, most of the international studies link Anglo-settler democracies (Canada, Australia, Aotearoa/New Zealand and the United States), despite these countries representing a small fraction of the world's Indigenous people (Stephens C et al., Lancet 2005). There is therefore a lack of mutual reflections between the different national contexts of the southern part of the world, their different epistemologies and strategies developed to provide culturally appropriate health care and participation for Indigenous people.

This paper presents a critical comparative perspective on Indigenous health policy by focusing on the provision of culturally appropriate and Indigenous participation in health care in Australia, Brazil, Chile and New Zealand. We analyze and compare the strategies formulated and operationalized by the national health policies and legislation and discuss them from the critical point of view of the national scientific literature contributions. The paper considers elements including governmental recognition of differential Indigenous health needs; engagement with Indigenous peoples in health; and official recognition of traditional knowledge.

Across the national legislations, there are differences in the conceptualization of culturally appropriate healthcare for Indigenous people and in the articulation between traditional and western medical knowledge. In all the national health systems, the participation of the Indigenous community in decision-making processes and the implementation of Indigenous health care services have led to the development of different types of organizational models. This is represented by a strong community control sector in Australia, a differentiated sub model of primary healthcare for Indigenous populations in Brazil, and, models to strengthen and valorize Indigenous health care systems in Chile and New Zealand. However, each of these systems also demonstrates limitations in the extent to which Indigenous peoples are able to develop and access appropriate health care.

The evidence produced by this study applies to the critical issues of different Indigenous health policies and provides good examples of culturally appropriate practices and strategies to improve Indigenous health care, cultural accessibility and participation. More comparative research could investigate in depth the relation between Indigenous participation in national policy decision-making process and the culturally appropriate responsiveness of public Indigenous health care s

Indigenous autonomy through community participation: Tensions and conflicts

Angeline Ferdinand (University of Melbourne)

Margaret Kelaher (University of Melbourne)

Background

Over the past few decades, interest has grown in the decentralisation of governing across fields as diverse as education, health, and justice, enacted through a reduction in rigid hierarchical structures, increasing partnerships with civil society and localised decision-making processes—an impulse that has gone hand-in-hand with the rising discourse of community participation in health. Community participation in

health is particularly relevant for Indigenous peoples, who are often excluded from decision-making and priority-setting in the development and implementation of health services. Indigenous community participation in health is not only a response to systemic barriers in accessing biomedical health care or a lack of culturally appropriate health care, but is underpinned by the principles of self-determination, autonomy, social justice and cultural retention.

Indigenous community participation in health in Chile has led to the development and implementation of a number of health services administered and governed by Indigenous community organisations. However, these decentralised governance structures, established to enable localised influence over policies, processes and services, are nevertheless contradictory in that they are strongly shaped by State power. This paper examines how staff from Chilean Indigenous community health care services perceive the concept and purpose of Indigenous community participation in relation to State policies and frameworks.

Methods

Semi-structured interviews were undertaken between August 2015 and June 2016 with twelve Makewe Hospital staff members and four Boroa Filulawen Intercultural Health Centre staff members. Interviews were designed to allow for some consistency and comparison between participants while incorporating flexibility to explore particular issues important to the individual. The topics covered in the interview schedule were derived from literature regarding ambiguity and complexity in defining the elements of community participation; the role of participatory processes in determining and defining the health needs of a community; the influence of contextual factors and institutions on community participation in health; and the level of decision-making power communities have through the processes of participation.

Recorded interviews were transcribed. Directive content analysis was used, with coding categories identified a priori (to explore key issues outlined above) and additional categories developed to describe issues that emerged from the data.

Ethics approval was granted by the University of Melbourne Human Ethics Subcommittee (Application number 1544845) on 20 July 2015.

Results

In examining the perceived role of Indigenous community participation in health, there were apparent tensions between the themes of community 'empowerment' and 'responsibilisation'. Taken as a whole, interviews with staff from community controlled health centres highlighted a dual discourse around community participation and the relationship between community organisations and the State: interviewees spoke about the responsibilisation of Indigenous communities on the one hand—that is, devolution to communities of the responsibility for service provision and attendant risks that would otherwise lie with the State—and on the other, a desire to increase Indigenous autonomy in health and more generally through the assumption of roles that allow for engagement and representation within the Chilean State. Corresponding processes are those by which the State shifts responsibility for service provision to communities and community organisations, but retains control of the ways service is provided through imposition of regulations and obligations, normally tied to financial arrangements. Here, interviewees articulated the utilisation of participatory processes to increase Indigenous independence while at the same time being mindful of the necessity of compliance with such regulations imposed by the State in order to maintain this position.

