Aiming for inclusion: a case study of motivations for involvement in mental health-care governance by ethnic minority users

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Abstract

Objective To examine the motivations for involvement in mental health-care governance by socially disadvantaged ethnic minority users.

Design and setting A qualitative case study approach was employed to investigate the involvement of minority north-eastern users in mental health-care governance at CAPS Pedro Pellegrino in Rio de Janeiro, Brazil. Semi-structured interviews with minority Northeasterners ($n = 12$) and institutional stakeholders ($n = 26$) were complemented by participant observation of user assembly and user movement meetings.

Findings Minority Northeasterners express both individual and collective motivations for involvement in mental health-care governance. Individual motivations include the desire to increase social interaction, acquire meaningful social roles and overcome the stigma attached to mental illness. Collective motivations include the intent to improve the responsiveness of mental health care and achieve social justice for people with mental problems. Taken together, these motivations demonstrate a strong aspiration by users to promote their social inclusion and the inclusion of others who also experience marginalization. Results also reveal that the involvement of long-term participants is driven mostly by collective goals while early-stage participants focus predominantly in dealing with individual concerns. This is at odds with the mutual incentives theory, which postulates that collective motivations prevail over individual motivations in explaining user involvement.

Conclusion Groups historically excluded from decision-making processes may identify social inclusion as the core goal of their involvement. Initiatives aiming to increase user participation in health-care governance must address the range of motivations driving the involvement of users, instead of focusing solely on issues related to health-care management and provision.

Introduction

User involvement has become an important element of health policy in countries across the five continents.[1–7] In Brazil, participation in health-care governance is a constitutional right.[8] The social movement commended for this achievement – the health reform movement – has also promoted the development of highly innovative mechanisms for citizen engagement.[9] Municipal and state health councils enable users to join with representatives of health workers, health secretariats and private service providers to vote on health-care plans and budgets. There are also periodic conferences at municipal, state and national levels where citizens deliberate over health policy alongside institutional actors.[9] Users can also participate in health-care planning and evaluation through user assemblies.[10] This broad set of participatory spaces[11] has enabled hundreds of thousands of citizens to have a voice in health decision-making.[12]

Despite all the investment made in user involvement, the Brazilian health participatory sphere has not yet become fully representative of the diversity of user groups in Brazil. Ethnic minorities, the poor and the elderly are excluded from health participatory spaces.[13] This risks deepening health inequities as policies designed within these spaces may come to neglect the needs of voiceless groups thus fostering structured exclusion instead of eliminating it.[14]

Low involvement by minority groups can be explained by thwarted expectations concerning the remit of participatory spaces (e.g. inability to enforce rights).[15] So far, few in-depth studies of what minority groups expect to achieve with participation have been made. This article aims to help fill this gap. By employing a qualitative case study approach, it examines the motivations for participation in mental health-care governance by socially disadvantaged minority north-eastern users in Rio de Janeiro. The mental health care reform currently taking place in Brazil faces several challenges (e.g. limited resources, implementation difficulties)[16]

that can benefit from inclusive user involvement. Learning about what motivates the participation of under-represented user groups can inform priority-setting for reform and help devise more responsive mental health policies and services.

Theoretical framework

User participation is explained by individual and structural factors.[17] This study requires therefore a theoretical framework that can account for the influence of both personal and contextual variables on users' decisions to get involved. Here, we combine Simmons and Birchall's[17] mutual incentives theory (MIT) with Rawls' theory of social justice,[18] and social inclusion[19] and citizenship[20] theories. MIT accounts for users' own motivations for engagement. The latter set of theories is particularly well suited to examine the contextual factors (e.g. weak welfare state, socio-economic deprivation, social injustice) that characterize our research setting and to assess their impact on participation.

