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EVIDENCE-BASED PUBLIC HEALTH POLICY AND PRACTICE

Social problems, primary care and pathways to help and support: addressing health inequalities at the individual level. Part II: lay perspectives

Jennie Popay, Ute Kowarzik, Sara Mallinson, Sara Mackian, Jacqui Barker

J Epidemiol Community Health 2007;61:972-977. doi: 10.1136/jech.2007.061945

Objectives: This study aimed to describe social problems presented to general practitioners (GPs) in UK inner cities and GPs' responses; describe patients help-seeking pathways; and consider how these pathways can be improved.

Methods: The study involved a pilot survey and follow-up qualitative interviews with patients in two inner city areas in London and Salford in 2001-2. The pilot survey involved five practices in each locality. GPs completed questionnaires on 57 people presenting with social problems. A diversity sample of 12 patients was followed up for interview.

Results: Study results are presented in two parts. Here (Part II) qualitative research results are reported highlighting four themes: the complex and enduring nature of social problems; the persistence people display seeking help; the fragmented and problematic pathways available; and the roles GPs play as: primary medical adviser; formal gateway to another service; advocates or facilitators to another service; and sources of support and advice during a process of recovery. Commonly, GPs occupied more than one role.

Conclusions: GPs do help people deal with social problems, but their responses are limited. More integrated pathways to help and advice for social problems are needed. Existing pathways could be more visible and accessible, and new pathways developed through commissioning and extending social prescribing. More partnerships across sectors may create more co-ordinated provision, but these are notoriously difficult, and other trends such as the focus on lifestyle issues and long-standing conditions may make it more difficult for people with social needs to access support.

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This is the second part of a two-part paper reporting on research that aimed to contribute to the development of a more effective role for general practice in particular and primary care in general in addressing the social causes of ill health. As we noted in Part I,¹ although many commentators have highlighted the potential role for primary care in the public health arena,²⁻¹¹ the development of a public health dimension to primary care has lacked strategic direction in the UK. In particular, the role of primary care in ameliorating the social causes of health inequalities has remained largely underdeveloped. Relevant background literature to the study was reviewed in Part I of the paper. In particular, in that paper we argued that whilst current models of the social causes of health inequalities highlight the multifactorial character of the pathways leading to health inequalities and are strongly social in their orientation, the macro perspective inherent in such models neglects the lived experience of inequalities at the individual level. Without this parallel micro focus, we suggest, explanations for health inequalities will tend to be deterministic in their orientation: failing to recognise that the individuals involved are not passive victims of social processes, but consciously act to protect and promote their own health and that of others, albeit within structural constraints largely outside their individual control. The pathways people follow as they seek help and support to deal with social problems can be expected to be complex, but arguably general practice is likely to have a key role in these pathways. However, on the basis of a brief review of the English language literature in Part I, we concluded that there is relatively little recent research on the nature and diversity of social problems (as opposed to psychosocial difficulties) presented to general practice. Additionally, limited though it is, the available research

suggests that some people find it difficult to report social problems directly to their general practitioner (GP) and that identifying problems of a social nature is challenging for GPs. It was in this context that the research reported in this paper was conducted.

The research was part of a larger programme of work on the relationship between public health and primary care in two local health systems in England.¹²⁻¹⁶ The research reported on in Part I and Part II of this paper had two linked strands: a focus on the nature of social problems presenting to general practice in UK inner cities and how GPs respond to these; and qualitative research on the pathways people follow as they seek help to deal with a wide range of social problems. Part I of this paper focused on the experience of GPs. The results of a pilot survey of 57 patients consulting GPs were reported and the ways in which GPs responded to these problems were described. Here, in Part II of the paper, we describe the design of the qualitative study of the pathways people followed as they sought help and support to deal with a wide range of social problems. We then consider the implications of both strands of work for policy and practice in primary care, general practice and public health.

METHODS

The research took place in 2001-2 in two inner city localities in the UK—one in London and the other in Greater Manchester—characterised by high levels of social and economic disadvantage. The population of one locality was culturally very diverse whereas the other was largely white. The objectives were:

Abbreviations: GP, general practitioner; LAA, Local Area Agreement; RSI, repetitive strain injury

- To describe the type of “social problems” GPs perceive patients to be presenting with.
- To identify the options GPs feel are available to them for responding to patients’ social problems.
- To describe the wider pathways people follow when they seek help and support to deal with social problems and the place of general practice within these.
- To consider how more effective support for people experiencing social problems could be developed.