Discussion

The intertwinement between processes that take place between the Mapuche community and the health centres and those situated in the wider realm of the health system demonstrate the ways that State processes and structures can serve to constrain community participation and representation. There is therefore a need for policy and legislative mechanisms that facilitate and recognise Indigenous governance in health. This would allow for the creation of policies that correspond to the reality of health service provision to Mapuche communities by Mapuche organisations, create space for systematic input and shared decision-making by Indigenous communities and organisations and possibly ease some of the burden currently experienced by Mapuche service providers attempting to fulfil inappropriate contractual obligations. The advocacy work engaged in by the community-based governance organisations is a way to navigate the tensions described by staff between the responsibilisation of communities on the one hand and on the other, a desire to increase Mapuche autonomy through engagement and representation within the Chilean State.

T05W22 / Promoting participation in health and social policy services and evaluation

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Session 4Other key emergent issues in the evaluation of health and social policy

Wednesday, June 27th 13:45 to 17:00 (Posvar Hall - 3600)

Discussants

Khic-Houy Prang (University of Melbourne)

Health activism and Embodied Health Movement: the case of Sickle Cell Disease and Chronic Myeloid Leukemia

Leny Trad (Federal University of Bahia)

Clarice Mota (Federal University of Bahia)

Yeimi Alexandra Alzate Lopez (Federal University of Bahia)

Ana Angélica Rocha (Federal University of Bahia)

Considering the importance of community participation in health outcomes, especially among groups affected by chronic diseases, it is relevant to analyze health policies through the perspective of Health Social Movements (HSM). Following the concept proposed by Phil Brown and his colleagues (2004, 2012), HSM is a type of health-related activism that struggles to improve the quality and access to health provision, while they challenge medical policy and politics, belief systems, research and practices, with the potential to reshape scientific research and to promote social and policy change (Morello-Frosch, 2006). The shared feeling of being neglected by society and the perception which health system is failing to address their needs, are elements to motivate and join a more specific type of movement, known as Embodied Health Movements (EHM) (Brown et al, 2011). The activism, in this case, is inspired by the lived experiences of those with the condition, which is unavailable to others. Through this activism, individuals come together to achieve medical recognition, treatment and research, as well as to advocate improved medical care. As a result of this process, a collective identity is built upon shared grievances that may result from discrimination, social disadvantages or shared values.

The conceptual framework of Health Social Movements is useful here to analyse the experience of individuals with Sickle Cell Disease (SCD) and Chronic Myeloid Leukemia (CML). Both are hematological and chronic diseases that present a challenge to the health system and to the lives of people and their families, which frequently are united and organized in Associations. Through shared experiences of suffering and the difficulties in accessing the health care system, they are able to develop a politicised collective illness identity. Especially in the case of SCD, considered a historically neglected condition, the Associations are more than a supporting group, as they are seeking structural changes in health provision and stablishing an agenda for health policies.

It is worth noting that the shared of experiences of social exclusion deriving from social disparities, racial or gender disadvantages may be considered a critical factor influencing the rise of Embodied Health Movements (BROWN et al, 2004). The organization of such movements are crucial for pursuing social recognition and equal dignity, since the right for full access to health care is essential for a democratic society. It is expected that this work can contribute not only to the debate concerning SCD and CML, but to other types of health activism.

Why Does the United States System of Health Care Cost So Much and Do So Little?

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The United States devotes a considerably higher proportion of its GDP to health care than do countries of comparable wealth. Yet, overall, the U.S. attains worse outcomes. This inefficient utilization of resources is the consequence of multiple factors and their interaction. One such influence lies in the origination of employer-based health insurance during WWII to offset wage controls during a time of labor force shortages. This system, however, is in a declining state and leaves a significant proportion of the populace outside. Until recently, about 15% of the population was uninsured and at least as large a proportion were underinsured.

A second factor lies in the institutional complexity of the American polity that privileges the status quo and, ordinarily, makes legislative change difficult. This, in turn, makes comprehensive reform regarding coverage and costs extremely difficult. Except for Medicare for the elderly, much of the public system is means-tested, and the high costs of the system often make private health insurance that is comprehensive unaffordable.

While social insurance origination in Europe has often been non-controversial, the ideological chasm that exists in the U.S. about the proper role of the state, taxes, and social benefits make the extension of social insurance highly controversial. Reform has come to mean different things to the left and the right. To the left, reform means the expansion of benefits as an entitlement. To the right, it has meant curtailing or contracting benefits and removing the state as a decision-maker and regulator.

