

Connected Communities

CHORDS: Community, Healthcare Organisation and Regulation in a Diverse Society

Scoping Study: Discussion Document

Dr. Sheelagh McGuinness & Dr. Tom Walker



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Executive Summary

The CHORDS scoping study set out to identify and critically examine the ways in which 'community' is conceptualised in health law and ethics. Drawing on a review of the existing literature, along with three in-depth case studies (on rural healthcare, organ transplants and alcohol policy), two main findings emerged. First, the community is frequently missing in legal and ethical analysis of healthcare, and where the term is used it is rare for there to be any critical analysis of the concept. Second, where the concept of community is used it carries considerable weight, with writers and policy-makers using it to support the legitimacy of actions and interventions. As a result we conclude that there is a need for further research critically analysing the ways in which concepts of community function in contemporary health law and ethics. More specifically there is a need for more research on the ways in which assumptions about the community are used in ethical and legal analysis of healthcare policy and practice, including the ways in which these are challenged by practices such as medical migration, and in critically analysing the way the good of the community is used in the justification of health policy.

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Key words

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1. Introduction

Drawing on selected case studies and an extensive review of the literature the CHORDS project examined the concept of community as it has developed in health law and ethics. The aim was to understand and explore the dominant ways in which community has been conceptualised and used in this area.

Historically the focus of medical law and ethics has been on the relationship between the patient and medical professional. This individualistic focus on the patient and resulting lack of consideration of the community has come under criticism from two sides. First, although the community may not be explicitly mentioned in accounts of how healthcare professionals ought to act, certain assumptions about community are implicit in the discussion (Purtilo, 1987; Wolf, 1996). Second, it is argued that a focus on the clinical relationship between an individual patient and healthcare provider misses important issues and that a different frame for discussion is needed. A growing body of literature in the area of public health law and ethics has done much to highlight this (see for example, Beauchamp, 1985; Gostin and Stone, 2007; Jennings, 2009; Dawson, 2011)

2. Main findings

2.1 Introduction

Our review of the literature had two main strands. Firstly we examined how communities were identified or conceptualised, as evidenced by discussion in the literature. Second, we examined political frameworks used by scholars to understand and explain healthcare policy.

2.2 Conceptualisations of Communities

There is much debate about how we define community and different accounts of what community means are evident in different disciplines (Delanty, 2003). Any definition of community can therefore be contested and debated. The purpose of our study was to identify rather than evaluate the different accounts found in the health law and ethics literature.

Some characteristics are general across conceptions. Most obviously, community implies a bounded plurality of persons. Crucially, the question of defining community hinges on establishing *by what* the persons are bounded. In examining how community has been

characterised in health law and ethics it became clear that three distinct ways of defining community – in terms of location, ideals, and interests – were prominent.

In relation to the first, 'community' **denotes** persons within or from a specific geographical region. For instance, underpinning much discussion of the National Health Service is a dominant understanding of community as politically defined and **jurisdictional (NHS Act 2006 'people of England')**. In this sense, people are **labelled 'a community' by virtue of their shared location**. Jurisdictional questions have clear implications in health law and policy. **Cotterrell describes this as the 'traditional' account** of community (Cotterrell, 1997). However, although health law has traditionally been largely focused within particular jurisdictions there are increasing exceptions to this, for example through the impact of supra-national legislation such as the law of the European Union (Hervey & McHale, 2004). Another important phenomenon that takes community beyond jurisdiction is that people travel in increasing numbers to access health services outside of their home jurisdiction. In the UK the impact of this sees individuals travelling abroad to access treatment (Shenfield, 2010). This is aided through technological advances and access to the internet, as well as more accessible travel options (McGuinness, 2011).

According to the second account we are bound together as a community through shared values such as solidarity and mutuality, not just geography. These common values have played a prominent role in the development of approaches to bioethics based on what **have been called 'European values' (Ashcroft, Campbell and Jones, 2000; Hayry, 2003; Houtepen and Ter Meulen, 2000)**. However, the language of common values and healthcare is evidenced in health law and ethics literature more broadly (see, for example, Beauchamp and Childress, 2009).

Regarding communities defined by reference to shared interests, what are important are the ends of healthcare policy. This account focuses on **matters such as 'shared goals' or 'shared aims'**. In the health law and ethics literature this conception of community has particular force relating to questions of legitimacy and informing evaluations both of the public good, **and more narrowly of the nation's health**. At times there is a clear sense that the ends of health policy, most obviously improved health, are used to legitimise the actions of authorities that might otherwise seem illegitimate (Nuffield Council, 2007; Coggon, 2010).