MIT explains involvement on the basis of individual and collective incentives that create a demand for activism and motivate people to participate.[17] Individual incentives relate to the benefits of participation that people expect to acquire for themselves (e.g. skills, recognition, self-confidence). Collective incentives include the benefits that people expect to obtain for others with whom they identify or whose cause they support. They are influenced by shared values and goals and a sense of community. According to MIT, collective incentives are the primary mechanism influencing involvement, that is, they prevail over individual incentives in explaining people's decisions to get engaged. MIT also asserts that collective incentives strengthen progressively: 'with participation, people's collectivistic motivations are reinforced and their commitment to the group develops'.[17]

People's involvement in health-care governance may result from experiences of social exclusion and the need to change that by claiming equal opportunities and rights,[21,22] that is,

by demanding social justice. According to Rawls,[18] social justice entails two core principles: 'equal basic liberties' and 'fair equality of opportunity'. Basic liberties include freedom of thought, movement, speech, assembly and political liberty. Without these rights, citizens are unable to participate in the governance of their own affairs. The principle of equality of opportunity is concerned with people's holdings of 'primary goods' (e.g. liberty, self-respect, income) and with their fair distribution. Primary goods enable people to acquire the skills necessary to choose valued life plans.[23]

Daniels[24] argues that health must be seen as a primary good. Health is an essential good because 'it directly affects a person's well-being and is a prerequisite to her functioning as an agent'[23] whereas, arguably, ill health diminishes the array of life plans people can choose from.[25] Inequalities in health are therefore closely coupled to inequalities in citizens' basic liberties and opportunities.[23] Where health inequalities arise from illnesses that could be prevented or treated but are not, due to unfair constraints (e.g. poverty, stigma, limited health care access), we can speak of inequity and injustice.[26]

Access to basic rights and opportunities is also essential to tackle social exclusion. According to Scharf et al.,[19] exclusion is determined by deprivation in one of the following dimensions: economically and socially valued activities, social relationships, civil activities, basic services and community life. Social inclusion thus requires participation in all the five dimensions described.[19] That can only be achieved when life opportunities are fairly distributed and individuals' rights are enforced. If we understand citizenship to be both a set of rights and the ability to participate in the socio-political arena,[20] then social inclusion can be understood as an expression of full citizenship.

Research setting and methods

This article draws on a case study of user involvement in a community-based mental health-care service – CAPS Pedro Pellegrino – in Rio de Janeiro and it examines the motivations for involvement expressed by minority north-eastern users. We selected this group because it is one of the least represented in Brazil's health participatory sphere.

North-eastern migrants are one of the largest ethnic minorities in Rio de Janeiro, where internal migrants make up 29% of the population.[27] Mass migration from the north-east to south-east Brazil began in the 1950s, when millions of Northeasterners started leaving their homes to escape environmental disasters, unemployment and hardship.[28] The intense inflow of poor migrants to Rio de Janeiro changed the city's landscape: entire mountains were taken by favelas (slums). Internal migrants have since been associated with favelados (slum dwellers) who are perceived as lazy, socially and politically disorganized[29] and dangerous.[30] These negative traits are also ascribed to north-eastern migrants. Moreover, their ethnic differences (e.g. conservatism, religiosity, patriarchy) make them susceptible to further stereotyping as backward peasants who are unable to adapt to urban life.[31,32]

Most of our participants lived in slums on Rio de Janeiro's West Zone, where CAPS Pedro Pellegrino is located. In addition to providing care to descendants of north-eastern migrants, CAPS promoted their involvement in health-care governance by adopting a participatory approach to care delivery that extended beyond the service itself. It encouraged users' participation in service planning and evaluation through the assembleia – a weekly meeting created to enable users and professionals to make joint decisions concerning care provision – and it invested in establishing a participatory channel between the service and the community. This was achieved through two strategies. First, CAPS invited users' family members to participate in the service through grupão – a monthly session where they met users and professionals to discuss care delivery and community support. Second, it motivated users to engage in activities (e.g. meetings, demonstrations) promoted by participatory spaces outside

Table 1 Socio-demographic characteristics of involved minority north-eastern users (*n* = 12) and duration of involvement in participatory activities

