Social Science & Medicine 72 (2011) 763–772

Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

Access to primary mental health care for hard-to-reach groups: From 'silent suffering' to 'making it work'

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ARTICLE INFO

Article history:
Available online 21 December 2010

Keywords:
Mental health
Hard-to-reach groups
Access
Primary care
UK

ABSTRACT

Equitable access to primary care for people with common mental health problems in the UK remains problematic. The experiences of people from hard-to-reach groups offer important insights into barriers to accessing care. In this study, we report on secondary analysis of qualitative data generated within seven previously-reported studies. Thirty-three of ninety-two available transcripts were re-analysed using a new heuristic of access, generated to frame narrative-based comparative case analysis. The remaining transcripts were used to triangulate the findings via a process of collaborative analysis between a secondary researcher, naïve to research findings of the original studies, and primary researchers involved in data generation and analysis within the original studies. This method provided a rich body of 'fine grain' insights into the ways in which problem formulation, help-seeking, use of services and perceptions of service quality are interlinked in a recursive and socially embedded matrix of inequitable access to primary mental health care. The findings indicate both extensive commonalities between experiences of people from different 'hard-to-reach groups', and considerable diversity within each group. An idiographic generalisation and aggregation of this variety of experiences points to one main common facilitator (communicated availability of acceptable mental health services) and two main common barriers (lack of effective information and multiple forms of stigma*)* to equitable access to primary mental health care. We conclude that there is a need to provide local care that is pluralistic, adaptive, holistic, resonant and socially conscious in order to ensure that equitable access to mental health services can become a reality.

Introduction

Adequate and timely support for common mental health problems within primary care is less likely to be accessed by certain groups of individuals (Borowsky et al., 2000). Some people, such as those with medically unexplained symptoms or with advanced cancer, have problems in obtaining appropriate primary mental health care (Aabom & Pfeiffer, 2009; Ring, Dowrick, Humphris, Davies, & Salmon, 2005), while others, such as people from racialised minorities (Brubaker, 2004) have problems in gaining equitable access to health care in general (Commander, Sashi Dharan, Odell, & Surtees, 1997). Given that the UK's National Health Service (NHS) has an explicit equity-driven health policy framework (DH, 2005, 2008), it is necessary to understand how and why inequity of access to professional help for common mental health problems is sustained.

This paper contributes to understanding why people from 'hard-to-reach groups' have difficulties in accessing mental health support in primary care and how these difficulties could be overcome. We present findings from a secondary analysis of qualitative data, conducted within a research and development programme to improve equity of access to primary mental health care (Dowrick, Gask, Edwards, Aseem, Bower, Burroughs et al. 2009). The term 'hard-to-reach-group' is used in this paper to describe population clusters who, in comparison to the average population of primary care users, are less likely to receive mental health support within primary care when needed. We explore this phenomenon by comparing the experiences of people from five exemplar groups known to be at risk of inequitable access:

- people with advanced cancer (Aabom & Pfeiffer, 2009),
- people with medically unexplained symptoms (MUS) (Peters, Rogers, Salmon, Gask, Towey, Clifford et al. 2009),
- people from Black and minority ethnic (BME) groups (Commander et al., 1997),

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doi:10.1016/j.socscimed.2010.11.027

- people on prolonged sickness absence from work (Edwards & Gabbay, 2007), and
- elderly people (Burroughs et al., 2006).

Conceptualising and researching access to mental health support in primary care

Access to health and welfare services has been researched within different conceptual and methodological approaches. On one side, health services research traditionally examines access from the point of entrance to the formal system of care. Key concepts such as demand, availability, utilisation and patterns of use are developed in a functionalist view of the relationship between service provision and use where access is conceptualised as an interaction between supply and demand rationalised by professionally-defined need for services (for an overview see Dixon-Woods, Cavers, Agarwal, Annandale, Arthur, Harvey et al. 2006). On the other side, behavioural and social sciences traditions, within the 'help-seeking' literature, focus mainly on 'out-of-services' perspectives i.e. on processes that happen before the point of entrance into formal systems of care. Broadhurst's (2003) review of this literature identifies a three-stage model of help-seeking, summarizing variations in a) problem definition, b) deciding to seek help and c) actively seeking help. Liang, Goodman, Tummala-Narra, and Weintraub (2005) extend this further to incorporate bidirectional, dialectical relations between the stages and a set of individual, interpersonal and societal influences that effect behaviour in each of the help-seeking stages. However, literature aiming to integrate these two distinctive perspectives is emerging (e.g. Dixon-Woods, Annandale, Arthur, Harvey, Hsu, Katbamna et al., 2005; Dixon-Woods et al., 2006).

We identify three particularly useful concepts in relation to researching access: *candidacy, concordance* and *recursivity*. Candidacy refers to the processes by which people's eligibility to use a particular service is formulated in locally situated interactions between health services and themselves (Dixon-Woods et al., 2005, 2006). Concordance indicates the importance of a match between users' and practitioners' narratives and resources for successful access to medical attention and intervention (Stevenson & Scambler, 2005). Recursivity refers to interdependency between a user's experiences of health services and her/his future actions in regards to health and help-seeking (Rogers, Hassell, & Nicolaas, 1999). The relevance of these concepts rest in their capacity to connect two traditionally separate streams of academic inquiry which split people's experiences of access into compartments of help-seeking (addressed mainly in behavioural and social sciences literature) and use of services (addressed mainly in health services research literature). Acknowledging the recurring nature of help-seeking behaviour and use of health services, the concept of recursivity is particularly relevant in adding a diachronic dimension to the phenomenon of access and ultimately bringing the notion of quality and outcomes of care into the scope of academic inquiry of access.