This research involved a pilot survey of the type of social problems presented to GPs and their responses to these, and a follow-up qualitative study of help-seeking behaviour amongst a sample of people drawn from the survey. The design of the pilot survey of general practice consultation is described elsewhere.¹ Here we describe the qualitative study of help-seeking pathways.

During the pilot survey, the 57 patients identified by their GP as presenting with social problems were asked if they would consent to be involved in the qualitative follow-up, and around two-thirds agreed. From these, the research team selected 12 to reflect diversity in terms of the social problems identified by the GP and the characteristics of the patient (including age, ethnicity and gender). The 12 patients came from different ethnic backgrounds, including African, Asian, Caribbean, Irish, Middle Eastern and white British communities. They were aged from early twenties to early fifties: eight were women and four were men. Five were working either full-time or part-time, two were students, and five were on state welfare benefits—three due to disability and two due to unemployment. Most had been living in their neighbourhood for many years, with two having arrived recently in the UK. They lived in owner-occupied, public housing and privately rented housing. One family was threatened with eviction at the time of the interview, and a young male refugee, who had been evicted, was housed in temporary bed and breakfast accommodation.

Two members of the research team conducted the qualitative interviews. Most took place in the home of the interviewee, but one interviewee asked to meet in a public place. The interviews were structured using a topic guide which prompted people to “tell the story” of the problem they had consulted their GP with during the original survey and their help seeking before and after the consultation.

The interviews ranged from 30 min to 1 h 30 min, and with respondents’ consent, they were recorded and transcribed. Transcripts were repeatedly read to identify and consolidate recurring themes, and the results of analysis by two researchers were compared to check the robustness of the thematic framework that emerged. The disadvantage of this approach to analysis is that it breaks apart the connectedness of people’s experiences, making less visible the complex and dialectical relationship between problem and response in these people’s lives. The benefit is that the approach allows the analyst to identify commonalities in the respondents’ narratives in terms of the meanings they attach to experiences, despite the considerable diversity in their social circumstances and in the type of social problems they reported. It is these patterns, and the link that can be made with wider social theory, that moves qualitative research findings such as those reported here beyond the anecdotal.

RESULTS

The analysis highlighted four recurring themes in these respondents’ narratives: the complex and enduring nature of the problems experienced; the persistent agency people display as they seek to resolve their difficulties; the fragmented, often inadequate and sometimes inaccessible support pathways

available to them; and the particular role within these pathways for general practice and primary care.

Complex and enduring social needs

The interview narratives revealed direct linkages between physical and/or psychological problems people initially presented with during the survey consultation and wider social determinants of health inequalities. For example, a Middle Eastern man had consulted the GP with a hand injury that had been caused during a racial attack, and a middle-aged white woman, who consulted with depression, was living in a neighbourhood she felt to be dangerous and deteriorating, having recently witnessed the violent death of a teenage girl outside her front door. She commented on how her fear of young people had grown since this incident and how this was affecting her health:

... I never went (to the GP), I didn’t need to go, but over the past year my health has just gone worse, I don’t go out of the door.... I mean it’s just the area has gone so bad, at one time I was always out ... I could hear them all the time, and I was thinking god, what if they throw something at each other it’s going go through my windows, it’s my kids I’m thinking about. And I’m literally sitting up all night listening to them.

In other cases the relationship between physical, psychological and social problems was less direct. One lone mother, for example, sought a letter to aid in her struggle to find a school that would accept her 14-year-old son excluded from his previous school for over a year.

Many of the social problems these people were experiencing reflected precarious living situations: low income from paid work or welfare benefits; restricted choices in the housing and labour markets; or physical and social environments full of conflict. Sometimes, as in the case of Mrs A, a single life event in the past—her husband’s ill health and subsequent unemployment—could snowball, affecting all other spheres of life and leading, eventually, to eviction and possibly homelessness.

