‘The Needs of Strangers’: Understanding Social Determinants of Mental Illness

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This article explores the social determinants of mental illness in order to stimulate debate and advocate for improved services, and greater understanding and acceptance for people with serious mental illness in their community. Systemic and broader social mechanisms that perpetuate stigma and inequity are briefly examined. Research findings from a study of the culture of smoking for psychiatric populations are used to demonstrate the complexity of these mechanisms and to show how they impact on the social determinants of mental illness for people with serious mental illness. From this discussion, broad system and policy options are offered.

Introduction

Have you ever looked at those dishevelled street dwelling men who sit on the local park bench with what looks like their worldly possessions in a plastic bag or two, seemingly talking to themselves, and wondered how they came to be there? Have you wondered what sort of journey they had had through life and what their life might have been like before this apparent turn of fortune, when they were somebody’s brother or son, someone’s workmate, or someone’s friend who sat next to them in primary school? To develop understanding requires some comprehension of the social determinants of mental illness. At the heart of this understanding are the relationships that variously bind us together or segregate us as a community of citizens.

This article aims to raise awareness of the social determinants of mental illness, particularly, the impact of mental illness and how it shapes the person’s experience of the community in which they live and their participation within it. A social determinants of health view recognises that a range of economic, environmental, political and cultural factors influence health beyond the limits of a behavioural, biological and genetic view of health (Marmot & Wilkinson 1999; Kelly, et al., 2007). This involves the person’s access to resources such as secure housing and income, meaningful employment, and adequate education, transport and other services, but also the notions of security, respect, support, care and acceptance that all community citizens perceive as important in living a purposeful life. Various structures and circumstances within the current social, economic and political environment create fundamental inequalities that not only contribute to the development of mental illness but then also perpetuate adverse cycles of poor physical and mental health outcomes for those people. This is a relationship that can be argued to begin before the person is born (Barker 1990; Najman & Davey Smith 2000). Therefore, addressing the social practices that perpetuate a situation where ‘children born of the socio-economically disadvantaged are born more physically, cognitively and emotionally impaired’ is necessary (Najman & Davey Smith 2000, 4).

Currently, clinical approaches to mental illness can tend to perceive the individual as ‘the problem’ requiring treatment and do little to address their level of acceptance within their community. Despite efforts to respond to people’s needs according to a bio-psychosocial approach, many continue to feel the insidious effects of mental illness (Burchardt 2003). Perhaps it is because the individual psychosocial interventions offered do little to address the broader barrier of social stigma which acts as a glass ceiling for many people with mental illness. As part of attempting to live in their community, they are still often seen as ‘other’, as separate, which perpetuates their social inequality and alienation.

Ignatieff (1994) asks what is it that a person needs to live a human life, to live to their full potential. Looking at modern welfare, Ignatieff asks whether the provision of basic necessities of human survival is enough, whether this translation of needs into rights and rights into care is enough for us to then perceive ourselves as a moral community in which our responsibilities to each other are met. He argues that:

[what we need in order to survive, and what we need in order to flourish are two different things, [and that] we are more than rights bearing creatures, and there is more to respect in a person than his (sic) rights. The administrative good conscience of our time seems to consist in respecting
individuals’ rights while demeaning them as persons. In the best of our prisons and psychiatric hospitals, for example, inmates are fed, clothed and housed in adequate fashion... but it is another question altogether whether they have the respect and consideration of the officials who administer these rights’ (13).

Dignity and respect in this sense are argued to be entitlements that can not necessarily be guaranteed through rights discourse alone. Ignatieff further recognises that there is a contradiction at the heart of the welfare state in which respect for people requires us to treat people unequally, yet to also treat everyone equally like every other human being, as if their needs were the same. He says that, ‘in treating everyone the same [the welfare state] ends up treating everyone like a thing’ (17). So where does this leave us in our attempts to make policies to address social inequality and improve social equity for people with mental illness? What are the barriers that people with mental illness face that perpetuate their poor health, social and economic outcomes?