However, empirical research which employs these concepts is still scarce (Koehn, 2009). Additionally, the literature on barriers and facilitators to professional mental health support explores problems of access within individual hard-to-reach groups, or tends to focus on between-group difference rather than areas of commonality. Our work seeks to address these gaps. We explore access to primary mental health care as a complex social phenomenon shaped by links between help-seeking behaviour of individuals, processes underpinning the use of health services, and quality and outcomes of care. This was achieved by comparing barriers and facilitators to care experienced by people from a range of hard-to-reach groups. This paper presents an integrative methodological approach to undertaking that comparison. Further, we present identified areas of commonality between the groups, suggesting potential foci for developing policy and research.

Method

This paper is based on a collaborative comparative secondary analysis of qualitative data conducted as a part of a wider programme of research exploring stakeholders' perspectives on access to mental health services in primary care and aiming to develop interventions to improve access within the same programme of work (Dowrick et al., 2009). Secondary analysis is considered a suitable method of increasing utility of qualitative data, particularly for generating knowledge about people from vulnerable and hard-to-reach groups (Boydell, Gladstone, & Volpe, 2006; Heaton, 2008; Sandelowski, 1997). In this study, existing qualitative data from previous studies were re-examined within a new conceptual framework, based on new research questions and using an analytical model developed for the purpose of this particular study. The collaborative aspect of the method refers to analysis conducted between primary researchers (CCG, JR, SE, SP, DE, SA, LG & CD) who contributed data from their previous studies and a secondary researcher (MK) who was naïve to findings of the original studies and who led the analytical and interpretative process of the secondary research. The comparative aspect of the method relates primarily to examination between different hard-to-reach groups, although comparison was inherent in all aspects of analysis.

Taking into account debate on potentials and pitfalls of reuse of qualitative data (van den Berg, 2005; Mason, 2007; Moore, 2007; Heaton, 2008; Hammersley, 2010), we used secondary analysis as a strategy of engagement with our research problem, while still relying on standard methods of interpretivist inquiry (Denzin, 1989). The process employed to generate findings is best described as interpretative, case oriented, comparative analysis informed by narrative approaches to qualitative data, and facilitated with a heuristic tool built for the purpose of pragmatically-oriented research. The analysis was followed by idiographic generalisation and aggregation of findings in respect to the main facilitators and barriers to access and subsequent induction of potential solutions. This methodological approach was based on systematic linking of classical features of qualitative research such as case orientation (Sandelowski, 1996), constant comparison (Glaser, 1992) and idiographic/naturalistic generalisation (Lincoln & Guba, 1985; Stake & Trumbull, 1982), embedded in interpretivist epistemology (Denzin, 1989) and against the background of linguistic and narrative turns in reflexive and critical social science (Alvesson & Skoldberg, 2000; Georgekopoulou, 2007; Riessman, 2008). Each aspect of the method will now be briefly explained.

Data

Data comprised anonymised transcripts of semi-structured and in-depth interviews with White British, Black Caribbean and South Asian adult residents of North-West England. The interviews were conducted within seven different qualitative studies during a period from 2001 to 2007. Information on aims and recruitment for these studies can be found in Supplementary Table 1.

The secondary analysis dataset was conceived as a convenience sample of existing studies selected by the principal investigators (CD, LG & CCG) on bases of them having: a) access to the datasets and b) knowledge on the fit of existing datasets to provide insights to the new research questions of the secondary analysis. All selected studies explored experiences of people who were at some point in their life faced with common mental health problems and who belong to at least one of our exemplar groups. Accounts on access to services were inherent in all datasets with various levels of explicit inclusion of this topic into questions posed to the respondents. Six of these studies had ethical approvals for reuse of data for future research, while, for one data set, additional approval for secondary analysis was confirmed by the relevant ethics committee (Liverpool REC).

From the transcripts of the original studies ($N = 111$), the secondary dataset ($N = 92$) was formed after discarding transcripts containing no discussion of barriers or facilitators to accessing health care. Following the procedures recommended by May et al. (2004), a subset of up to five transcripts from each dataset was randomly selected for the comparative in-depth analysis (Fig. 1). This resulted in thirty-three transcripts (in one study only three transcripts remained after exclusion of irrelevant ones). The remaining fifty-nine relevant transcripts served for triangulation of initial findings and formulation of final results (we refer to triangulation as to a process of using different empirical angles to the observed phenomenon in order to challenge biases and limitations inherent in qualitative research).

The sample for the in-depth analysis ($n = 33$) included people diagnosed with a mental health problem and using professional services, and people who experienced problems but never had a mental health diagnosis nor used professional services. In the thirty-three selected transcripts, five participants were of South Asian origin, five were African-Caribbean and twenty-three were White British. The age within the sample spanned from twenty one to eighty. There were six men and twenty seven women. Exemplar quotations in the subsequent text refer to individual participants within particular samples.

Analysis

An analytical model (Fig. 2), informed by the literature review, was created by the secondary researcher (MK) as a heuristic device to engage with a heterogeneous set of qualitative data. It represents a linearised model of pathways to care where each stage of the model stands for an assumed process which may contain barriers and facilitators to access, and, hence, the understanding of which can practically inform design of an intervention to improve the equity of care. The model also included stages where access to health professional is actually gained, and where consequently, from a traditional medical perspective there should not be any barriers to obtaining the most appropriate care. These stages were included in order to capture the fact that interaction with health professionals may actually deter help-seeking or divert it into forms that do not address users' needs (Ring et al., 2005), and hence be a barrier to future access (represented in Fig. 2 by returning to previous stages or entering a 'labyrinth of inappropriate care').

While integrating distinct topics of health inquiry (help-seeking, use of services and quality of care) by merging concepts of candidacy, concordance and recursivity, this heuristic was built on five basic assumptions which enabled formulation of research sub-questions. Accordingly, we commenced the analysis hypothesising that, in the context of current health care systems, access to support for mental health in primary care may not be achieved if:

- a person experiencing certain symptoms which may be related to psychological suffering does not conceptualise them as a mental health problem;
- a person does not seek help from any available services, even if s/he formulates the suffering in a way which suggests that formal care and support may be warranted;
- despite seeking help, a person does not gain access to a health professional;
- a person does not get mental health support, even when access to appropriate health professionals is achieved;
- access to treatment is gained but the experience inhibits future engagement with services.