Name	Age	Gender	Civil status	Professional status	Social benefits	Duration of involvement in participatory activities (years)
Clara	33	F	Single	Unemployed (former primary school teacher)	Temporary sickness benefit	5
Gabriel	35	M	Single	Unemployed (former bouncer)	None	4
Benedita	42	F	Single	Pensioner (former accountant)	Pension	9
Vinícius	38	M	Single	Pensioner (former security guard)	Pension	8
Samuel	58	M	Single	Employed (assistant at CAPS)	None	7
Regina	46	F	Widow	Unemployed (former secretary)	None	2
Jenifer	24	F	Single	Unemployed (former saleswoman)	None	3
Gladys	41	F	Lives with partner	Unemployed (former cleaner)	None	6
Miguel	32	M	Single	Employed (doorman)	None	6
Jaderson	33	M	Single	Unemployed (former typist)	Free bus pass	3
Robson	31	M	Single	Unemployed (former salesman)	Free bus pass	2
Oscar	32	M	Lives with partner	Employed (factory worker)	None	3

the service, including the health council and the user movement.

Fieldwork took place between July 2006 and June 2007 upon the study's approval by the Research Ethics Committee of Rio de Janeiro's Municipal Health Secretary. Case study research entailed participant observation and in-depth semi-structured interviews with two clusters of participants recruited through purposive and snowball sampling:[33] (i) minority north-eastern mental health-care users (*n* = 12); and (ii) stakeholders in the field of mental health user involvement (*n* = 26) including 12 mental health and social care staff, five experts by experience,* four members of user and family associations, four members of health research centres and one member of the municipal health council. All minority north-eastern users were involved in CAPS Pedro Pellegrino's *assembleia* and *grupão* for a period ranging between 2 and 9 years (see Table 1). Nine were also engaged in the user movement and two participated in the health council.

*The term 'expert by experience' is used here to refer to people who have experiential knowledge[34] about mental illness, mental health-care and recovery.

The interviews explored issues related to users' motivations for involvement, including their experiences with mental health care, socio-economic position and social integration. Interview guides were designed and subsequently reformulated to integrate new questions emerging from analytical comparisons between the data collected and extant literature. Data collection continued until new information stopped adding original material to the findings and theoretical saturation[35] was reached. All interviews were audio-recorded with users' written consent and stakeholders' verbal consent. They lasted in average 1h 30 min, ranging between 1 and 2 h. The interviews were conducted, translated from Portuguese to English and analysed by the author, who also transcribed the interviews with north-eastern users. Interviews with stakeholders (*n* = 26) were transcribed by local transcribers. The transcripts were analysed with the assistance of MAXqda2 software (VERBI GmbH, Berlin, Germany) employing open, axial and selective coding and the constant comparison method.[35,36] These techniques enabled the identification of categories that were iteratively compared allowing the detection of relation-

ships between them and the specification of core categories. The constant comparison method was used to define the different dimensions of core categories and to assess their influence on users' involvement.

Participant observation focused on the dynamics of involvement, and it took place at several participatory spaces in Rio de Janeiro, including CAPS's user assembly and *grupão*, the municipal health council and the user movement meetings. Field notes were taken, translated into English and analysed with MAXqda2 by the author. Observation data were first analysed independently from interview data employing open, axial and selective coding. A comparative analysis between observation and interview data was carried out afterwards to fill in gaps and address inconsistencies, that is, we used triangulation methods to increase the robustness of the findings.

Results are reported using interview quotes followed by pseudonyms, in the case of service users, and occupation title, in the case of institutional stakeholders.

Findings

Minority Northeasterners' involvement in mental health-care governance was driven by both individual and collective motivations. Individual motivations include the need to deal with stigmatization and social isolation and to acquire positive social roles. Collective motivations entail a desire to improve the responsiveness of mental health care and achieve social justice for people affected by psychosocial problems.