Perpetuation of Social Inequality – The Example of Tobacco Addiction
Some time ago, I undertook a study of smoking among psychiatric populations, with the immediate objective of helping people with mental illness to quit (Lawn, 2001a; Lawn, Pols & Barber 2002). I quickly realised that smoking was merely the tool through which a much more complex set of social, economic and political arrangements and relationships were being mediated, communicated, reinforced and perpetuated over many decades, perpetuating further adverse consequences for these people. This microcosm reflected the broader community experience of people with mental illness. Barriers to quitting involved more than the person’s choice to smoke or motivation to quit. The majority of these people clearly wanted to quit but just felt unable, having become so disempowered by the social impact of their illness and the system of care that actively reinforced their smoking. Many staff had also succumbed to the institutionalisation of smoking, with high rates of smoking (particularly by nurses), reliance on cigarettes for clinical management of patients, and abrogation of responsibility for addressing the health implications by all staff, despite their training as health professionals. From a sociological viewpoint, then, smoking had clearly become a necessary addiction for both people with mental illness and those involved in their care.

It was not so much an anti-smoking stance that motivated this research, but sheer frustration at being a mental health worker watching the grinding cycle of poverty of clients and the routine calls to the public trustee, arguing over mere scraps for clients whose main priority was where the money for their next packet of cigarettes would be coming from, regardless of what debts they might have or what food they might not have in their cupboards. There was a strong sense that their choices were being restricted somehow by an addiction that was somehow beyond the person’s control, that staff seemed powerless or disengaged from the problem, that the presence of mental illness had created an uneven playing field from the outset and that this was simply not on, simply not fair.

The study began by asking people with mental illness about their smoking and attempts to quit. Semi-structured open-ended interviews were conducted with a purposive, convenience sample of twenty four clients from publicly funded community mental health services. Six clients from each of the diagnostic groups of schizophrenia, bipolar affective disorder, depression and personality disorder were interviewed (age range 25 -63 years; 12 men and 12 women). Interview length ranged from 60 to 120 minutes with data analysed using a grounded theory thematic approach (Strauss & Corbin, 1990).

Results revealed that cigarettes were overwhelmingly rated as a core need by all participants, given greater importance than food by many. Most descriptions about ensuring the supply of cigarettes involved significant degrees of self-degradation and humiliation, with consequent effects on self-esteem, self-respect, safety and relationships with others. Begging was not uncommon. A vicious cycle of need, anxiety, loss, debt and poor physical health was common for most participants.

(Mark -schizophrenia)
The first time when I had no money and I couldn’t get credit at the deli, I used to go around the streets looking for butts... looking for butts... I don’t know where or who they came from but I’d unroll them and join them all up again into one. (pause) It was just a smoke wasn’t it? I’ve been that bad. When you can’t have a smoke you just go around knocking on people’s door asking for smokes and some I didn’t even know the people, and they’d say, ‘Who are you and what do you want?’ Some just used to swear at me and push the door in my face, bang the door. It was just a smoke (pause). I would have done anything for one at the time.

Various structures and circumstances within the current social, economic and political environment create fundamental inequalities.
The feeling of safety, reassurance, and predictability that came with having an assured supply of cigarettes was clearly and strongly expressed by all participants. Cigarettes were described as the marker that kept every other aspect of their lives in control, providing order in the frequent chaos or in the monotony of their daily existence. The most striking feature of their decision to continue smoking was the sense of freedom it gave in the presence of overwhelming powerlessness to predict and decide their future. Smoking thus gave participants a greater sense of autonomy and control over their lives, especially when being treated in inpatient settings.

(Jenny – schizophrenia – speaking about the locked ward and staff)
The whole experience of being locked in a cage for five minutes to have a cigarette, it’s just a horrible experience…it’s like you get out of this cage and get into the other cage but at least I’m having a smoke, and they can’t control that bit.

Twenty-six mental health service staff from the cross-section of professionals in inpatient and community mental health services were also interviewed, also using a semi-structured, open-ended approach and grounded theory analysis of themes. The majority of staff believed that clients could not quit, that they needed to smoke to cope with their illness and its consequences.

(John – Consultant Psychiatrist)
In my heart of hearts, with patients with schizophrenia, I feel that they haven’t got much left for them, so good luck to them, if they want to smoke, let them.

Many staff openly acknowledged and condoned the ‘usefulness’ of cigarettes to clinically manage clients’ distress, to enhance engagement with clients and to cope with the role of providing care.

(Paul – Inpatient Psychiatric Nurse)
If they didn’t smoke, they wouldn’t come back to the door every half-an-hour either. There’s something about having a closed door between us that makes the difference. It’s a real power thing. It’s a typical “us and them” situation. The staff retreat to behind the closed door… to adopt a certain mentality of control just because of the environment. It’s easy to give people cigarettes. It’s easier than not giving them.