Analysis was framed by the five research sub-questions emerging from these assumptions (See Table 1) and organised along the adapted phases of initial, cumulative and condition comparative secondary analysis suggested by May et al. (2004).

Initial analysis and cumulative comparative analysis

The analysis started with a narrative reconstruction for each case within the samples of selected transcripts. The hypothetical stages of pathway to care formulated in the heuristic were used as a plot for reconstructing the participants' narratives. For each case

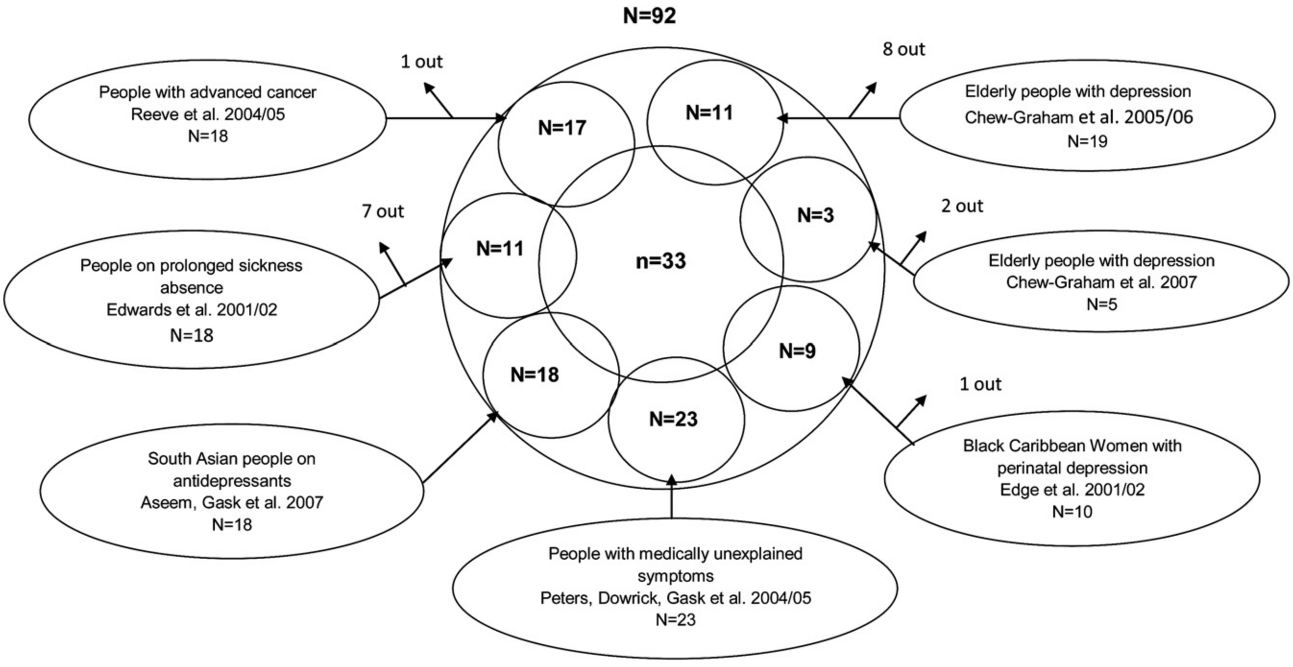

Fig. 1. Data and data management.

