

Exploring the impacts of organisational structure, policy and practice on the health inequalities of marginalised communities: Illustrative cases from the UK healthcare system

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Abstract

This paper explores how organisational structure, policies and practices in healthcare can inadvertently disadvantage marginalised populations (e.g. individuals from ethnic minority backgrounds) and reinforce health inequalities. We draw upon three diverse UK healthcare settings (long term care institutions, high security hospitals and community pharmacies) to illustrate how systemic injustices negatively impact on access to care, treatment and health outcomes. The first case study considers the care of older people within nursing homes; specifically the disempowering effects of this service structure and impacts of choice reduction upon health and their access to health provision. The second case study explores the impact of security restrictions upon patients within high security hospitals, focusing particularly on the maintenance of relationships and support networks outside of the hospital. The third and final case study, draws upon a national community pharmacy medicine management service to illustrate ways in which policies and guidelines inadvertently obstruct patients' engagement with the service within a community setting. We draw upon these settings to highlight inequalities within different contexts and to illustrate the ways in which well intended services can inadvertently disadvantage marginalised communities in multiple ways.

Key words:

Health inequalities, marginalised communities, care homes, medication reviews, secure hospitals, health policy

Highlights:

- This article highlights structures, policies and practices that inadvertently reinforce health inequalities amongst marginalised groups.
- Marginalised communities include people who are disadvantaged and underserved, and who experience poorer health and social outcomes.
- Experiences of marginalisation are compounded by marginalised people often belonging to more than one marginalised group.
- Health and social inequalities are reinforced and reproduced when marginalised communities are excluded from research.
- This paper illustrates that despite good intentions, policies and practices may inadvertently underserve people who are already marginalised.

Introduction

Marginalised communities are considered to be those who are disadvantaged, medically under-served or difficult to reach, who are more likely to experience health and social inequalities, and who frequently experience poorer health and social outcomes [1]. Personal characteristics including gender, ethnicity, education, employment and religious beliefs each influence access to, engagement with and experiences of health services [2]. However, the Equality Act (2010) requires all public bodies to advance equality of opportunity and to eliminate discrimination, disadvantage and to promote understanding of the needs of marginalised communities [3]. Marginalised communities may be socially isolated because of their geographical contexts (for example older people in long term care institutions); who do not fit the dominant models of healthcare (for example, Black, Asian and minority ethnic (BAME) communities and hybrid organisations or who are underserved because of their limited engagement with health service providers.

This paper presents three illustrative case studies as examples of where and how organisational structures and health policies might inadvertently exclude marginalised groups. The paper specifically examines long term care institutions (LTCIs) in considering geographical context and choice; high secure hospitals focusing on organisational structure and restrictions to social support; and community pharmacy and engagement with medicine use reviews.

Healthcare Illustration 1 – Long Term Care Institutions (LTCIs)

In the UK, there are approximately 425,000 people in a long term care institution (LTCI) [4]. The use of care homes for the provision of providing care for the UK older population is set to rise as we, like other developed nations, face an unprecedented rise in people over the age of 80 [5]. In addition, the diagnosis of neurodegenerative conditions such as Alzheimer's and Dementia, related conditions and multi-morbidity continues to increase resulting in many families turning to the care home sector to provide 24/7 care for their loved ones [6].

For the purposes of this case study, we refer to care homes (residential and nursing), that provide care for those over the age of 65 and where it is the resident's permanent place of residency [7]. Many residents are aged over 85, with as many as 75-80% receiving a diagnosis of dementia [8]. These residents are often classed as frail elderly having co-morbidities and requiring long term care. Meeting the daily care needs of residents is provided by staff employed by the care home either as health care assistants, care home managers and ancillary staff.

Reasons for individuals to be moved to live permanently in a care home are difficult decisions often made by family members and in most cases in consultation with healthcare professionals. In the UK it is frequently the case that many older people are moved into a care home due to an unplanned stay in hospital such as a result of a recent episode or fall [9]. It is not uncommon that older people who previously lived independently, often alone, find that after emergency admission to an acute setting that upon assessment it is deemed appropriate, and in their best interests, to move them permanently to a care home setting.