Interwoven in some accounts were self-reflections on the forces people felt had shaped their lives and caused their problems. In Ms P’s account, for example, experiencing the loss of her mother, being removed from a violent family environment and then being placed in foster care as a young child were all identified as precursors to an unsettled life. “Escaping” foster care, to seek independence and better circumstances, she described how, despite having obtained some qualifications before leaving school, she had one low paid job after another, unsure what direction to take, finally succumbing to severe depression. Similarly, a young refugee told how he had been forced to flee from his home country because of civil war. Having settled in Britain, he pursued education as a route to economic stability and independence. However, security eluded him and at the time of the interview he faced eviction and homelessness.

Persistent and creative action

A second major theme in these accounts was the persistence with which people sought solutions to their problems, often despite formidable psychological, social and/or material obstacles. Whilst in most cases these actions of self-agency had not resulted in sustainable solutions at the time of interview, they do highlight the resourcefulness displayed by these respondents amidst great adversity. In some accounts, although often tentative, people felt that the steps they had taken had the potential to transform their lives. Ms P illustrates this when, in the context of a recent decision to go to college, she notes:

Yeah, I'm loving it, and I've built some confidence up as well. ... I thought I was thick, you know I was going to be in these sort of jobs for the rest of my life, and you know for my last assignment... I got 97% and I was like oh my God I must be able to do it! ... I've gone to like me doctor to sort my brain out, see I'm sorting it out in two different ways at once..., it might be like hard, but... if I do it altogether. Better for me really isn't it.

In other instances, and from some perspectives, the actions taken could appear insignificant in the context of major life events or circumstances: but they reflect considerable courage. For example, Mr S recognised that he had to deal with his alcohol problems to keep his job:

I don't go out, all I do is drink, go to work, come home, eat and sleep, and I've got no social life whatsoever I feel that, erm, if I go on drinking and if my work performance dropped down then, err, there's no option that they will sack me.

He had self-referred to alcohol services (albeit that he had done this on other occasions) and had bought a guitar to join a club, aiming to build the social networks that might support him to stop drinking. The persistence, with which people sought solutions for difficulties, could be striking. Mrs K, for example, told how she reacted to the diagnosis of severe repetitive strain injury (RSI):

... And I didn't want to shift into thinking I'm disabled, because, if you think you are disabled ... does that mean I will never go to work again, so I resisted thinking in terms of disabilities, I kept on thinking in terms of ability, and it took me about 9 months ... now I kind of walk the fine balance between limitation and ability.

Mrs K described a relentless pursuit of her legitimate entitlement for benefits and her search for ways of better managing the pain, discomfort and limitations associated with RSI, using a range of alternative provision and finding support in self-help groups, alongside regular contact with her GP. She remained optimistic, holding on to the possibility that she would return to work on a part-time basis in the near future.

Fragmented and inaccessible pathways

In their efforts to find appropriate support, the pathways people followed through local systems were often difficult to access and were experienced as fragmented, inadequate and/or inaccessible. Problems with the welfare system were particularly prominent—a common strand in other research. Mrs K, for example, described a system seemingly designed to discourage the uptake of entitlements and confronting her repeatedly with her limitations.

... You don't get free prescriptions, so you have to fill in another form, and I phoned to get a form and they said "OK we'll send you one" and they've just written to me to say they haven't got the form can I phone up somewhere else, and they don't give you a telephone number or anything about where you phone, so you are on the phone, which costs a lot and I can't get, I can't hold the phone for long because of my condition, so I'll have to look about getting a loudspeaker phone ... and when you start to fill in a form it brings it all back and you end up feeling quite, you know, debilitated about the whole thing.

Mrs D describes similar difficulties in relation to education and social services. Following her decision to remove her son

from school, in order to avoid him being formally excluded, she describes the response of these services in terms of a string of misinformation, cancelled appointments, lack of transparency and shifting of responsibilities:

They are saying it's not their department, the exclusion officers have now said it's not their department so to be honest with you I don't even know where it's at, at the moment ... it's like everyone is out to help me and then slowly, but surely all the doors stop opening again, and then I've got to slowly reopen them...

The workings of housing departments could also be bewildering and on occasions could catapult families into what appear to be avoidable crises. During the interview, Mrs A was waiting with her family for the bailiff to arrive to evict them from the privately rented property, because the landlord had (legally) taken it back for his own purposes. She commented on the housing department's decision to refuse to re-house them close to their GP and their insistence that the family had to be homeless before they could be re-housed.