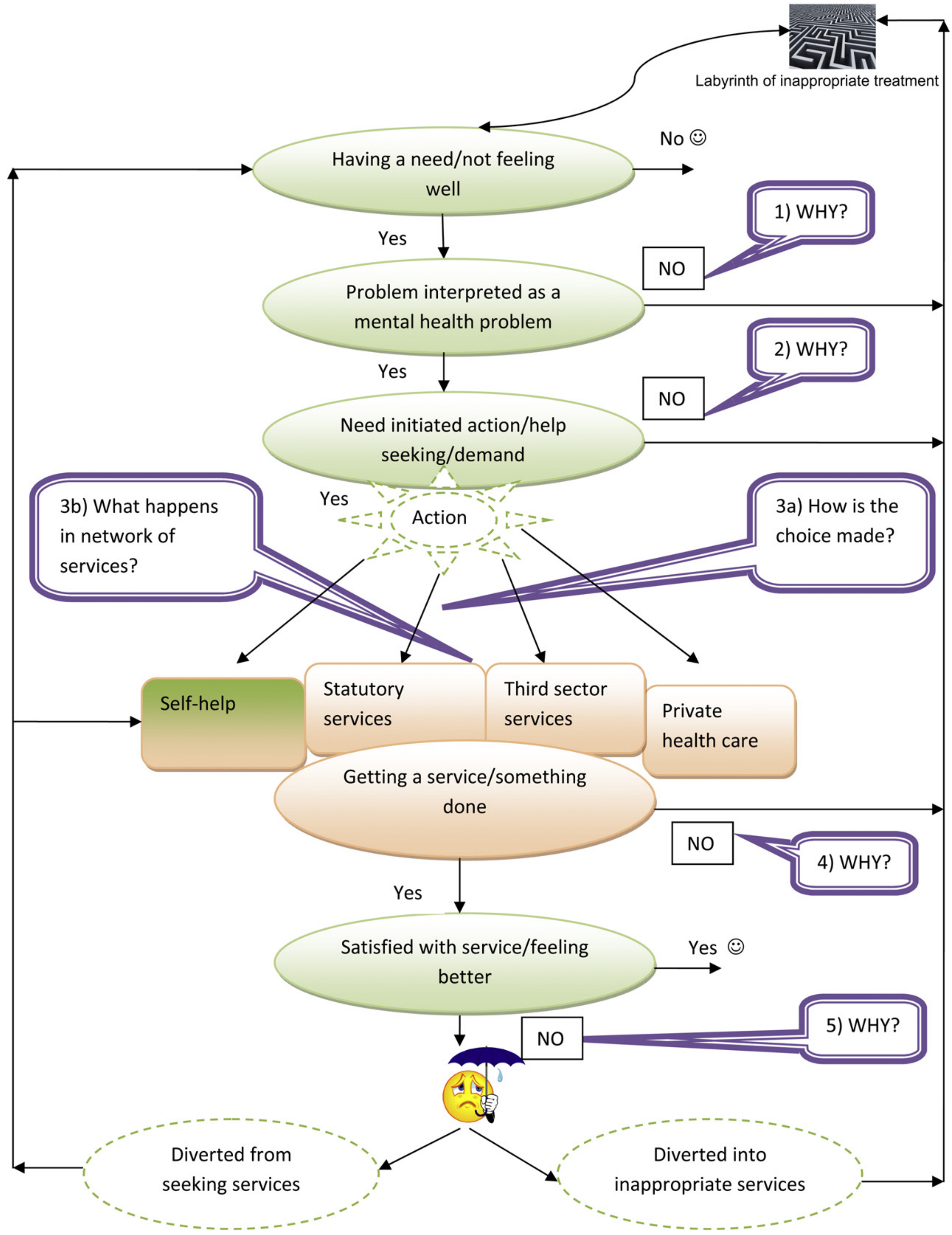

Fig. 2. Analytical model: a heuristic for researching access to primary mental health care.

Table 1
Summary of findings.

What are barriers and facilitators to equitable access to high quality mental health support in primary care?			
Research sub-question	Analytical section	‘Fine grain’ findings	‘Large grain’ findings
i) Why a person may or may not formulate her/his experience of suffering into a mental health problem?	Silent suffering	*Common issues that create barriers and facilitators of access* Different orders of things • Calling it different names • Suffering from life and not from mental health problem • Embodied suffering *Stigma of dis-ease*	Main barriers: 1. Lack of effective information 2. Multiple stigma(s) Main facilitator: 1. Communicated availability of acceptable services Changes needed to improve equity of access require primary care which is: 1. Pluralistic 2. Adaptive 3. Holistic 4. Resonant 5. Socially conscious
ii) What may prevent or facilitate placement of demand to health services even if problem is formulated as related to mental health?	In between suffering, coping and seeking help	Self-help and lay hierarchy Information Social networks Paradox of demand Stigma of dis-ease Previous experiences and expectations • Mediated experience • Imagined services	
iii) What may prevent or facilitate a contact with a health professional once an initial act of help-seeking is performed?	Navigating networks of services	User’s resources and skills: • Feelings of ownership over NHS • Information • Social networks • Time and money • Mobility Permeability of services: • Configuration • Receptivity	
iv) What may prevent or facilitate a prescription/allocation and uptake of mental-health-supportive intervention once the relevant professional is reached?	Negotiating acceptable treatment	User’s attitude and articulation Practitioners resources and culture Institutional culture and resources	
v) What may prevent or facilitate positive outcomes and user’s satisfaction even if a mental-health-supportive intervention is allocated and accepted?	Making it work	Appropriate balance between agency and dependence Patient-defined and ‘fluid’ holism	

the secondary analyst started with a question: How can the story this person tells provide answers to my research questions? The analysis was built on close reading of the transcripts where, along with understanding offered directly by a narrator, attention was also paid to ‘what was not said’: significant absences, contradictions in a narration and the context of research situation in which the stories were told.

In order to contest secondary researcher’s understanding of the cases, three primary researchers conducted parallel independent analysis of the same subset of cases from their respective datasets. This parallel analysis was done for datasets on people with advance cancer (JR), people on prolonged sickness absence from work (SE) and elderly (CCG) and it accounted for 18 out of 33 transcripts selected for in-depth analysis. Using the same approach to analysis, the rest of 15 transcripts from datasets on MUS and BME (South Asian and Black Caribbean) were analysed in this phase only by the secondary researcher.

The secondary researcher then compared and critically reflected findings for each case and across the cases from the same hard-to-reach group in order to produce cumulative accounts of issues involved in preventing or facilitating access for each group. These accounts (with references to particular cases the findings originate from) were then sent to respective primary researcher/s for each exemplar group. The primary researchers, who were familiar with their complete datasets, critically interrogated these initial findings with respect to the whole dataset and, where relevant, the findings of the original analysis, in order to generate further insights that were contradictory, confirmatory or complementary to the findings generated by the secondary researcher. The resulting suggestions for further elaboration of findings (with reference to any of the transcripts from the whole respective dataset) were fed back to the secondary researcher who critically integrated these into preliminary findings for each exemplar group.

‘Condition’ or group comparative analysis

These preliminary findings were further compared between chosen exemplar groups to produce the final findings. While May et al. (2004) used medical conditions as the bases for comparison we used belonging to a particular hard-to-reach group as ‘conditions’ we wanted to compare in respect to our research question. This involved a complex cognitive process of multi-layered comparisons and synthesis that can be summarised as the secondary researcher’s journey through three consecutive reflective stages (followed at the end by another cycle of validation by primary researchers against the totality of respective datasets).

The first reflective stage looked at findings related to each section of the analytical model and sought to find through the process of analytic induction what is common to all observed groups in respect to each section. Identifying a commonality meant that the issue in question cannot be said to be non-existent in any of the observed groups on the basis of evidence that the issue was identifiable in at least one case from each group. The result of this process led to what is presented in the first part of findings of this paper ('Fine grain' findings).

Once the commonalities were extracted, the second reflective stage looked at findings that remained specific to a particular exemplar group (not presented in this paper due to the current focus on commonalities).