In England, moving in to a care home can create uncertainty for individuals due to the complexity of funding and structuring of health and social care provision. Indeed the British Geriatrics Society (2011) estimate that over half of older people in care homes do not have access to all the services and support they require from the National Health Service (NHS) [10, 11]. The BGS (2012) also reports "that there also appears to be little consensus among commissioners about what services people in care homes need, or how these should be delivered" [11]. This is particularly pertinent when an older person,

prior to a hospital admission and then subsequently a care home, is likely to be more mobile, independent and less reliant on professional carers to assist with gaining access to healthcare provision. For example, how people choose their local dental or podiatrist services where patient choice is paramount.

One example is the provision of dental care for those older people residing in a care home. A recent quality improvement study, PEACH (Proactive Healthcare of Older People in Care Homes) [12] noted that many of the recruited residents were receiving minimal if no regular dental visits instead in most cases having a basic oral check. Whereas the current policy deems that all adults have access to dental care which may be freely provided under the NHS or individuals choose to pay privately. Furthermore it is widely accepted that good quality preventive care will reduce, in the long term, further complications and potential admissions to hospital. We know that regular checks make for sound economic sense and improved health outcomes for our populations across the age spectrums.

The NICE oral health guidelines (2017) [134] state that the provision of dental care is incumbent on the care home and healthcare professionals to conduct routine mouth assessments on new residents and on an ongoing basis (see statement 1 – 3). Within the care home sector this presents additional challenges. The resident will require additional assistance to visit the dentist, this may be from either a family member or care staff to attend with the resident, in addition to presenting additional challenges due to their cognitive condition, all of which impacts upon access to health provision.

This lack of consistency in healthcare provision stems from a number of areas.. The British Dental Association (BDA) along with the National Institute for Health and Care Excellence (NICE) has provided guidance in the new 2017 Oral Health in Care Homes guidance [134]. NICE state that “this quality standard covers oral health, including dental health and daily mouth care, for adults in care homes (with and without nursing provision). It describes high-quality care in priority areas for improvement” [134]. However, whilst the statements refer to the care home and care home staff providing this care at first admission to the care home there is ambiguity as to how this is actually conducted. Likewise seeking a local dentist practice convenient to the care home resident is often cited as challenging for care home managers [14] one care home manager quoted saying that “*Acquiring dental services for care homes is very difficult*” [pg 4:15]. For many older people they often use the same dentist, doctor and other healthcare services in close proximity to their home which often is not in the same location as their care home [15] which could cause unfair access and variations in levels of care. The reality is that are simply isn’t the number of registered dentists who will provide free care for NHS patients, for which many older people will be entitled to under the associated benefits [16]. There are also issues of access arrangements for older frail people, such as transport requirements and the associated costs, ease of access into the practice itself (whether there are stairs to negotiate) as well as the dental practice having capacity to deal with patients who have a cognitive impairment and/or challenging behaviors [16].

Healthcare Illustration 2 – Black, Asian and Minority Ethnic (BAME) individuals located in high security hospitals

High security hospitals represent a unique context where mental health and criminal justice systems converge. There are three high security hospitals in England and Wales, accommodating approximately 800 patients in total [17]. High security hospitals represent the most restrictive of environments in England and Wales. The security arrangements of these hospitals are equivalent to Category B prisons [18], however, these environments are considered to be hospitals not prisons, those accommodated are notably patients not prisoners and those working within these environments are healthcare professionals, not prison guards or security officers [19].

High security hospitals are governed by the criminal justice system in terms of their physical, procedural and relational security arrangements and by health policies where the mental health needs of individuals are concerned. Those accommodated within high security hospitals are deemed to have 'dangerous, violent and criminal propensities' proportionate to requiring the highest levels of secure accommodation [20]. Patients within these institutions are considered the most dangerous within society due to their potential for dangerous, violent and criminal acts, yet on the other, they are also most vulnerable due to the severity of their mental health problems [17]. These juxtaposing positions in how this population are viewed, creates conflicts in attitudes, feelings and behaviours towards how these individuals are treated [21]. Attitudes towards the forensic psychiatric population have been documented as one of 'abjection and fear' [22], policies frequently outline a need for 'least restrictive practices' [23,24] yet numbers of forensic psychiatric detentions have increased by 50% between 2003 and 2016 [25] and restrictive interventions remain used by healthcare professionals when they see 'no other option' [26,27].