The array of motivations encouraging the participation of minority Northeasterners has a common denominator. When taken together, they demonstrate a concerted effort by participants to foster social inclusion, not just their own but of everyone enduring discrimination due to mental illness. This preoccupation with the collective is more salient among 'old hands', that is, users with a long-standing experience of participation. The majority of early-stage participants, in contrast, puts most of

their energy into pursuing solutions to problems affecting them personally. For those who stay involved over a period of time, however, individual motivations tend to shift into collective concerns.

Individual motivations

We identified three types of individual motivations for participation: increasing social interaction, acquiring meaningful social roles and overcoming the stigma attached to mental illness.

Increasing social interaction

Liaising with others and exchanging experiences, thoughts and worries was something many users could no longer do after the symptoms of their psychosocial distress started showing. Ignorance and fear led people to exclude them.

> I'd like us to be looked at with other eyes, not like people with a mental illness who are going to harm society. (…) Society treats us without respect, often because of ignorance. We're also human beings. (…) I used to work but nowadays I'm not as productive as a normal person. The others look at me and say I'm crazy. They put me aside. (Oscar)

Participants endured much humiliation and discrimination. As Oscar explained, a bus driver once refused his rightfully assigned free bus card (FBC) shouting for everybody to hear: 'this guy thinks he can travel for free just because he is crazy!' For some users, experiences of disparagement and mistreatment were so extreme that they began to fear venturing into public space. Talking about a young man receiving care at an outpatient mental health service, a social worker noted how difficult it was to persuade him to participate in activities outside the service premises: 'It took me months to convince him to come with us. He didn't want to. He was afraid people would throw stones at him'.

Intolerance, shame and discrimination caused the (self-)estrangement of many users from their communities, impeding their partici-

pation in social activities and robbing them of a sense of belonging that is crucial for both personal empowerment and active citizenship. Asked about what could foster the citizenship of people suffering from psychosocial distress, the president of a family association responded:

> Society needs to embrace them. The myth that having mad people in the streets is dangerous must end. I usually say that mental illness is like any other pathology. It's like cancer or AIDS. People embrace those pathologies but not mental illness.

The idea of 'embracing mental illness' refers to the efforts required to change social attitudes and dispel the fears and prejudices that undermine the social inclusion of people with mental health problems. For some users, participation was the first opportunity they had to take part in a collective that respected their ideas and individuality. For others, it was a way to visit new places and meet people.

> [I participate] to get out a bit and go to the city [centre]. I like to go there [user movement meetings] to see people and know what's going on. Most users know nothing about what goes on outside [CAPS]. (Jenifer)

Finding a meaningful social role

To feel included in society, people need to engage in valued relationships. The ability to build interpersonal relationships depends on people's social, moral and emotional competencies[37] and on how others perceive them. These perceptions are influenced by the social roles people occupy: those holding valued roles are more likely to benefit from positive social interactions.[38] Having a meaningful social role is crucial, thus to develop rewarding relationships and to promoting inclusion.

Participants considered involvement in economically and/or cultural valued activities a key strategy to foster the access of people with mental problems to valued roles. Employment, however, was viewed as the most powerful means to attaining more positive social roles.

I got my pension for disability but I'd like to [work] … Many people think that's crazy. But I think: 'I have money but I don't have work. (…) I'm excluded from society'. You know, a person who doesn't work or who doesn't study, she doesn't have much value for society, especially in a third world country. (Expert by experience 3)

Only a small number of the users interviewed had access to social benefits, and even fewer succeeded in getting a job. Those who worked felt that employment gave them a sense of accomplishment, financial security and respect.

Users also tried to change public attitudes towards the 'mentally ill' through music performances, art exhibitions and volunteer work. Some were particularly aware of the influence of social environments on their access to valued roles.

> I've been defending at the [user] movement [meetings] that we need to open ourselves more to society. We have to make more public events to show ourselves, our bijou jewellery, our craftwork. We need to show that we're capable of producing things. (…) Because we deal with psychiatry and society is afraid. They think we're aggressive. So prejudice is a barrier we have to break. (Vinícius)

This quote shows that obtaining competencies and engaging in economic and cultural activities may not suffice to improve the image of people with mental problems if myths about their dangerousness persist. Increasing their access to socially valued roles requires also that the barriers set up by prejudice be broken.