Finally the third reflective stage came as a response to a request to succinctly present the findings of the study to a group of decision-makers. The secondary researcher looked again at the commonalities, but this time searching for the most prominent common issues among exemplar groups irrespective to the sections of the analytical model and with a view of providing generic recommendations for transforming primary care. This process was based on an ideographic generalisation in respect to main barriers and facilitators of access, followed by cross-case comparison and aggregation (Sandelowski, 1996) with subsequent induction of recommended changes in primary care necessary to improve equity of access for common mental health problems (presented in the second part of findings – 'Large grain' findings).

Findings and discussion

In this paper, we present only identified *commonalities* between the observed hard-to-reach groups. In the first part of findings ('Fine grain'), we present the outcome of the first stage of reflection on what was common to all groups in respect to research sub-questions emerging from our analytical model. We then present 'Large grain' findings with the messages coming from the third and final stage of reflection on more generic commonalities (see Table 1, Summary of findings).

'Fine grain' findings

Our analysis confirms the hypothesised existence of at least five ways in which problems of access to primary mental health care are clustered. In reference to the data and identified *processes*, rather than *things* of concern, we describe them as: i) silent suffering; ii) in between suffering, coping and seeking help iii) navigating networks of services; iv) negotiating acceptable treatment; and v) 'making it work' (see Fig. 2 and Table 1).

Silent suffering

Access to mental health interventions via primary care is problematic where individuals do not conceptualise their suffering as a mental health issue. When this is the case, there is no conceptual base on which the process of candidacy could possibly evolve. We named this phenomenon 'silent suffering' characterised by participants' descriptions of periods of psychological distress which were not formulated into mental health problems. Accordingly, they remained 'silent' in terms of engaging in related help-seeking activity:

> […] I was suffering from about eighteen although I didn't know it. […]. I had two children, my marriage wasn't a good one so after I had my first child in [1960s][…] looking back I must have had post-natal depression or something and then when I was having the second one it flared up, so that knocked me even further into it. And I don't think I ever really recovered. (ELD-D2, P4)

We identify two main explanations common to all exemplar groups. First is a mismatch between the general understanding of mental health problems held by a particular person, and her/his perception and understanding of her/his own suffering in a particular moment:

> I was totally down when I was pregnant, I was really, really down […] But - no, I wouldn't say I was [depressed]… even though I did get very down, very emotional. (BME-BC, I3)

Acknowledging Foucault's (1989) ideas we name this situation *different orders of things*, and see it as extending the notions of explanatory frameworks (Karasz, 2005) and lay aetiology (Prior, Wood, Lewis, & Pill, 2003). People's explanatory, but also perceptual frameworks may differ not only from professional explanatory models but also from the models they use for others, insofar as they apply them differently to themselves. In doing so they may: a) refer to their own problems calling them different names from what they know to be a real mental health problem (such as being down, being tired, thinking too much, sitting and crying, having bad nerves and not really being depressed, anxious or manic) b) conceptualise their suffering as suffering from life while seeing mental health problems, even if acknowledged, as just consequences but not causes of suffering and so not the avenues to solve the problem, or c) experience and express problems in the physical rather than the mental sphere of their being, not necessarily because they don't have mental health concepts in their conceptual maps but because they feel and express their problems through their body in a very real way, even if their symptoms may not be matched with understandings supported by biomedical science and medical care. The last observation was captured in our analysis by a concept of *embodied suffering* which needs further explorations within the research on MUS.

Secondly, silent suffering is sustained by suppressing awareness or hiding expressions of suffering due to social unacceptability of being unwell:

> It's like hiding a thing you know. If you can't see it – I'm ok. I've got no problems. And that keeps me strong. I've always been a strong person. […] And you know – you keep going. You can't just hide in a corner crying cos no one takes any notice. Or people get fed up don't they? (AC, P16)

We named this phenomenon *stigma of dis-ease*. When recalling experiences of suffering, people talked about crying as silly, tiredness as unreasonable, fear and sadness as burden to others, and of inability to cope with demands of everyday life as a personal failure and expression of weakness and damaged identity (Goffman, 1986).

These attitudes indicate that such symptoms are unacceptable, and should be avoided or at least hidden from others. This consequently forms a barrier to accessing any kind of mental health support, whether formal or informal:

> I think there's a stigma as well… about failure and not being able to cope. The whole word 'depression'… it's got such negative connotations… so perhaps that actually keeps us from actually going to ask for help. (BME-BC, I12)

Recognising the phenomenon of silent suffering does not assume that formulating frustration and unhappiness into a medical problem is necessarily desirable (Dowrick, 2009), but simply indicates that access to mental health support can be obstructed by differing explanations and expressions of suffering.

In between suffering, coping and seeking help

Even if suffering is formulated in ways that could lead to formal help-seeking in primary care, people may hesitate to do so. As noted by Pescosolido, Gardner, and Lubell (1998), we found that the lack of decision and/or action towards getting formal help is often more complicated and non-linear than a rational decision making theory would imply. Our findings thus confirm literature which describes lay hierarchy of services, and priorities that people give to self-help and informal support over professional support (Edge &

Rogers, 2005; Scambler, 2008). We also found an apparent paradox in the role of social networks in accessing services. Both existence and lack of close social networks can impede demand for professional help. While existence of informed and supportive micro social milieu can be a facilitator to accessing services, it may equally act as a barrier either due to a network's capacity to fulfil its members' needs for support, or due to stigma, incomplete information and disapproval of the help available outside. On the other side, lack of close social networks hinders access via lack of information and support and this is connected to what we identified as the 'paradox of demand'.

Describing periods when help was most needed, people indicated that their distress could hamper their ability to reach available support, regardless of information available. This paradoxical position points to what one participant described as a '*disability of depression*' (BME-SA, QD115). The nature of demand for services, which requires an active and fully capable role for a user, may act as a barrier in circumstances when decision-making and initiating action is held back by the nature of need itself.