Whilst the community in all these senses plays a role in the medical ethics and law literature, the particular account in use in a given instance is frequently under-described. Furthermore, it is frequently the case that the reason for focusing on a particular community, or type of community, is not specified. These features give rise to three areas of potential concern.

The first is most clearly seen by a consideration of policies that state that healthcare delivery should be informed by, and reflect the needs of, the local community – where this is taken to be a geographically defined community (NHS constitution, 2009; Veenstra and Lomas, 1999). Whilst such policies argue that decisions about things like

what treatments to fund should reflect the needs of the local community, it is taken for granted that the way healthcare professionals ought to act should be the same across all communities. But geographic communities have structural features that may well be relevant to the consideration of how these professionals should act. The absence of discussion of this means that in practice all local communities are assumed to be the **same. In other countries there is a growing body of literature under the heading of 'rural health care ethics'** (Nelson et al, 2006). Within this literature there is a discussion of how models of health care provision often overlook the particularities of healthcare delivery in rural settings by assuming an urban environment (Purtilo, 1987; Glover, 2001; Kelly, 2003). This can create problems in terms of practical delivery of care when, for example, professional codes clash with the reality of life in certain settings (Roberts et al, 1999).

Our second concern arises where a particular ideal or interest based community is asserted as being relevant in determining healthcare policy but the reasons for picking out that community are left unclear. At times, it has been argued that particular communities have been singled out because they are seen as a threat to the dominant community (Morone, 1997). At others it appears that communities are identified as being normatively relevant to healthcare policy simply because our data gathering techniques categorise individuals in particular ways. In such cases the focus on the community can create problems by obscuring pertinent issues.

Finally, justifications for healthcare interventions based on a community of interest (in health) can be based on that community having either an intrinsic or an instrumental interest in health (Gostin and Stone, 2007). As a community of interest health can be used to justify measures that promote this aim for the community as a whole. However, it has been argued that at times the common interest, or value, of health is treated as overarching (Radoilska, 2009). Furthermore, a narrow focus on health as the interest that binds a community can obscure other interests, including the interests of individuals, which are also important. As such, there is a danger that coercive measures **will be legitimated through the use of 'community justifications' without properly** assessing the costs of doing so.

2.3 Frameworks

The extent to which the good of the community justifies interfering in the lives of individuals is one of the considerations that distinguish different frameworks for thinking about health law and ethics. These frameworks have been particularly prominent in discussions of public health, where the idea of community has been reintroduced for the most part by challenging the predominantly liberal conception that underlies much thinking about the limits of interventions to protect or promote health (Beauchamp, 1985; Galarneau, 2002; Gross, 2004; Jennings, 2007).

In conceptualising what justice in health care requires liberalism seeks to abstract from the communal and cultural affiliations that individuals have, and to deal with them even-handedly as individuals (Beauchamp and Childress, 2009). Alongside this focus on the

fair treatment of individuals, liberalism has also been taken to require that those individuals be free from interference in their lives, except where such interference is needed to prevent harm to others (Mill, 1859; Jennings, 2009). For this reason advocates of liberalism could argue for restrictions on smoking in public places on the grounds of preventing harm to others, but would not accept restrictions on smoking intended to reduce harm to smokers themselves.

The individualistic focus of these liberal accounts has come under attack from those advocating two related alternatives within political philosophy: communitarianism (Tauber, 2002; Black and Mooney, 2002) and civic republicanism (Jennings, 2007). These critical approaches to liberalism conceptualise the individual as inherently embedded within a particular community, and aim to balance the needs of the individual with those of the community as a whole. Furthermore, they hold that the community itself is valuable, in part because it is only possible for individuals to flourish as members of a community. The developments in theory here are echoed in feminist approaches to public health (Baylis et al, 2008).

These alternatives give an important place to the public or common good in a way that liberalism generally does not (see for contrast Coggon, 2008; Dawson & Verwij, 2008). Whilst some common goods are merely the aggregate of individual goods, others exist only as common goods (Widdows and Cordell, 2011). It has been argued that health is one such common good because without a certain level of health communities cannot function in ways that are needed to ensure their survival (Quinn, 2000; Galarneau, 2002; Gostin, 2008). Because of their recognition of the good of the community as a whole communitarian or republican approaches are more likely than liberalism to allow policies that restrict the liberty of individuals for the good of the whole (see for contrast Epstein, 2003; Epstein, 2004). The individual who is restricted will himself benefit from those goods, and has an avowable interest in policies that protect the community (Gostin and Bloche, 2003).

