

## Popular epidemiology

## Highlighting the importance of “popular epidemiology”

Gareth Morgan

Common sense dictates that communities that feel most understood in terms of daily experience will also be the ones most receptive to a health improvement policy.

In Wales, the community councils represent the lowest tier of local government. From personal service experience in one of the councils it seems that day to day, people are concerned with matters such as dog fouling, small scale vandalism, litter, and car parking facilities. These community concerns have an impact upon health and wellbeing in a variety of ways and might be appropriately termed “popular epidemiology”.

Anecdotally, it seems that family doctors working in the Welsh mining communities tended to be very aware of the importance of “popular

epidemiology”. This awareness may have been related to several factors including high social capital and general openness between people. It therefore seems that “popular epidemiology” has less prominence now than it had historically and this is probably to the detriment of public health practice.

Does the concept of “popular epidemiology” fit into a theoretical scientific paradigm? Perhaps not as it is dynamic and highly dependent on virtually every factor imaginable. While scientific paradigms tend to focus on specific problems depending on the method used, “popular epidemiology”

integrates multiple factors through life experience. Therefore, it relates strongly to perceptions, values, and belief systems and these can be variable.

So while “popular epidemiology” may seem to be a nebulous concept, it does have a potential to support public health practice. Indeed, common sense dictates that communities that feel most understood in terms of daily experience will also be the ones most receptive to a health improvement policy.

Over the past 40 years, the Archie Cochrane legacy has done much to further the cause of the evidence based movement and the benefits of the legacy have been enormous. Yet there has been no emphasis on “popular epidemiology”. This paper highlights the importance of “popular epidemiology” so that it may be considered with the mainstream public health agenda.

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## Common mental disorders

## Absence of spatial variation in rates of the common mental disorders

Scott Weich

Place may still matter—but not in the ways that have been studied to date.

The intuitive importance of location as a determinant of life chances<sup>1,2</sup> contrasts with growing evidence of little or no variation in the prevalence of the most common mental disorders (CMD), anxiety and depression, across small and mid-sized areas—particularly after adjusting for the characteristics of individual residents.<sup>3–9</sup> The study by Henderson and her colleagues,<sup>10</sup> based on an urban US sample confirms this. By contrast, larger area level effects are

found for psychotic illnesses (such as schizophrenia) and more severe forms of depression.<sup>11–15</sup> Should we conclude that place doesn't matter for the most CMD, or are there alternative explanations for these negative findings?

### ARE WE STUDYING THE WRONG SPATIAL SCALE?

The spatial scale at which contextual factors might have an impact on mental health remains unknown. Most studies

have used data collected within administrative boundaries.<sup>2,16</sup> Studies of large areas, such as UK regions (with hundreds of thousands of residents), are difficult to interpret.<sup>17–19</sup> Recent studies have examined effects over smaller areas, ranging from Amsterdam boroughs (average population 33 000), postcode sectors and neighbourhoods (average population 8000–10 000),<sup>19</sup> to UK electoral wards (average population 5500),<sup>3,4,7</sup> and US census tracts (average population 4000).<sup>9</sup> Effect sizes at these levels are small and rarely statistically significant—percentage of variance in symptoms of anxiety and depression ranges from 0.5% to 4% before adjusting for residents' characteristics, to less than 1% after doing so.

Wards may be too large and heterogeneous to detect contextual effect, and variance in CMD may be greater over smaller areas.<sup>20</sup> The significance of this modest trend remains unclear, and there have been few studies of very small areas. A study using postcode

units (average population 150) in South Wales (Glyn Lewis, personal communication) found results that differed little from those across UK electoral wards. "Neighbourhood" remains notoriously difficult to define.<sup>21</sup> While some studies have defined neighbourhoods using natural boundaries,<sup>22–24</sup> others have used "neighbourhood" to describe administrative units such as US census tracts.<sup>25–27</sup> Other studies avoid this altogether, asking survey respondents to make implicit judgements about boundaries of "their neighbourhood" or "their area".<sup>28</sup>

One notable finding is substantial between household variation in rates of CMD in Britain, although most studies overlook this as a discrete level.<sup>3 5 14</sup> In a national study, over 10% of variance in score on the 12 item general health questionnaire occurred at household level. This finding was not changed, even by adjusting for characteristics of individuals (including marital status, ethnicity, education, employment status, financial strain, and the number of current physical health problems), households (income, car access, housing tenure, social class, composition), or wards.<sup>4</sup> This finding remains unexplained, but could be attributable to exposures operating at a spatial level between ward and household.