As already mentioned, stigma plays an important role in preventing demand to services. In addition to our earlier description of *stigma of dis-ease* (which prevents awareness and recognition of symptoms), we also identified a *stigma of disease* (i.e. stigma associated with formal mental illness) confirming what is already known (Roeloffs et al., 2003). Expressions of stigma of disease were found in people's unwillingness to label themselves as somebody with a mental health problem, as well as in direct accounts of stigmatising experiences in relation to diagnosis and treatment. Detailed analysis revealed several sources of stigma, including diagnostic label, psychiatric treatment and poor reputation of psychiatric services.

Finally, previous experiences and expectations of services were important factors in preventing demand, and in the most direct relation to previously noted concepts of candidacy and recursivity. One of the most prominent aspects of candidacy in our analysis relates to reliance on general practitioners (GPs): some people perceived GPs as not worth contacting in relation to mental health, either because they are perceived as being too busy and have other more serious things to do,

> I think he's got enough on his plate (AC, P16)

or because they are perceived as not knowledgeable about mental health, and unable to understand the person's problems:

> I think it's just that's it's the psychiatrist's field and it's not the doctor's field you know (MUS, 20792);
>
> Honestly GPs are hopeless. In my opinion GPs don't know mental health, and that's not just one GP. (ELD-D2, P4)

Here we see candidacy working bi-directionally: not only in determining users' eligibility for a particular service, but also in assessment of practitioners' eligibility to offer useful support.

In terms of recursivity, our analysis suggests strong interdependence between previous experiences of care and future help-seeking strategies. In this context, the concept of recursivity might be expanded by means of two sub-concepts. First, *mediated experience* points to a finding that help-seeking behaviour is not necessarily generated through personal experience of health services, but may be mediated via storytelling in social networks or media, and internalised as if it were a personal experience:

> People do say don't take it [anti-depressants], it's not good….I don't know about the English but all the Asian people they do say they're not good. (BME-SA, QD102)

This relates to the notion of a 'general narrative' described by Feldmann, Bensing, de Ruijter, and Boeije (2007), with the emphasis here on the process of internalising others' experiences and stories, so that they are not easily distinguished from personal experience in the way they are enacted. Second, the concept of *imagined services* refers to underlying cultural assumptions about services, rather than to stories or narratives traceable within certain groups. For example, in the statement "*you go to the doctor to get well*" (BME-SA, QD108*)* it is not possible to trace where this belief comes from: it is expressed as unquestionable truth. This concept of imagined services is generated in reference to Benedict's (1991) concept of 'imagined communities' and it may be a useful avenue for rethinking the problems of access to primary mental health care.

Navigating networks of services

Once the attempt of placing demand is enacted, it is still not certain that the relevant health professional will be reached. Here we see further expressions of processes captured by concepts of candidacy and recursivity. We found two main groups of factors influencing navigation through the system of professional services: a) users' resources and skills, and b) permeability of services.

Users' resources that influenced care pathways included feeling of ownership over the NHS (acting as a facilitator when present and as a barrier when not); adequate and timely information about available services; availability of social networks to assist a pathway to care; time available for engagement with services; access to finances including the ability to afford time (e.g. freedom from other duties including child care), transport and fees where necessary; and finally, mobility, defined as more than having transport to also include a habitual, motivational and symbolic readiness to pursue the pathways of accessing mental health support.

In line with findings reported by (Dixon-Woods et al. 2005, 2006) we identified two main aspects of services' permeability: *configuration* and *receptivity of services*.

Important aspects of service configuration are geographic and physical accessibility. Distance from users' homes and need for transport, as well as inappropriate or unpleasant architecture and design of the facilities, are considered as barriers to access. However, the importance of proximity to users' homes and of home visits is controversial. While for some, home visits and availability of mental health support in their local community were facilitators to effective access, others expressed serious concerns about mental health support within community settings:

> And then they [mental health professionals] don't like you going into hospital or owt like that, it's treatment in the community. […] so they're coming to the door and you're you know it's back to being stigmatised again when all you need is a bit of help. (ELD-D2, P4)

Our findings draw attention to the stigmatising effect of segregation of mental health services from general health services, by making people with mental health problems undesirably distinctive in local settings. We also found that fragmentation is a barrier for people who need support that addresses both mind and body problems. In consequence, people may withdraw their demand, or turn to private or voluntary sectors for the care they consider adequate to their needs. Conversely, some participants prefer services to be fragmented, because they don't perceive generalist care as adequate for their mental health problems and prefer direct access to the expertise of psychiatrists. Finally, along with physical, geographical and conceptual concerns of service configuration we also identified a problem of organisation of time and failures to respond to users' rhythms of life and the unpredictability of their mental health needs and crises.

Receptivity of services is another important factor identified in respect to permeability of services. For example, one Black Caribbean woman suffering from perinatal depression described the importance of health professionals creating a sense of openness which translated to future use of services: "*I was welcomed to go there at any time" (*BME-BC, I3). In contrast, a White British man suffering from various medically unexplained symptoms, including a problem with his knee, and being a frequent attendee to general practice, describes the case where the inappropriate reaction of a receptionist jeopardised the overall receptivity of services, shaping his future access to health care:

> So I rang up after a fortnight and I asked the receptionist for an appointment to see Dr […..] regarding my knee, the results of my knee. She said "I can tell you Mr [….], there's nothing wrong with your knee". So this is the receptionist. I said "Excuse me but have you become a doctor over night?" I said "I know there's something wrong with my knee, you don't need to tell me, what do you think I'm coming to the doctors for". So that was the time I decided to go private. (MUS, 10607)

Negotiating acceptable treatment

Access to effective and acceptable help is not guaranteed even if a person actually gains access to a relevant health professional. This domain of the problems of access relates mostly to the concept of concordance (Stevenson & Scambler, 2005) but also to availability of choices. Our analysis points to several explanations for the limited fruitfulness of 'consulting room negotiations', concerning patient, practitioner and institution.