Individuals from BAME communities are disproportionately overrepresented in mental health and legal systems [28, 29]. There is well established evidence regarding the health and social inequalities experienced by individuals of BAME backgrounds [30]. Evidence consistently demonstrates that BAME populations are likely to experience poorer education [31], lower levels of employment [32], poorer housing [33] and higher rates of physical and mental health problems [34]. Individuals from BAME backgrounds are more likely to be detained under the Mental Health Act (1983) [35], to receive poorer mental health care and to experience restrictive practices more often [30]. Individuals from BAME backgrounds therefore face even greater challenges in accessing, engaging with and being discharged from mental health services. These challenges are notably greater where BAME individuals are accommodated within high security hospitals, when English is not a first language and where this already marginalised, and indeed often multiply stigmatized population, becomes increasingly in the minority [31].

The need for interpreters is recognised in delivering high quality, equitable, effective healthcare services that are responsive to all patients' needs [36]. The uses of interpreters can enable access to healthcare, maintain relationships and social networks, improve health outcomes and patients' experience [37, 38]. The challenge of working with interpreters, however, remains within the context of high security hospitals, where interpreters are required to undergo security training, to have security clearance to enter the hospital and to have access to the patients who require their services, and be available at the times when required given the highly routinised schedules of the wards. For individuals whose first language is not English, comfort may be found in speaking with relatives and close friends in their first language [39, 40]. For individuals accommodated within the greatest levels of security, relationships with those beyond the hospitals become ever more important in offering hope and aspirations through continued relationships [40]. It is therefore vital that the organisational structures and policies relating to the security measures of the hospital to do not inadvertently create greater inequalities or impinge upon the care, mental health and wellbeing of those whom they are supported to serve.

Healthcare illustration 3 – Community Pharmacists and Medicines Use Reviews (MURs)

In our last example, we turn to the community pharmacy context and a policy and service known as 'Medicines Use Reviews' (MURs). Provision of these services have been made available nationally since 2005 though community pharmacies in England and are free to patients. Pharmacy contractors receive a professional fee of £28 for each MUR undertaken. It is one of a number of medicines management policy initiatives that seek to help people better manage their medicines [41], as well as to reduce their cost of

waste due to their inappropriate use. The evidence for extra support is strong as it is estimated that medicine non-adherence could be up to 50% [42, 43] leading to a substantial worsening of disease, associated increased rates of hospitalization and a significant economic impact [44]. Patients with poly-pharmacy, have multiple morbidities, have problems with adherence (intentional and non-intentional) as well as those who may be marginalised from mainstream services could therefore benefit the most.

MURs form part of a wider national medication review agenda that has been defined as "a structured, critical examination of a person's medicines with the objective of reaching an agreement with the person about treatment, optimising the impact of medicines, minimising the number of medication-related problems and reducing waste [41]. Pharmacy's professional and representative bodies are keen to engage with such 'medicines optimization' initiatives as they extend the pharmacist's role, and provide a means to enhance professional status [41].

The service is organized as an annual one-to-one, 'sit-down' consultation, allowing pharmacists to sit with patients and provide an opportunity to hold private and more detailed discussions about the use of medicines. Pharmacists are required to include, in their discussion, both prescribed and over-the-counter (OTC) use of medicines within the MUR. The aim of the service is to improve patient 'knowledge, and use of medicines' and this differs from more accustomed but limited, brief 'shop floor counselling' interaction that occurs when medicines are supplied or brought. In England, approximately 3 million MURs are conducted annually [45]. Similar community medication review schemes are provided in other countries including Australia [46], United States [47] and New Zealand [48].

Regarding eligibility for a MUR, patients are mainly invited to the service by the pharmacy team. Although they can self-refer, there is still low awareness amongst patients of the service. Patients are therefore selected based on broad guidelines and are eligible for the service if they are taking one or more medicines and have been receiving pharmaceutical services (i.e. have had their prescriptions dispensed) from the pharmacy for at least three months [41].

However, as well intentioned as this service is, there have been questions raised with concerns over pharmacist pragmatically accommodating additional work without additional resource [49], lack of inter-professional collaboration [50] and whether the service is effective at improving patients' knowledge and use of medicines [51]. Furthermore, research into the implementation of MURs has raised questions over their value to patients and whether they are being targeted to "local needs and patient priorities" [52]. There are significant challenges for pharmacist on the front line to identify who could benefit the most and how medically-under-served, such as those described earlier and may be identified as from marginalised groups. Moreover, those who may benefit from MURs are not a homogenous group, as some may have variable health needs when compared to the rest of the population or require additional support to manage their medicines.