Whilst bringing the community back into the debate about what healthcare policies ought to be adopted, these alternatives have not always been explicit about what communities they are concerned with. In theory such approaches might justify radically different policies and obligations in relation to different communities. Communitarians, for example, hold that values come from the community, and as such there may be no universal way of deciding on priorities in healthcare. Because of this it can be argued that decisions should reflect each community's values – potentially resulting in different policies in different communities (Gross, 2004; Black and Mooney, 2002). Whilst this conclusion is drawn in some cases, in many others it is avoided by an assumption that communities below the level of the nation are sufficiently similar that this will not happen. This latter assumption has been criticised for focusing on the community at the level of the nation, thus creating a system where medical ethics and regulation are concerned only with the individual or the State and ignore the levels of community between these (Galarneau, 2002; Wolf, 1996). One problem that this creates is that it can obscure the relative impact of healthcare policy on different communities located within the national community. As such the overall effect of a policy may be detrimental

to the health of some of these smaller communities (see Wilkinson, 2010), with consequent implications for the fairness of such policies.

2.4 Key Conclusions

Our examination of the literatures led to two main findings.

- i. The concept of community is rarely articulated, and frequently is un- or under examined: the term is used in analysis of healthcare law, ethics, and policy, but often without sufficient attention to critical content or import.
- ii. Despite this the concept of community carries considerable weight when used in policy documents. The strength of the term is not merely rhetorical, and thus it is clear that whilst attention may not be given to substantive conceptual analysis, writers and policy-makers use it to denote the legitimacy of actions and interventions.

The clear implication of these findings is that more awareness is needed in health law and ethics of the ways in which concepts of community are founded, and how they can and do relate to questions of legitimacy in social and political studies.

3. Emergent themes for future research

Our study highlighted several areas that would repay follow up research.

3.1 General

- i. It would be valuable to see research that explicates the assumptions about the community that underlie standard accounts of medical law and ethics in relation to clinical medicine, and analyses the extent to which these assumptions apply across the range of communities that exist. For example, guidance on doctors treating close family members must acknowledge the limitations of resources in rural areas as the current GMC review of the issue acknowledges (GMC, Good Medical Practice Review).
- ii. Research is needed on the ways in which the use of community in healthcare policy can either disguise the real issues or mask the way the community is thought of, and the implications of this for health law and ethics. For example, rather than assuming that religious or cultural beliefs explain why refusal rates for organ donation are lower among certain ethnic groups, analysts should examine age, gender, and geographical location as well.
- iii. Medical migration challenges the traditional jurisdictional understanding of the community bounded by health law and policy. This is particularly true when people travel to access services that would be illegal in their home jurisdiction. What are the ethical and legal issues raised by such travel and how ought we to respond to them?

- iv. Exploration is needed of the ethical and legal implications of healthcare policies that aim to improve the common good at a national level but have a negative effect on some communities within that broader community (particularly in terms of what justice requires in these cases). As part of this more research is needed on how public health policies conceptualise the common good.

3.2 Specific:

- i. Research is needed on the extent to which assumptions about community that underlie standard accounts of health law and ethics are problematic in rural or inner-city contexts.
- ii. In an era of increased travel is there a case for extra-territorial policing of certain **'health crimes'** and if not, what are the implications of this for the legitimacy or efficacy of domestic regulation?
- iii. It would be valuable to study **the use of 'community' in debates about organ transplants**, and whether the ways in which the community is used in these debates is justified.
- iv. Analysis should be conducted into the extent to which public health policy, for example regarding alcohol and drugs, ignores differences between communities at a sub-national level, and the ethical implications of this, particularly in relation to whether imposing such policies are just.

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The Connected Communities

Connected Communities is a cross-Council Programme being led by the AHRC in partnership with the EPSRC, ESRC, MRC and NERC and a range of external partners. The current vision for the Programme is:

"to mobilise the potential for increasingly inter-connected, culturally diverse, communities to enhance participation, prosperity, sustainability, health & well-being by better connecting research, stakeholders and communities."

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