There were also examples of professionals who appear to be insensitive to the constraints imposed on people's actions by the context in which they lived. Mrs W, for example, described how the police had asked her to alert them when young people they wished to speak to were near her house—an action, she suggests would put her and her family in danger:

I told em, "I can not make them come in to you, I've given them the numbers you give me, but, what more can I do?" My house would be in flames before you knew it ... you've got to be very careful with them. But I can get away with a lot because they grew up with me ... [but] Oh God, I've seen them terrorise people ... I wouldn't trust them.

In some instances the inefficiency of staff and/or their disrespectful attitudes acted as barriers to access. Mrs M, for example, was first confused, later upset about the response she had received from the front-line staff of the one-stop shop: "They were angry and they said 'there is no such bloody form' ". Similarly, Mr T said of the doctor conducting the assessment for incapacity benefit: "I went down there, no examination, he just fired questions at me".

In other cases the obstacles to accessing services were financial. For example, Mrs N, a lone mother in her forties, described how she could not get to a hospital appointment because she had given all her money to the children for the bus journey to school. Similarly, Mr T could only afford one of the three medications the GP had prescribed.

There were a few respondents who were at a loss as to what to do to ameliorate their situation with no knowledge of where to go or of how to find out what services may be available to help them. In this situation, two respondents were contemplating up-rooting their families and leaving their homes to find social support and/or a sense of security elsewhere.

In many of these accounts there was a sense that the health and welfare system was at best irrelevant and at worse exacerbating the difficulties people were experiencing. Mrs K vividly sums up the experience of people constantly frustrated in their help-seeking endeavours by the way the system operate, and appreciates the irony of the situation:

It's a feeling of struggle for the littlest thing, and sometimes, I don't know if it's built into the system that you'll give up ... (laughs), I feel daunted by the whole thing, and you think ...

I'll go and live in a box in the street at least I don't have to worry so much ... if ... you were supported physically as well as in other ways, I think people would recover quicker and be back into the workforce, but because you feel like the whole system ... doesn't support you, it makes you feel ... as if you have to justify every time, everything...

The role of general practice in help-seeking pathways

When asked why they had consulted their GP in the original survey, most respondents initially described a medical problem, such as high blood pressure, severe back pain, depression or the pain associated with RSI. However, people then moved on to describe a wider context for these specific 'medical' problems, linking them to social circumstances and life events, and elaborating other reasons for consulting a GP.

The most common element of this wider role for GPs was as an advocate—helping people to access services and resources within and beyond the National Health Service (NHS). Most frequently, this would involve a request for a GP to provide a letter asking for another service to be provided or complaining about some element of the service already provided. In this sample, GPs wrote letters to support people's requests to be rehoused on health grounds, to ask for changes in the level and/or type of support provided by educational and/or social services, to complain about a delay in the provision of home adaptations in the context of a disabling condition and to request leniency from a court dealing with a patient's eviction order. In these situations, people were approaching their GP because they felt s/he would carry more weight with services than their own requests. For example, Mr R, the young refugee, asked his GP to write a letter to the housing department after it had rejected his claim for re-housing. The department had subsequently revised their decision and placed the young man in temporary accommodation. In some cases, the GP's advocacy role went beyond writing a letter. When the workers at the one-stop shop told Mrs M there was no form for claiming a disablement badge for her car she went to the doctor and as she said, "he phoned for the form, and then the very next day, I got the form".

In most cases people had asked the GP to get involved. However, some people recognised that their GP's formal gatekeeper role included an element of surveillance as well as advocacy. Asked why she had gone to her GP in relation to her search for a new school for her son, for example, Mrs D explained that:

... every time you've got an issue with schools and stuff like that you've normally got to get referred by your doctor, they've got to have an involvement, yeah, for most things.

In this case, the GP letter was reported to have had little, if any, impact on the way other services were responding.

GPs were also described as providing a "holding" environment: a space in which people could reflect on their decisions and choices as they searched for appropriate support to help them cope with and/or resolve their difficulties. For example, Mrs K noted that her GP was always there to discuss ways around the seemingly never-ending obstacles she encountered as she sought to carve out an appropriate and effective pathway to support.