### ARE WE STUDYING THE WRONG EXPOSURES?

As most studies are secondary analyses,<sup>2</sup> places are often characterised using census based aggregate measures of the population composition. The most commonly used measures are those reflecting prevailing socioeconomic circumstances, such as (un)employment, housing tenure, and proportion of single adult households, either singly or in combination,<sup>5 6 9 10</sup> or income inequality.<sup>10a</sup> None of these is associated with the prevalence of CMD to a statistically significant degree after adjusting for individual characteristics.

"Contextual" measures reflect characteristics of places rather than residents. The latter are rare in the literature, notable exceptions being studies with independent observations of the built environment.<sup>24 26 27</sup> The distinction from compositional indices may not be clear cut,<sup>2</sup> as variables measured at the individual level (for example, educational attainment, employment) may be influenced by area characteristics (for example, quality of local schools, job opportunities, public transport). Unfortunately, the dearth of validated contextual measures precludes empirical investigation of this hypothesis. The work of MacIntyre and her colleagues, who are developing measures of place

based on needs, represents a major empirical advance.<sup>28</sup>

Summary statistics from surveys of residents' perceptions of their local environment<sup>25 29</sup> are one alternative to census based descriptors. This approach is common in social capital research, which has been criticised theoretically and empirically (Health Development Agency, 2004). Another approach has been to classify small areas according to a particular characteristic. Several UK studies have found a higher prevalence of CMD among those living in "urban" (compared with "rural" or "suburban") areas.<sup>30–33</sup> Suicide rates are also higher in urban than rural areas of Britain,<sup>34</sup> although this gradient may be falling.<sup>35</sup> In Sweden, a study of the entire population aged 25–64 found a statistically significant linear association between increasing population density and rates of first admission for depression.<sup>15</sup> By contrast, studies in New Zealand,<sup>36</sup> USA,<sup>37</sup> Scandinavia,<sup>33</sup> and Canada<sup>38</sup> found no evidence of statistically significant urban-rural differences in CMD prevalence. These inconsistencies may be partly methodological, especially given varying definitions of "urban" and "rural". Cross national comparisons are difficult given historic, socioeconomic, and ethnic differences in rural and urban populations in different countries.<sup>39</sup>

Population density (for example, Sundquist *et al*<sup>15</sup> and Wang<sup>38</sup>) may fail to capture aspects such as geographical remoteness,<sup>35</sup> and some researchers have resorted to subjective or impressionistic definitions.<sup>31 33</sup> The assumption that rural residents are less deprived and healthier than their urban counterparts has also been challenged statistically. Rural wards (in the UK) are smaller, and have greater internal (between individual) variability with respect to deprivation than urban wards. While rural areas are more internally heterogeneous, even over areas smaller than wards, there is less variation in deprivation between rural areas than their urban counterparts.<sup>40</sup> Associations between area level socioeconomic deprivation and worse health emerge for rural areas when wards are aggregated to approximate the greater size of urban wards.<sup>40</sup>

### ARE WE STUDYING THE WRONG OUTCOMES?

Reliance on secondary analysis and the need for large samples means that most studies use self report measures of anxiety and depression symptoms. In studies of individual socioeconomic status and CMD, larger effect sizes are observed in studies that use standardised clinical interviews.<sup>41 42</sup> The same may also be true for place and CMD.<sup>14</sup> Standardised clinical interviews might

capture more severe episodes of disorder, and be less prone to "false positives" arising from mild or transient disturbance, or physical ill health. However, traditional objections to findings not based on clinical diagnostic categories are lessened by evidence that CMD are most validly represented as a single dimension encompassing comorbid anxiety and depression.<sup>43–45</sup> One important problem is that measures such as the general health questionnaire may be prone to socioeconomic response bias, with those in lower occupational grades underreporting symptoms.<sup>46</sup>

The dearth of prospective studies is striking. This is especially problematic in studies of chronic or recurrent disorders such as anxiety and depression, because cross sectional studies may conceal associations between risk factors and either the onset or outcome of episodes of disorder. Evidence that socioeconomic adversity is associated with longer episodes of the CMD but not episode onset<sup>47–49</sup> suggests that episode duration should be longer in areas with the highest levels of socioeconomic deprivation.

### ARE OUR MODELS MISSPECIFIED?

Substantial variance in CMD at household level is little changed by controlling for a host of household and individual level characteristics. As this variance remains unexplained, our models remain incomplete. The findings at household level are consistent with spousal similarity in depressive symptoms,<sup>50</sup> and intra-household processes warrant scrutiny.