(Marg – Inpatient Psychiatric Nurse)
We’ve had people agitated and escalating and we have desperately found cigarettes. All of the nursing staff have given cigarettes to give this person. And to tell you honestly, it’s probably my own nicotine addiction that influences how I view patients’ need. When I’m stressed about something, I usually have a cigarette and pace.

Despite efforts to respond to people’s needs according to a bio-psycho-social approach, many continue to feel the insidious effects of mental illness.

The focus of this study was smoking and how the reliance on cigarettes has served to confuse and pervert what should be good clinical care. In such a system, clients and staff have become so co-opted into the culture of smoking that they have become alienated from each other with real ethical implications for the way care is provided. Many staff reported that they just don’t think about it. Analysis of client and staff interviews, triangulated with an extensive participant observation of the settings showed that a complex range of players, roles, rules, structures, ideologies, artefacts, beliefs and values combine to create an entrenched culture of smoking (Lawn, 2001a). The system’s response to smoking mirrors how we fundamentally seem to treat and view people with mental illness, cigarettes are merely the tool used to mediate these arrangements. This was clearly demonstrated by a recent protest against inpatient smoking bans by small number of New South Wales consumers whose main argument was that smoking was one of their few pleasures within a system that seems all powerful (Right to Choose, 2008).

Why was this their main argument? How did it all get so perverted so that they felt this was their only option? Why wasn’t good clinical care, respect and meaningful citizenship their main demand? These arrangements are indeed tragic and provide insight into how social determinants of mental illness are perpetuated. They demonstrate how and why an already disadvantaged section of the population smokes up to three times more than the general population. This is in the context of established research findings that people with mental illness have two and a half times the morbidity and mortality from all major physical health conditions than people without mental illness (Coghlan, Lawrence, Holman & Jablensky, 2001). Quality of the person’s life, not merely providing the basics, is important, as Ignatieff reminds us. The smoking study showed that even basic needs were missing or under threat for many people with mental illness. It also questioned how much the community and service systems ‘care’ about these people.

Conclusions
The World Health Organisation (WHO) discusses the role of drugs in relation to the social determinants of health (Murray and Lopez, 1996), saying that people turn to tobacco and other drugs to numb the pain of harsh economic and social conditions. But the causes of becoming addicted are not necessarily
what maintain drug addiction. Likewise, the strategies for preventing it may not be the same as those we pursue for addressing it. Given the physical barriers to quitting, combined with psychological and social barriers and reinforcement through peers, workers, and systems of care, it is little wonder that smoking is a major contributor to social disadvantage and disability for people with mental illness. Some of these people spend between one third and one half of their income on ensuring the supply of cigarettes from their already minimal finances (Lawn 2001b). The experience of mental illness, often self-medicated with cigarettes and other drugs, becomes an embedded relationship with perpetuating cycles of poverty and poor overall health outcomes. It creates ghettos in which people with mental illness live intertwined with drug dealers, neglected children, the aged poor, and other disadvantaged groups, creating a breeding ground for further psychiatric problems. How did it all come to this? And more importantly, how do we fix it?

We do a lot of research on various social problems related to our health and well-being. We spend a lot of money attempting to address the growing burden of chronic disease (AGDOHA, 2008). We devise many recommendations for better health based on our findings:

- Don't smoke. If you can, stop. If you can't, cut down.
- Follow a balanced diet with plenty of fruit and vegetables.
- Keep physically active.
- Manage stress by, for example, talking things through and making time to relax.
- Practice safer sex.
- But does anything really change or change at the pace that we hope for? Are we even asking the right questions in the first place?
- Don't be poor. If you are poor, try not to be poor for too long.
- Don't live in a deprived area. If you do, move.
- Don't be disabled. Don't live in low quality housing or be homeless.
- Be able to afford to pay for social activities and annual holidays.
- Don't be sexually abused. If you live in an abusive environment, move. (NHS 1999)

Will the solution be merely in addressing basic needs as defined by Ignatieff, or is it more complicated, given that people from the full spectrum of the social strata can experience mental illness and be significantly socially and economically disadvantaged by it? The role of access to purposeful social and recreational activity, acceptance by others, minimising social exclusion, and access to meaningful and rewarding employment would all seem important. Yet, the provision of meaningful work is complex. Toynbee (2003) talks about the demeaning experience of low paid work and challenges the notion that ‘any job is better than none’. We need to take great care than we do not propose token solutions that have the potential to do more harm than good by, for example, inadvertently blaming the person when they do not achieve the recovery or self-management goals we hold for them.