The quality of the relationship people had with their GP was an important factor shaping their decisions to "consult" with social problems. For some people, although importantly not all, a key aspect of this relationship was the mutual trust and knowledge built up over time. Because of this, people would remain registered with the same GP, even though they or the

GP moved away from the immediate neighbourhood. Ms E, for instance, had followed her GP to a new surgery because she had "always been able to talk to him". Similarly, Mrs D had stayed with the GP when she moved out of the area because she valued the relationship and understanding that had been built up over years. Clinical competence also featured in these accounts, albeit to a lesser extent, closely linked to the GP's personal knowledge of people and their families, as this quote from Mrs A illustrates:

There is a local doctor around the corner, who is pretty nearby, but we see this Dr M basically because he is a very good doctor, he can diagnose, we find him good ... because, err, he knows the ins and outs of our family ... he can diagnose very well.

Not all of the respondents had acted on the GP referral during the survey consultation. In one instance, for example, concern about high blood pressure had meant that a respondent had not yet sought the benefit advice suggested by the GP. In another, the respondent had decided to move away from an area, in which she feared violence from young people, rather than acting on her GP's referral to counselling services. Similarly, a GP's advice to contact the police about a racial attack was not followed up because the respondent did not trust the police service. Also, for a few respondents, the GP was not seen to be an appropriate person to discuss social problems with. For example, Ms P had only just signed on at her practice. She felt that the GP was too far removed from the type of circumstances in which she lived and would not be able to understand her difficulties.

DISCUSSION

The research reported here aimed to contribute to more effective ways of responding at the individual level to the social problems that contribute to health inequalities. Part I of the paper focused on GPs' perspectives on the social problems experienced by their patients and how they respond to these.¹ Here we have described the wider help-seeking pathways followed by some of the patients included in the GP survey highlighting the complex and often long-term nature of the social problems presented to GPs; the resilience shown by people experiencing these social problems; the persistence with which they pursue help and advice; and the obstacles they face in seeking to manage their problems.

Most of the people interviewed reported that the GP was a valuable source of support, although some people lacked the time or other resources to act on the advice from their GP, and in a few cases the referral was perceived to be inappropriate. Some people used general practice because they felt it was a non-stigmatising service and/or because their GP was familiar with the intimate details of their lives. GPs were also seen to carry authority and weight in a system in which people felt they were not taken seriously and which sometimes treated them with casual neglect. However, support from a GP was typically only one element of complex help-seeking pathways.

On these pathways, respondents frequently found it difficult to access services they felt to be appropriate, services were rarely integrated and most respondents had not found resolution or lasting relief from their difficulties by the time of the interview. Indeed, for some of these respondents, interaction with public services was a source of additional stress rather than helping to ameliorate their problems.

So what are the implications of this research for primary care and public health practice and policy? In Part I of the paper we discussed the scope for developing and supporting a more effective role for primary care practitioners in responding to the

social causes of health inequalities at the individual level. There we argued that better informed primary care professionals, greater legitimacy and recognition for primary care practice focusing on social problems and new or extended referral options have an important contribution to make to developing better support for people experiencing a wide range of social problems. However, resolution, or perhaps at best amelioration, of the complex and enduring social problems described in this research requires high quality integrated provision from different services and/or sectors beyond primary care.

Despite numerous policy initiatives and practical interventions, the ideal of “joined up” planning and delivery of services across the UK NHS and local government has remained stubbornly elusive,¹⁷ but the changing shape of primary care, and the public sector more generally, in the UK and other developed countries could be creating opportunities to develop new pathways beyond primary care that are more appropriate and effective in supporting people experiencing social problems. These changes are rapid and would have been unimaginable by most people at the time this research was undertaken. The implications for the delivery of public health are currently uncertain, but they may be profound. As a recent article in the *Health Service Journal* noted: “How will health improvement fare in a new world of voice, choice, contestability and alternative provision?”¹⁸ One possible model being muted is the establishment of public health trusts: new organisations—perhaps virtual—dedicated to delivering population health improvements and reductions in health inequalities and bringing together different workers, organisations and sectors. A second delivery model already being implemented is Local Area Agreements (LAAs). These agreements, which specify a range of shared outcomes with associated indicators, targets and funding streams, are signed by partnerships including local authorities, the NHS, the voluntary sector, police, business, education, community groups and regional government offices working on behalf of central government. The focus of the first wave of 21 pilot LAAs suggests that public health issues are high on the agenda for these partnerships, with a concentration on delivering safer, stronger and healthier communities. Lastly, there are those who believe that eventually the commissioning of health and social care—including public health—will be the responsibility of local government, a change which in theory has great integrative potential.