The effects of place may also vary with individual and households characteristics.<sup>2</sup> This is reflected in an urban excess of CMD only among those who were economically inactive,<sup>51</sup> variation in suicide rates with area level and individual socioeconomic factors, particularly unemployment,<sup>52 53</sup> and interaction between ethnicity and urban/rural location in the association with depressive symptoms among those living in poverty in the USA.<sup>54</sup> Thus, place may only affect those with specific vulnerabilities.<sup>13</sup>

### ARE WE ASKING THE WRONG QUESTIONS?

It is inconceivable that the effects of place on mental health are instantaneous, and cross sectional studies are arguably the least informative. The most potent risk factors may be those operating during childhood.<sup>55</sup> Educational and employment opportunities vary considerably between places. Adjusting for the socioeconomic characteristics of residents overlooks the fact that these are likely to be determined in part by where they live (or have lived). We know that deprived people live in deprived places

and are less healthy than those living in affluent areas. We need to know much more about residential mobility, who moves between areas, why they move, and what effect this has on their health. The health effects of residential mobility (or lack thereof)—like those of place more generally—may vary with individual circumstances, including health.<sup>56</sup>

## CONCLUSIONS

There is little cross sectional variance in the prevalence of the CMD between areas with populations of 5000–8000 in the UK, Netherlands, and USA. Such areas may be too large to observe effects at a very localised level. Substantial variance at the household level may provide partial support for this view.

Place may still matter—but not in ways that have been studied to date. Anxiety and depression are important public health problems in their own right, and their prevalence is not declining. These conditions are also associated with mortality and physical morbidity, particularly cardiovascular disease. As acute and chronic environmental stressors are potent drivers of onset and outcome, living in places with fewer amenities, or where personal safety is less secure, might lead to higher rates of psychiatric morbidity. Alternatively, risk may be confined to those with specific vulnerabilities, or those exposed to such environments at developmentally critical times. If this is so, modifying the physical or social environments could lead to substantial reductions in rates of the most common mental disorders.

Most existing studies are limited by reliance on secondary and cross sectional data sources, administrative rather than natural geographical boundaries, and compositional measures of place. There is a need for more hypothesis driven primary research, and more measures of place that do not rely on residents' characteristics or perceptions of their locale, and that describe places at different spatial scales. Research needs to be longitudinal, based on population samples large enough to test hypotheses about interactions between people and places, and inclusive of household level exposures and outcomes.

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## Surveys

# Population ideals and sample realities—why we still need access to comprehensive information about populations

Geraldine Barrett, Janet L Peacock

Public health population research will be rendered impossible if individual consent for all secondary uses of health data becomes the norm.

Much epidemiological and health services research relies on surveys and Jousilahti *et al's* paper<sup>1</sup> is a timely reminder to us about the biases caused by participants' non-response. Although we all know that non-response is a socially patterned phenomenon, this knowledge is so familiar that it is easy to become complacent—how many of us have ticked the mental boxes of “>70%” and “information about response biases” as markers of a good quality survey when reading or reviewing a paper? Jousilahti *et al's* paper is valuable in that it provides data from several national, large scale, well conducted Finnish surveys with high response rates, and it shows the differences in health outcome, in this case mortality, according to responder status. It is sobering to realise that even with an aggregate response rate of >80% findings may still be subject to substantial bias.

As if Jousilathi *et al's* findings were not important enough, with their implications for the conduct and interpretation of population surveys, their study also has wider relevance. Unlike Finland, where studies such as this are possible because of the comprehensive records infrastructure (a national register, permissions for record linkage), other countries, such as the UK, Australia, Canada, and the USA, are moving towards a requirement of individual consent for the use of identifiable medical data in health research.<sup>2–4</sup> Hence in these countries investigators are experiencing increased difficulties in

identifying unbiased samples for cross sectional surveys and cohort and case-control studies and in assembling accurate, comprehensive datasets for records based analysis. Published evidence has already shown the hugely detrimental effect of a requirement of individual consent.<sup>5–6</sup> However, the regulatory authorities seem unconvinced that bias in data is a legitimate concern and maintain that they are safeguarding the rights of the patient, for example:

“I would have to say that I've heard an argument made and I've heard a lot of anecdotal evidence that not having the full sample somehow badly skews epidemiological research. Not to say it is not out there, but I have not seen the persuasive evidence that this is in fact the case.”<sup>7</sup>

“We have received a number of applications for Section 60 support to cover research studies where it has been argued that it would not be appropriate to seek consent from patients because failure of any patients to agree to participate in the study may bias the research findings. ... It is not sufficient for applicants to simply state that certain groups are less likely to provide consent; we seek evidence to justify such comments.”<sup>8</sup>

Perhaps this paper will help provide the evidence that bodies such as these

seek. If individual consent for all secondary uses of health data becomes the established norm then most public health and health services population based research will be rendered impossible, to the detriment of the health evidence base. To prevent this, the public health community needs to convince those outside the research arena that existing (and recent) uses of identifiable health data are in the public interest.

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