Vulnerable groups and access to health care: a critical interpretive review

Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)

April 2005, revised August 2005

Prepared by

Mary Dixon Woods

Ms Deborah Kirk

Ms Shona Agarwal

Dr Ellen Annandale

Dr Tony Arthur

Dr Janet Harvey

Dr Ronald Hsu

Dr Savita Katbamna

Dr Richard Olsen

Dr Lucy Smith

Dr Richard Riley

Dr Alex Sutton

Address for correspondence

Mary Dixon-Woods

University of Leicester

22-28 Princess Road West

Leicester, UK

LE1 6TP

Executive summary

Aim of the review

We report a critical interpretive review of access to health care by vulnerable groups. An interpretive synthesis does not simply produce a summary of the evidence; it interprets it in ways that are insightful and useful. Our aim was to produce *theory*: a logical, plausible and useful explanation, grounded in a comprehensive but not exhaustive body of evidence, about access to health care.

Methodology

We developed a new methodology, with its origins in meta-ethnography, in order to conduct the review. This methodology, which we termed 'critical interpretive synthesis' starts with a fuzzy and tentatively defined phenomenon; conducts extensive though not exhaustive searching; strategically samples from the literature; conducts appraisal and critique of the included papers and, through a process similar to primary qualitative research, aims to produce a theoretical output in the form of synthesising argument.

Findings

- Precise definitions of access to health care and equity of access have remained elusive. It has proved even more difficult to operationalise these for purposes of research.
- The practical consequence of problems of defining and measuring access is a set of methodological, conceptual, and theoretical problems in investigating access, and in investigating the extent to which access is equitable in particular.
- Studies of utilisation and receipt of health care show some evidence of distinctive patterning according to age, gender, socioeconomic advantage and ethnicity, but the data remain difficult to interpret and inconclusive. For example the evidence does not consistently point to poorer access for socio-economically disadvantaged people, even when need is accounted for: some studies even suggest that there is a pro-poor bias in the NHS.
- The most useful way of understanding access to health care is in terms of 'candidacy'. Candidacy describes the ways in which people's eligibility for medical attention and intervention is jointly negotiated between individuals and health services. Candidacy is a dynamic and contingent process, constantly being defined and redefined through interactions between individuals and professionals, and managed in the context of operating conditions, including the biography of the relationship between patients and staff, the typifications staff use in categorising people and diseases, availability of resources, local pressures, and policy imperatives.

NCCSDO © 2005

- Cultural expectations affect people's help-seeking. For example expectations of what is gender-appropriate may deter men from seeking help, while those living in conditions of socio-economic disadvantage or older people may 'normalise' symptoms with reference to those around them.
- People's preferences for particular forms of services, and their perceptions of the quality of services, influence their willingness to use services. People are especially unwilling to use services that they perceive to be of poor quality or to be hostile to them.
- People need to be able to identify and evaluate their symptoms and to negotiate routes to health care, and these tasks may require particular sets of competencies and resources that may patterned by age, gender, social class, or ethnicity.
- Ability to attend health services may depend on being able to make arrangements – for example in relation to language, transport, and care of others – that may make using health services more difficult for some groups. The help available for making such arrangements is variable.
- There has been an effort to ensure that health services are not over-burdened by people seeking help for minor, self-limiting illnesses. The moral character that has been imposed on helpseeking as a result has made people highly sensitive to the demands on professional time.
- Services can be conceptualised in terms of how porous or permeable they are. High permeability services are those that are most comfortable for people to use, that demand the fewest qualifications for candidacy, and that require less work. Services that are less permeable require much more work in order to gain a point of entry and sustain engagement with the service.
- Health care organisations often rely implicitly on an 'ideal user',
 who is able to match the precise set of competencies and
 resources to the way in which the service is intended to be used by
 providers, and whose preferences are in line with the way the
 service is organised and delivered.
- Cultural dissonance discord between the cultural norms of health care organisations and their imagined ideal user – creates low permeability. People of minority ethnicity may become alienated from organisations that appear to stereotype them or treat them with a lack of sensitivity, though the direct evidence of interactions between minority users and providers is lacking.
- Lack of capacity, variations in quality, differences in resource allocation and features of service configuration, including geographical patterning and concentration of services, all create access-disadvantaged groups, but the effects of increasing capacity are not well understood.