CONCLUSIONS

The research reported in Parts I and II of this paper highlights the important role primary care can and is playing, working with other services in local systems, in developing more effective pathways of support for people experiencing the type of social problems that have been implicated as the causes of health inequalities. However, it also demonstrates the gap between the aspirations of government policy and the reality of many people’s attempts to resolve these problems.

All of the respondents in the qualitative study found it difficult to access advice and support appropriate to their needs. GP responses were considered helpful, but the study has also pointed to some ways in which the contribution of individual primary care professionals could be improved.

The study findings also point to areas for action beyond primary care (as currently practised in the UK), but resistance to these types of development has long been recognised. Traditionally, for example, general practice in the UK has resisted becoming involved in public health practice focusing on the wider social causes of ill health, and multidisciplinary working faces many barriers.^{15–17} There has been relatively little in the way of experimentation with social models of primary care, such as the Community Oriented Primary Care model

developed in other countries.⁷ Similarly, despite many years of effort, attempts to link general practice and primary care into other services, such as social care, or to encourage general practice to accommodate other services (notably welfare rights for instance), have had very limited impact. The research also points tentatively to ways, in which the operation of local public services may be exacerbating social problems. Whilst the intended aim of many rules is to monitor entitlement and protect against fraud, the unintended consequences could contribute to the social causes of ill health. More research on the nature and scale of these types of difficulties is needed.

On a broader canvas, there are new routes opening up for improving the quality, relevance and integration of public services aimed at promoting population health and reducing health inequalities. Early signs in the UK are that new delivery models do hold out the hope of transcending at least some of the problems that have beset attempts at integration in the past, and there certainly seems to be strong political support for radical change to achieve this. However, this does not mean that the type of social problems considered in this paper will be the focus of sustained attention. Public health in the UK continues to be dominated by a focus on major diseases and lifestyle issues. Some of the people interviewed in this research were experiencing long-standing conditions that could be given

Key points

- Policy aimed at reducing health inequalities must address the needs of people experiencing social problems at an individual level.
- Primary care medical practitioners see many social problems that have been shown by research to be implicated in the genesis of health inequalities.
- People experiencing social problems are resilient in their search for support and persist in help seeking despite many obstacles.
- GPs are a valuable source of support but only one stop on complex help-seeking pathways characterised by inappropriate, inaccessible and/or fragmented services.

Policy implications

- Recent policy developments, such as health trainers and the re-introduction of practice-based commissioning, may offer new ways of transcending financial and cultural barriers to the development of more appropriate and accessible individual level responses to the social causes of health inequalities within primary care.
- New service delivery models—for example, public health trusts and Local Area Agreements—could improve the quality, relevance and integration of public services aimed at improving population health and reducing health inequalities.
- However, increasing targeting of public health provision may make it more, rather than less, difficult for people experiencing the social problems implicated in the genesis of health inequalities to access the help and support they need.

priority, such as depression, high blood pressure and alcohol dependency, so they might find more visible and appropriate pathways developing for them, if new commissioning and/or delivery models result in more integrated high quality provision for these target groups.

However, what of people, who do not—yet—have such long-standing conditions or have conditions such as RSI that are not seen as priorities? Their lifestyles may well bring them to the attention of public health practitioners seeking to improve diet, increase physical exercise or reduce smoking, but the respondents in this research were seeking help to deal with or resolve social problems not to change their lifestyles. For these people, generic improvements in the integration of public services and new innovative ways of delivering appropriate support and advice are needed. Such improvements could be a side product of the pursuit of specific lifestyle outcomes for particular population groups or conditions, but, just as some commentators are arguing that welfare systems are becoming increasingly residual, providing help only for the “demonstrably needy”,¹⁹ so public health action, at least in the UK, is becoming increasingly targeted at particular groups or health needs which could make it more, rather than less, difficult for people experiencing generic social problems to find the help and support they are looking for.

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