Patients may not articulate their problem as one that would be recognised as a legitimate mental health problem from the perspective of clinical criteria. They may also be hesitant to ask for the type of treatment that they perceive they need:

> At the time I was too scared to ask really it was like 'well, you know, they're being nice you can't really say 'you've not done this' and 'you've not done that'. (BME-BC, I3)

Additionally, patients may not clearly express their dissatisfaction with allocated support, leading either to intentional non-compliance or unwilling compliance. In the first case, the access has been gained from the perspective of services but not from the perspective of user: for example, a man who accepts a prescription for anti-depressant medication collects the pills from the pharmacists but then throws them down the toilet. In the second, compliance with the therapy may create ambiguities to treatment and barriers to future engagement with services: this was mainly expressed in relation to pharmacological therapy, but was also present for psychosocial interventions. The hesitant attitudes and lack of clear articulation of needs from the side of patients may reflect a sense of inferiority to professional discourse, as already reported in the literature (Dixon-Woods et al., 2006).

In respect to limitations of concordance due to practitioner's factors, there was substantial uncertainty about practitioners' capacity to relate to patients, and to understand expressions of suffering that are not directly translatable into a professionally understood mental health need. '*They don't listen*' was a common criticism, more obvious in relation to medical staff than to allied health professionals such as district nurses or midwives. We identified two possible explanations: a) lack, or inappropriate presentation, of GP's knowledge and skills, and b) GP's cultural 'unfitness'.

Narratives indicated many situations where GPs' knowledge of mental health was insufficiently expressed to assure patients that they were 'listened to'. This might have been because of lack of professional knowledge beyond biomedical models of care (Dowrick, 2009), or deficiencies in communication skills. Both situations create difficulties in constructing a shared narrative on appropriate treatment.

The set of meanings and values embedded in practitioners' own lives may also act as a barrier to 'relating and understanding' in the clinical encounter. As Sweeney (2005, p.224) comments: "*Doctors are people too; we are not immunised by our medical education from the fears, prejudices, successes and failures of normal lay life*. […] *This underlines the importance of the self and reminds us that there are two selves in any consultation."* It is in the (im)possibility of cultural resonance and mutual creation of meaning between patient and professional, that some barriers to accessing mental health support in primary care may be traced. This brings another layer of complexity to what Martin, Peterson, Robinson, and Sturmberg (2009) described as a problem of finding the 'right GP'. It may be that doctors, who still tend to come from privileged groups in society, are more challenged in their capacity to understand the complexity of lives of disadvantaged patients than other health professionals, traditionally recruited from less privileged societal cohorts.

Both of these sets of problems in negotiating acceptable treatment may be compounded by the institutional context within which health care communication takes place. We identified several factors that may facilitate this process: time available for consultation and treatment; availability of therapeutic options sufficient to transform the possibility of choice into actual diversity of services; ability to integrate aspects of care experienced by users as fragmented; ability to restructure systems of allocation of practitioners to provide – as one participant formulated it – clinical encounters on the '*same wavelength*' (*BME-BC, I12*); and the extent of adaptability of institutions to the changing needs and circumstances of the life histories of users.

Making it work

Finally, even if access to treatment is fully gained, the work of recursivity identified earlier implies the need to look at the factors influencing satisfaction with the quality and personal perceptions of effectiveness of treatment in order to secure future access. Drawing on the described accounts of personal and mediated experience of services, we identified two domains that are important to future formulations of candidacy and engagement within services: a) balance between agency and dependence, and b) patient-defined, fluid holism.

For some people, preservation of the capacity to act independently towards changes in their mental health status is essential for positive outcomes of treatment.

> I have gotta work my way through it. It's you know, no happy pills is gonna make things go away, everything the next day, is going to be there. So I've gotta do it meself. (EMP, R9)

For others, certain dependency such as connection and attachment to practitioner and treatment is important. This highlights the need for appropriate and individually tailored levels of agency and attachment.

Personal perceptions of effectiveness of treatment are related to capacity of practitioners and services to acknowledge and address everything that really matters to an individual patient, at a particular time. We describe this as patient-defined and fluid holism.

> I was depressed all the way through my pregnancy, me. […] I don't like pregnancy, and [on the] top of that, I'd split up with my partner, we weren't getting on too well, it was just a whole mess, it was, I was ill. I was ill, high blood pressure, left, right and centre. It was a nightmare. […] So each time I'd go in there'd be another thing, there's be another change in tablets, there'd be, "Oh, what now?" (BME-BC, I12)

> I went to see him about all the things I've been suffering from; arthritis, arachnoiditis [sic], irritable bowel and all this and told him that I wasn't happy with what was going on and wanted a bit more, not treatment, but things sorting out. (MUS, 10607)

The essential difference from common notions of holistic treatment (Fulder, 2005) is that this is not holism as defined by a professional, but by the patient. Moreover, it recognizes that what matters and what is acceptable will develop and change with time, and must be continuously reassessed in order for treatment to work:

> If you were here and I was depressed, severely depressed where I wasn't on medication and I was going completely mental I would be sitting here so quiet that you would have to do all the talking [….]. But now [after taking medication] I've come to a point where I'm getting my confidence back where I can approach people or talk to people freely and not hesitate so that would help [joining a psychosocial therapy group]. (BME-SA, QD115)

All identified issues presented in this section of 'Fine grain' findings need to be addressed in order to improve access to primary mental health care for people from hard-to-reach groups, and hence improve equity of access. However the issues presented are complex and discussion of ways to address them is beyond the scope of this article. Preliminary recommendations for practice in relation to each of the five clusters of problems are presented in Supplementary Table 2 .