Finally, both outcomes and system costs are affected by societal dysfunctions that add to a relatively dismal picture on health outcomes. The high level of socio-economic inequality in the U.S. also produces a picture of disparate health care and well being across class and racial divides that is greater than in Europe and Canada.

Although this paper mainly focuses on the U.S. in comparison with countries of comparable wealth, there are important lessons for Latin American countries. A combination of high inequality and political fragmentation may make it virtually impossible to reach a political consensus to improve insurance coverage, induce greater efficiencies in the health care system, and achieve better outcomes.

A Study on Working hours and Adult Competencies in South Korea: Using OECD PIAAC

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Adult competencies (literacy, numeracy, and Problem solving in technology-rich environments) have a major impact on each individual's life chances. Adult competencies transform lives, generate prosperity and promote social inclusion. Without the right adult competencies, people are kept at the margins of society, technological progress does not translate into economic growth, and enterprises and countries can't compete in today's globally connected and increasingly complex world.

Korean students are showing excellent academic achievements on PISA which surveyed by OECD. However, according to the PIAAC survey, Korea is among the three lowest-performing countries when comparing the skills proficiency of 55-65 year-olds; however, when comparing proficiency among 16-24 year-olds, Korea ranks second only to Japan. And working hours of Korea is the longest among OECD countries(OECD, 2017). Since Korea has chronic overtime work, the government recently announced a policy to cut the maximum working hours per week from 68 hours to 52 hours. The purpose of this study is to analyze how long working hours affect adult competencies.

We used structural equation modeling (SEM) to analysis how the independent variables including individual factors(gender, age, education, income, health) and the working hours influence the adult competencies. Specifically, we examine the will of learning as a mediating variable between the independent variables and the adult competencies. And then we divided into three groups(30-40 hours and 41-52 hours, over 53 hours) according to working hours per week. We use PIAAC (the Program for the International Assessment of Adult Competencies) data collected by OECD. The survey was co013rraden, 2001, p. 2nducted on adults aged 16-65 from August, 2011 to March, 2012.

Results from the preliminary analysis indicate that long working hours negatively influence the will of learning, and the will of learning is associated with the adult competencies in the third group(over 53 hours per week). On the other hand, in the first group(30-40 hours per week), an increase in working hours has a

positive effect on the will of learning and then positively influenced adult competencies. And working hours and the will of learning were not statistically significant in the second group(41-52 hours per week). Therefore, The Korean government needs a policy to reduce working hours per week to less than 52 hours, and societies need to respond to these policies. In addition, people who do not have good jobs can grow their adult competencies through work, so governments and societies need to provide them with quality jobs.

MORAL TENSIONS IN DECISION-MAKING ON PUBLIC HEALTH POLICIES AND PROGRAMS, WITHIN THE COMPETITIVE MARKETPLACE MODEL OF THE COLOMBIAN HEALTH SYSTEM: AN EXPERIENCE USING MIXED METHODS RESEARCH, 2012-2016.

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Background: The Colombian Health System has experienced significant reforms from 1993 intended to improve coverage, accessibility and quality of health service provision. These reforms, based on a competitive marketplace model, increased the participation of the private insurers and providers and at the same time constrained the public health sector; also public health policies and programs were discouraged affecting negatively the accessibility of the population to the preventive programs and the public health. Â

Objective: To understand the implications of policy decision-making in determining access and quality of public health policies and programs within the competitive marketplace model of the Colombian Health System.

Methodology: A sequential mixed methods research (MMR) approach was conducted in two-stages from 2012-2016. In the first stage, a qualitative study was conducted in six Colombian cities using Grounded Theory method; for that 120 individual interviews were conducted to health professionals, who were working at least five years in the provision and management of public health policies and programs, within private and/or public institutions. Also 14 focus group of community leaders were conducted. The second stage, involved: 1) two quantitative studies: a) a survey about the labor conditions of the personnel working in public health policies and programs, and b) a geo-coding investigation about geographical accessibility of the population to public health programs; 2) other qualitative study employing a narrative approach, to carry out a in-depth Â analysis about the values, administrative, professional and personal strategies that some health professionals put in place to overcome the limitations that the community faces to access to public health programs. Â

Findings: Two sets of values were found to be in conflict, resulting in significant moral tensions in the decision-making processes regarding the provision of public health programs. One values set fosters health as a human right and the other assumes health as a commodity that can be bought and sold within the health care marketplace.

The MMR approach allowed for obtaining a more comprehensive understanding of the human resource limitations, geographical barriers in delivering public health programs.

Conclusion: Â The competitive marketplace model of the health system has generated a conflicted set of values affecting the decision-making regarding provision of public health policies and programs, and poor people tackle geographical barriers to access to these services, along with limited quality of them.