Overcoming stigma

Brazilian society endorses many stigmatizing ideas about mental illness,[39] and the internalization of those ideas induces self-stigma.

> Interviewer: You mentioned taboo. Is mental illness very stigmatised here?

> Psychiatrist 1: Yes, it is. Even by patients themselves. (…) A patient I had been treating for 8 years … he was doing very well. He no longer had psychotic episodes. But he couldn't bear the idea of being a patient. He asked me for a medical report. When I wrote down a diagnosis of schizophrenia he couldn't accept it. (…) The real

problem is being associated with [a mental health] institution. (…) The stigma is a horrible burden. It becomes almost impossible to live when you get such a diagnosis.

Self-stigmatization can cause such personal devaluation that some people feel compelled to abdicate from their rights.

> Interviewer: Did participation help you personally?
>
> Vinícius: Yes. (…) I resisted a lot to get my Free Bus Card [FBC] at first. I thought that was … it was as if they're putting a sign in my forehead: 'You have a problem'. When you show that little card everyone knows that you have a [mental] problem, that you're a special person. I, myself, had a huge prejudice about it. I was ashamed of telling people I got treatment in psychiatry. Nowadays, that's over. (…) I learned to value myself more. I know that I'm capable of doing many things and so are other users. If that [FBC] was a right of mine I should fight for it.

Involvement can contribute to eliminating long-lasting prejudices by enabling users to deconstruct negative beliefs and develop a sense of justice. As Vinícius notes, rights are something one must be informed about and fight for. This realization reinforced his commitment to engage in health participatory spaces. In other cases, it helped users act upon their rights concerning treatment.

> I got to know my rights. (…) I know I can question things if I think they're wrong. I can also ask the doctor if I think the medicines aren't good for me. I can talk to them [professionals] about what's best for me. (Robson)

Collective motivations

Participants also expressed collective motivations for involvement, namely the need to improve mental health care and increase social justice.

Improving the responsiveness of mental health care

Getting involved in participatory spaces designed to foster the inclusion of marginalized groups (e.g. user movement) can help members of these groups to gain awareness of the mechanisms determining their (self-)stigmatization and exclusion. As they realize the sources of their disadvantage, some develop a righteous anger[40] that can rouse them to recast themselves as political actors. This happened with Vinícius. Once he realized the harm caused by his own stigma, he rebounded by pursuing an active role in health-care governance. He started by engaging in his mental health-care service assembly.

> Vinícius: (…) *Assembleia* is there for us to discuss things and to make our claims. Everyone should participate. It's not only meant for criticism. It's meant for us to give our opinions about the service. (…)
>
> Interviewer: And what's necessary to make CAPS a better service?
>
> Vinícius: There aren't enough staff. The building is too small. We don't have a room to seat and talk to each other. We need a bigger building. The user groups are too big. We need more income generation workshops.

When I interviewed Vinícius, CAPS had already enjoyed some changes resulting from users' involvement in the assembly (e.g. an extra psychiatrist was hired). However, as noted by Benedita, who was involved for 9 years, some aspects of service organization (e.g. getting better facilities) escape the control of service coordinators. They are a responsibility of the municipal government. When asked whether changes could be demanded through other mechanisms, Vinícius explained how he went to the municipal health council to express dissatisfaction with service delivery and determine liability:

> I went to the health council and I told them all about what's missing. It was funny because they [public health managers] go there [council] and they start describing everything they've done so far. And I started thinking: 'We're in another city. We're in another world. I can't see any of that'. So I told him: 'there aren't enough doctors. We don't have enough space. There's a lot missing in CAPS and you're saying you did this and that. I don't see anything done!' I said that to the Secretary of Health.

Improving the responsiveness of mental health care became a priority of Vinícius' participatory efforts. However, that was not a goal he pursued just for himself. When he started voicing his views at the council, he was in the last phase of treatment at CAPS. His advocacy for adequate mental care was largely concerned with promoting the rights and well-being of a group he came to identify strongly with – the mentally ill. This illustrates how individual incentives for involvement can evolve into wider concerns with a collective one feels part of.