What is clear, is that research indicates that patients who are marginalised may find accessing the service more challenging [53, 54]. For example, the 3 month restrictions placed on contractors may mean that people from the Gypsy, Roma and Traveller (GRT) communities are less likely to be offered the service, the lack of translational or interpretative services could see people with English as a second language to be disadvantaged (ibid), or even a lack of wheelchair access to consultation rooms. The lack of incentives to offer domiciliary MURs may also contribute to inequitable access despite the evidence that MURs potential improve care to this group [55].

In conclusion, it is well known that people from marginalised groups generally have poorer inequitable access to health care due to them experiencing greater physical barriers to accessibility, encountering poorer patient-professional communication and are significantly disadvantaged where a service is not tailored to their unique needs or preferences [56, 57]. The lack of awareness of how the delivery of pharmacy services may be contributing to health inequalities is unknown. The low levels of research evidence to support medication reviews in these populations, principally because such populations are generally under-represented in research or considered 'hard-to-reach' [58], also hinders efforts to tailor care to those who are vulnerable and may need support the most.

Discussion

The right to physical and mental health is a universal human right. However, in practice marginalised communities often face significant obstacles to receiving basic health and social care. This paper provides case studies on how healthcare structures and policies often fail to adequately address those most vulnerable in our society. Individuals from medically under-served groups find accessing healthcare provision more challenging and from the healthcare professional perspective, the service setting makes it difficult to offer equitable care. Organisational structures and policies are often tailored to the needs of the majority of the population, with little consideration of those in minority groups who remain excluded. This has shown to deepen the divide and exasperate those that continue to experience healthcare injustices [30, 31].

The three illustrations draw attention to a wider problem of how healthcare is structured, how policies are fashioned top-down and how they may inadvertently marginalise certain sectors of the community. Structural inequalities that are driven by policies and enacted in everyday practices become embedded into healthcare systems and society, and lead to inequitable distribution of health and social outcomes [59, 60]. Health policy is often advanced through political will, influences from professional bodies (lobbying) and evidence based practice [60]. The problem for policy makers is that there remains low levels of evidence to support interventions for these groups as they are generally underrepresented in research. Furthermore, any reforms to target and orientate professional services towards these groups may be additional complicated due to ambiguity over who should be classed as being marginalised and the practicalities of how they can be identified or approached within any given setting. Structural inequalities are related to discriminated, individuals and institutional racism, poverty and social exclusion [60].

Although public policy as a determinant of health is routinely acknowledged, there remains an absence of understanding about how politics, power and ideology influences people's health [61]. Furthermore, there is under-representation of people medically under-served in empirical evidence, particularly participation in randomized controlled trials [62]. This entails the integrations of the best research evidence, patient values and clinical practice into the decision naming process in order to improve patient care. Organisations that rely solely on evidence-based practice and evidence-based medicine oversimplifies actual practice which is found to be more complex.

Marginalised communities often do not fit the inclusion criteria of research studies. For example, either through lack of opportunity or because dominant discourses and ideals are generalized to majority populations [63]. There is growing recognition that in many countries, including the UK the population and its diversity means that a one-size all policy may not be fit for purpose for our healthcare systems [64].

Our paper demonstrates that even though often well intentioned, structures and policies do not always support the needs of marginalised groups. Barriers for marginalised engagement, e.g. policies may not recognize the diversity of people that they serve (policy limitation), organizational constraints on how the policy is delivered; how policies

are delivered by those charged with serving these communities (street level bureaucrats/lack of staff diversity); even if all of this was delivered, people from marginalised communities may not feel enabled to engage with particular services.

Conclusion

Marginalised communities experience health and social inequalities relating to organisational structures, policies and practices. These inequalities occur within different contexts (e.g. inpatient, community settings) and through different means (e.g. organisational structures, policies and practices). Most often, marginalisation is experienced in multiple ways, leading to further exclusion, disadvantage and isolation.

Lack of inclusion or inadvertent exclusion in each of these processes negates further disadvantage for the underserved; firstly through generalization of empirical evidence where marginalised communities are in the minority; through policies being based on evidence and through practices that are informed by policies serving the majority [65].

Despite good intentions, the structures and policies of health care organisations tend to cater for the majority of the population without adequately addressing the needs of marginalised populations who become increasingly excluded, disengaged and under-served.

It appears that for these marginalised groups their healthcare needs may change or indeed due to their personal circumstances their rights to access healthcare in the same way that they previously were entitled is somehow altered. In a civilized society is it not the case that we should be providing care for all vulnerable groups regardless of their status or level of frailty or mental health condition and that policies should reflect and be implemented in that way.

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