Mental illness often brings with it isolation, unemployment, poverty, loss, grief, loss of freedom, fear, lack of safety, disruption of education and career, and disruption of goals and dreams for the person experiencing the condition. Added to this can be significant social stigma and high rates of cigarette smoking and other drug abuse. It is too easy to sit back and think that these problems are largely brought on by the person as a result of their own choices; that they could simply change or improve their circumstances by educating themselves, taking more responsibility for their health and life choices, undertaking work training, being more physically active, or giving up smoking. This ignores the fact that difficulties with motivation and lack of insight can be actual symptoms of mental illness.

Recovery is not always a clear path, as much of the current policy around recovery-based practice implies; it is not a mere model (Davidson, et al., 2001). Recovery involves an ongoing process of learning how to successfully self-management that requires its own set of economic, social and emotional resources, often when the person is least likely to have such resources at their disposal. It also involves delivery of meaningful and recovery-based practice that is fundamentally underpinned by service providers who believe that recovery is possible, that people with mental illness can make choices, and have the right to do so as part of a person-centred approach to service delivery (Michie, Miles & Weinman, 2003). Appropriate psychosocial supports that are adequately resourced are crucial to address the social determinants that perpetuate mental illness. They have the potential to not only foster this necessary values shift; they very often offer a more engaging alternative to the traditional illness model of care (Weitz, 2007). The increasing role of voluntary and paid mental health peer support is one example of this changing landscape of psychosocial support, policy and practice. The Personal Helpers and Mentors Program is one such initiative of the Council
of Australian Governments (FaHCSIA, 2008). These areas of policy and practice reform have implications for the clients and staff noted in the smoking study and beyond because they attempt to build processes where care is collaborative rather than controlled by services that are arguably judgemental towards clients and which deny their strengths and potential, and role as the expert of their experience.

The descriptions of cultural reinforcement of smoking in psychiatric settings proffered here demonstrate more generally that those providing support and care have a significant role to play in reinforcing disadvantage and helping overcome it. Marmot and Siegrist (2004) argue that health and respect are basic needs. Bosma and colleagues (1999) have found perceived control and sense of powerlessness to be significant contributors to increased mortality rates and that this is clearly linked to low socio-economic groups but is not necessarily the only criteria involved. Diderichsen and colleagues (2001) argue that both the upstream mechanisms prevention and early intervention in the community and downstream mechanisms of how people cope with disease and disability need to also be considered.

Wilkinson and Marmot (2003) stress that policies shaping the social environment in ways conducive to better health (and mental health) needs to occur at all levels; government, public and private institutions, workplaces and local community; that we each and all have a shared responsibility. They state that it also requires a greater understanding of ‘the interaction between material disadvantage and its social meanings. It is not simply that poor material circumstances are harmful to health. The social meaning of being poor, unemployed, socially excluded, or otherwise stigmatised also matters’ (9). Such a circumstance demands that service providers understand the social determinants of mental illness and the impact of their values and behaviours on the clients they serve.

In order to understand what to do, we need a clearer understanding of what is going on in the first place, what is the nature of the complex relationships between social determinants of mental illness, onset of disability, barriers to recovery, the role of service providers, the importance of belonging and community, and the impacts of social exclusion. The views of people with mental illness continue to be largely hidden and under-reported. And they are not a mere minority if we accept the notion that one in five people experience mental health problems and that by the year 2020, the WHO predicts that depression alone will rate second as producing the greatest burden of disease behind heart disease (WHO, 2001).

In Australia, several policy initiatives have attempted to address the social determinants of mental illness, both within mental health services and as part of larger community policy. National mental health plans over more than a decade have focused on, for example, consumer rights, the relationship between mental health services and the general health sector, promotion and prevention, carers, mental health workforce, standards, the development of partnerships in service reform, quality and effectiveness of service delivery, media, and community awareness (Australian Health Ministers, 2003; AGDOHA 2006). As a part of the social inclusion agenda, the Australian Government is also developing a national mental health and disability employment strategy that aims to address the barriers faced by people with disability and/or mental illness that make it harder for them to gain and keep work (Australian Government, 2008). The rising input of mental health advocacy groups and increasing respect for the input of peers to policy, decision–making processes within agencies, and service delivery are good examples of how problems and solutions can be worked on more effectively and respectfully. As workers, we need more education, reflection, questioning and discussion about the various factors that keep people in a position of disadvantage and our role within it. We need to look at the ethics of our work, be true to the values underpinning these many policy initiatives, and to more generally to keep asking what it is to be a moral community.

We need to take great care than we do not propose token solutions that have the potential to do more harm than good.

References