'Large grain' findings

In an attempt to succinctly convey the above described complexity of access-related needs to a group of decision-makers (procedure described at the end of the Methods section), we identified two main barriers and one main facilitator of achieving equity of access to high quality primary mental health care.

The first barrier is the phenomenon of *multiple stigma(s)*, faced – and in some instances simultaneously enacted – by the people associated with hard-to-reach groups. The layers of this multiplicity include: stigma of dis-ease or stigma associated with symptoms of suffering and unwellness; stigma of mental illness associated with stigmatising effects of mental health diagnosis, treatment and services; and stigma of being socially marginalised on a basis other than having a mental health problem, such as living with terminal cancer, being old, being out of work or belonging to an ethnic minority.

The second barrier is *lack of effective information* both about mental health and available support. This insight comes more from the absences and contradictions in the analysed texts, than from positive statements of respondents, and therefore needs further exploration. We infer from the available data that effective information must be culturally sensitive, requiring necessarily an adequacy of content, media, and time and place of information delivery.

The main facilitator to equitable access is *communicated availability of acceptable services*. When we considered the vast diversity of what would be acceptable for different people whose accounts were analysed, a set of five generic principles emerged. In order to provide availability of acceptable service, primary care needs to transform into a system that is:

1. *Pluralistic* – offering a wide range of services and approaches to mental health care;
2. *Adaptive* – developing effective feedback loops and inherent mechanisms of change;
3. *Holistic* – assessing individual patient's ideas of what creates ill-health and designing the course of treatment accordingly;
4. *Resonant* – acknowledging the importance of a 'right fit' in therapeutic encounters and accordingly adjusting the systems of registration/allocation and change of practitioners;
5. *Socially conscious* – establishing mechanisms of responsiveness to social determinants of mental health.

Conclusions and recommendations

Presented 'fine grain' insights demonstrate the ways in which problem formulation, help-seeking, use of services and experience of service quality are interlinked in a recursive and socially embedded matrix of inequitable access to mental health support in primary care. Despite the diversity of insights available from this detailed analysis, three core issues stand out with important implications for addressing existing inequities. Eliminating compounding effects of multiple stigma(s) and related lack of effective information are necessary to improve equity of access to primary mental health. However, even if these barriers were removed, access would remain problematic for people from under-served groups unless available services were more acceptable and 'in tune' with their needs and preferences. Our analysis indicates that developing acceptable services is the main facilitator to equitable access.

The method used in this study demonstrates the fruitfulness of re-examining existing qualitative data, particularly when it is possible to gain access to heterogeneous datasets exploring similar problems in different study populations. This research also demonstrates the efficiency of secondary analysis in terms of decreasing respondent burden and research resources that would be otherwise spent on recruitment, interviewing and transcribing, while multiplying effects of respondents' and primary researchers' efforts.

However, the method has limitations. The problems of decontextualisation of data (van den Berg, 2005; Moore, 2007) are addressed to some extent by detailed attention to the context of participants' life as narrated by participants as well as by taking account of the original research contexts, including perpetual contest of the secondary researcher's interpretations by primary researchers who generated and originally analysed the data. The lack of control in generating data leaves a space for the existence of undetectable problems and details as not all participants were necessarily asked explicitly about access to mental health services. Additionally, the lack of control over recruitment for the original studies also limits the power of the method since participant selection for the original studies did not necessarily cover the variability of experiences and needs examined in this study. These limitations are compounded by the pragmatic and justifiable (May et al. 2004) decision to select a random subset from the available datasets for in-depth analysis. Nevertheless, our findings demonstrate important insights into our research question. This was due not only to the elaborated analytical framework and the richness of the original data, but also due to the narrative approach used in the initial case analysis of the selected transcripts, and the multidisciplinary team which established multiple feedback processes of a collaborative analysis.

In conclusion, we highlight that this study demonstrates an extensive overlap between observed hard-to-reach groups in terms of problems with accessing primary mental health care. It also shows that members of hard-to-reach groups are not experiencing radically different problems than those of the general population. For example, our findings cohere with previous lay accounts of inability to define/configure psychological distress as mental health problems – 'silent suffering' in our account. However, we conclude that there are issues specific to so called 'hard-to-reach' groups. Membership of disadvantaged, marginalised and under-served groups has a multiplying effect on the stigma associated with mental illness, even at the primary care level. Changes wider then within health system are needed to address this problem, but more inclusive design of health information and services would certainly improve the equity of access.

Within England, our findings resonate strongly with the Department of Health's *New Horizons* initiative, which proposes "*a national and local cross-government approach working with local* *government, in partnership with the third sector, communities and individuals*" in order to "*achieve the changes that will reduce the burden of mental illness and unlock the benefits of wellbeing and mental health for the whole population*" (DH 2009, p. 9). In this context we recommend that policy to improve equity of access focus on three main domains: improved understanding in the general population and in primary care of both psychological and social determinants of mental health and health inequalities; improved configuration, availability and communication within and about services; and improved experiences and expectations of generalist care – all based on the premise that services and information should be pluralistic, adaptive, holistic, resonant and socially conscious. The application of these generic principles to practice reconfiguration needs to be responsive to in-depth knowledge of local contexts, which means that different sets of interventions and activities are likely in different primary care contexts.

Acknowledgments

We are grateful to Derek Hibbert, Dan Heartly, two anonymous peer reviewers and the AMP Study Group for helpful comments and suggestions. We would also like to thank Heather Burroughs, Helen Sanderson and Aisha Waquas who contributed to generation of some of the data. The research presented in this paper was a part of the AMP Programme which received the Department of Health's financial support from the NIHR Programme Grants for Applied Research funding scheme (NIHR RP-PG-0606-1071). The views and opinions expressed in this paper do not necessarily reflect those of the Department of Health or NIHR.

Appendix. Supplementary data

Supplementary data related to this article can be found online at doi:10.1016/j.socscimed.2010.11.027

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