Pursuing social justice

Most users were poor and lived in slums with high rates of violent crime and economic hardship, low-quality schools and few health-care services. These circumstances reduce their life opportunities putting them, and their offspring, on trajectories of low job prospects and low income.[41] Moreover, socio-economic disadvantage plays an important role in ethnic inequalities in health,[42] which tend to grow when people are also discriminated as a result of mental illness.[43] Social adversity over the life course and multiple types of discrimination associated with low socio-economic status, ethnicity and mental illness, thus seem to exacerbate health inequities.[44]

Gladys described several forms of discrimination endured by herself and others, which are likely to impact negatively on their health.

> Gladys: I participate because people who go mad are at the mercy of discrimination. They're totally helpless. Nobody cares. They're looked down on. They're misunderstood in their homes, like I was. It's a total exclusion. (…) While other people get things easily, we need to carry a huge cross to get just a few things which are our rights.
>
> Interviewer: What rights do you mean?
>
> Gladys: (…) Having a place to live. The right to pension. Jobs for those who can work. Many people here at CAPS send curriculums but they're never called back. (…) We need jobs, housing and, above all, respect.

Gladys speaks of limited life opportunities (e.g. restricted access to jobs and income) and unenforced rights (e.g. housing, social benefits) that undermine users' capabilities to pursue valued life goals,[45] casting them into a socially disadvantaged position. Moreover, people suffering from psychosocial distress are also subjected to institutional discrimination. General care providers often deny them access to health care.

> Professionals are afraid of what users might do. I don't know if you heard about Joana's case. She went [to a healthcare centre] with a professional from CAPS and when she arrived the doctor didn't want to consult her. She [doctor] said: 'if she causes trouble who's going to take care of my patients?' And she didn't accept her. (Psychologist 4)

Many minority Northeasterners were committed to achieving social justice for people affected by mental problems, which they tried to do by demanding the enforcement of their rights and by lobbying for inclusive policies. The latter focused mainly on increasing their access to work opportunities. This entails breaking down interpersonal and institutional barriers. Acknowledging the lengthiness of these processes, some users also advocated for direct measures, including affirmative action.

> We need to change the minds of employers out there so they can see us with other eyes, like people who can work. They think that if we have a psychotic episode we can't take up responsibility again. But that's not true. I think we need to get into the quota system. (Oscar)

The FBC is a good example of how users' attempted to bring more substance to their rights. The FBC enables poor people with disabilities to travel by bus free of charge. This has meant a loss in profit for transportation companies that have been lobbying incessantly to get that right revoked. In addition, disability assessments made by doctors follow very strict criteria. This results in the denial of FBC to people like Gladys, whose life chances are clearly undermined by disability but whose diagnosis is not considered serious enough.

> One thing I fought really hard for myself and others, and they got it and I didn't, was the

FBC. They told me that FBC is not for people with depression, that depression is not an illness. (…) I went to so many places to try to get it. (…) But they always tell me I don't have the right to it.

The FBC is a valuable resource. It enables users to travel to mental health services and to societal and participatory spaces. Like Gladys, many users felt personally victimized when refused the FBC. However, after discussing this at the user movement meetings, they became aware of the motives impeding its allocation. Moreover, they realized they could join efforts to demand more fairness in its distribution. This resulted in a hearing with the local ombudsman in which user representatives formalized a complaint against unjust rejections of the FBC and requested investigation of improper conduct by transportation companies. This was a critical manifestation of active citizenship and a call for inclusion.

Discussion

User involvement is a right and a fundamental principle of the Brazilian public health system promoted to increase citizens' control over the development and implementation of health-care policy and delivery.[9] As our study shows, minority north-eastern users want to be involved in improving the responsiveness of mental health care. However, their motivations for participation go far beyond that to include aims such as increasing social interaction, acquiring meaningful social roles, countering stigma and achieving social justice for people affected by psychosocial problems. When put together, these individual and collective concerns demonstrate a strong aspiration for social inclusion. They show a pressing need by users to gain access to social relationships, work, recreation, services and civil activities. They also say a great deal about the position that marginalized users find themselves in and about their commitment to fight exclusion.