- Dedicated services for specific conditions or specific patient groups have been evaluated in several settings, and while they appear to be popular with patients, require more comprehensive evaluation, particularly as to their system-level effects.
- People in more deprived circumstances do show a readiness to consult, but are more likely to manage health as a series of minor and major crises, rather than treating diseases as requiring maintenance and prevention. This is likely to be linked to the normalisation of ill-health in more deprived communities as well as the range of resources people are required to mobilise to use services.
- Using health services requires considerable work on the part of people. People have to mobilise a range of resources, including knowledge and information resources, social, language and support resources, and practical resources. There is evidence that socioeconomically deprived people, older people, and people of minority ethnicity may be disadvantaged in their access to these resources.
- Provision of language and interpreting services is variable and patchy, and causes difficulty for people who cannot speak English.
- Having to co-ordinate aspects of candidacy through organisational turbulence and fragmented boundaries poses considerable challenges and drains resources.
- Being a resident of a nursing or residential home is a barrier to accessing both mainstream and specialist NHS services.
- By putting in an appearance at health services, people are making a claim to candidacy for medical attention or intervention.
 However, their ability to make presentations that allow their candidacy to be judged appropriately is variable.
- Health professionals are required to make 'adjudications' based on their judgements of health needs. There is concern that the ways in which adjudications are made by health professionals may disadvantage people of minority ethnicity, different genders, older people, and socio-economically disadvantaged people.
 Adjudications are made in the context of operating conditions, including scarcity of resources.
- Health professionals may make offers of health care to people, based on their adjudications of people's candidacy. People may therefore choose to decline offers made by health services, but this important aspect of access has been relatively little studied.
- There is also need for caution and attention to the unwanted consequences of identifying and making offers to people on the basis of assumptions about 'unmet need'.

Conclusions

A focus on candidacy helps to identify where and when people are vulnerable: at the stage of recognising and acting on candidacy, in navigating routes to enter and sustain engagement with services; in the ways they present at services; in the ways in which claims to candidacy are judged and adjudicated; in the offers that are made to them; and in their willingness or ability to accept or reject those offers. It also helps to recognize the influence of 'operating conditions' in the form of wider contexts. Particular groups may experience amplified vulnerabilities in relation to some aspects of candidacy.

Recommendations for future research

Research is needed across the entire range of candidacy issues. Areas that are particularly under-researched include: whether the amount of work people have to do to use health services varies systematically between different groups; how practitioners make judgements and categorisations of people's eligibility for health care; whether evidence-based guidelines tend to disadvantage particular groups through their specification of eligibility criteria; exploration of whether 'acceptance' by patients of offers made by practitioners varies between different groups, and why; research on the impact of dedicated services, and evaluations of anti-discrimination interventions.

Recommendations for policy and practice

- Information resources about illness should be available in forms
 that people can find and use readily, but it should also be accepted
 that educational interventions are likely to have only limited impact
 in altering help-seeking behaviour, and only then for specified
 conditions.
- Simplistic assumptions about 'deficits' in people's knowledge should be avoided. The potential for interventions aimed at promoting 'appropriate' help-seeking to discourage 'appropriate' help-seeking, by imposing a moral character on using health services, needs to be recognised.
- The proliferation of organisational forms in the NHS needs to be managed carefully to avoid creating risks for candidacy.
- High levels of non-attendance at services should be treated as a signal of low permeability i.e. a service that is difficult for people to use. Services should assess the extent to which there is social, ethnic, gender, or age patterning of non-attendance and investigate (probably using qualitative methods) reasons for these.
- Services need to establish how much work people have to do, how many resources they need to mobilise in order to use them, and how comfortable people feel about using services. This may be achieved by audits where users are asked about, for example,

- transport, workplace and childcare arrangements and arrangements for accompaniment or language.
- Services, particularly those that offer preventive or healthmaintaining care, need to evaluate how they can make themselves most congruent with the ways in which potentially vulnerable groups tend to use health care.
- Practitioners need to be reflexive (i.e. engage in critical self-reflection) and be explicit about how they respond to presentations and make adjudications about people; and they need to identify the heuristics (rules of thumb) they use in assessing people's eligibility for particular services.
- It will also be important to recognise the team-based nature of many decision-making processes, and to understand the contributions that different members of the team make, as well as how the patient's view is incorporated in the negotiations.
- The impact on equity of evidence-based guidelines on managing health conditions should be assessed.
- The debate about whether there should be specialised services for particular groups has not yet been resolved. Any evaluation of specialised services needs to pay careful attention to the unwanted effects of specialised services.

Disclaimer

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the SDO programme or the Department of Health

Addendum

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene and Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact sdo@southampton.ac.uk