The motivations identified by our study are not exclusive to minority users in Brazil. Studies in the UK, for example, found that mental health and stroke service users share similar goals for involvement and that their participation is motivated by, but not limited to, the desire to improve health care.[46–48] What has been less explored by the literature is how socially disadvantaged users appropriate health participatory spaces to promote their social inclusion and to demand the inclusion of others who also experience discrimination. For marginalized people, participatory spaces may well be one of the few spaces where they feel wanted and welcome. Promoting the sustainability of their participation in these spaces, however, will depend on whether their concerns are really listened to.

Our findings indicate differences between early-stage and long-term participants' motivations for involvement. While the latter focused predominantly on reaching collective goals, newcomers geared their participatory efforts mostly towards the satisfaction of individual needs. This is consistent with the MIT,[17] which postulates that collective motivations become increasingly strong as people continue to participate and start to develop relational ties with others who they identify and share values with.[49] As Passy[50] observes and Barnes and colleagues'[22] case studies demonstrate, participation enables people to become embedded in social networks and to absorb values such as social justice. These values are conducive to the development of a concern with the common good, which reinforces collective incentives for participation.

This is not to argue, however, that individual motivations are secondary to collective incentives in determining involvement, as the MIT asserts.[17] In our study, individual concerns played a major role in getting users started in participatory initiatives. Moreover, the appeal of those initiatives was largely dependent on users' perception of their ability to generate individual benefits. This incongruence with the MIT seems to be explained by the socio-economic deprivation experienced by many of our participants, which impelled them to concentrate their participatory efforts on fulfilling unmet basic needs (e.g. shelter, care, social

interaction). Less marginalized groups, in contrast, may be less troubled by these concerns and subsequently express more collective motivations for engagement. Disentangling the effects of social disadvantage on users' motivations for participation would require, however, a comparison with another case study of involvement in mental health care by well-off minority users. This is a limitation of our study that suggests the need for further research.

Guaranteeing the representativeness of the health participatory sphere has been a key challenge in user participation policy. Our study has practical implications for those tasked with addressing this problem. It suggests that, to increase the inclusiveness of health participatory spaces, more attention has to be given to clarifying the role and remit of these spaces and of the user groups they are meant to represent.[51,52] It also indicates that participatory spaces need to include users with short- and long-term experience of participation to accomplish individual and collective goals. As we argued elsewhere,[15] mismatches between minority users' motivations for involvement and the goals and actions undertaken within participatory spaces may render those spaces unappealing and bring participation to a halt. While actions aimed at promoting the common good may be well suited for 'old hands', who had the time and opportunity to absorb values, norms and identities[22] and to acquire the resources necessary to embrace a collective agenda for participation, socially disadvantaged early-stage participants need support in dealing with individual concerns before being asked to pursue collective goals.

Increasing the representation of socially disadvantaged minority groups also requires that these groups be equipped with the skills and confidence necessary to make their voices heard. This will entail an investment on equalizing their life opportunities and enforcing their basic rights. Such measures are likely to have a positive impact not only on promoting involvement but also on reducing the health inequities that undermine minority users' active citizenship and full participation in society.

Conclusion

Groups historically excluded from decision-making processes may identify social inclusion as the core goal of their involvement. Failing to recognize this multidimensional motivation for participation can compromise the success of participatory spaces seeking to engage socially disadvantaged minority users. Strategies aiming to promote inclusive health participatory spheres must acknowledge both the costs of participation[13,15,21,47,53–55] and the broad range of incentives motivating users' involvement, instead of focusing solely on issues related to health-care management and provision.

Conflicts of interest

The contents of this article are the responsibility of the author alone. They are not influenced by the study's sponsor in any way. I declare no conflict of interests.

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