posits, that reflects “almost exclusively a white, middle class, perspective”.

Second, the options available to women once they have test results are, in reality, quite limited. Their capacity to control their circumstances may be restricted to a simple decision about whether to continue with a pregnancy or not. One can imagine ways in which we might expand the available choices, for example, by ensuring that whatever diseases or conditions a child is born with will be treatable and/or manageable by available resources.7

Finally, even if we accept that there is a demand for information, particularly in the burgeoning realm of screening for genetic conditions, how much people actually understand about the conditions for which they may be screened is unclear. How well are people able to interpret information about genetic status, particularly if that information includes complex statements about risk and susceptibility to disease? If we are contemplating mass screening for genetic conditions, we need also to factor in the possibility that those who provide information about screening may not be competent to explain the nature of screening to their patients, or to answer questions before and after test results are available.8

Conclusions

The principles that guide screening have been well described for almost 40 years. For most of this period, ethical debate about the interpretation of these principles has focused on the extent to which screening programs can prevent or reduce the burden of disease. More recently, some screening programs, particularly in prenatal and genetic testing, have been justified in terms of their capacity to enhance personal autonomy. This paper has suggested that neither the preventive nor the autonomy enhancing rationale can be taken at face value. In both cases, arguments about whether a screening program is, indeed, “good” will need to be made on a case by case basis, with careful attention to the circumstances and context of the individual program.

References


THEORETICAL AND CONCEPTUAL ISSUES AROUND EQUITY IN HEALTHCARE: APPLICATION TO CERVICAL CANCER SCREENING IN SOUTH AUSTRALIA

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Introduction

Across the world, terms like “inequalities,” “disparities” and “inequities” are often used interchangeably in academic and policy literatures.1 Even when they are defined, there seems little consensus about their meaning or measurement.2,3

The rationale for this paper is to distinguish “inequity” from both “inequality” and “disparity” and to go on to highlight how we might measure and monitor the equity of healthcare provided to groups or populations. The paper is divided into two main sections. The first section focuses on the definition, measurement and monitoring of the equity of healthcare. The second section uses actual data on cervical screening rates in South Australia to highlight issues around the inequitable uptake of preventive services. Throughout both sections of the paper, we outline some of the suggested reasons for inequitable healthcare services and suggestions for future research.

Whilst much of the public health research literature on equity focuses on equity in health (i.e., in terms of morbidity, mortality, and proxies of illness/wellbeing using measures like quality adjusted life-years, disability adjusted life-years, SF36, etc), this paper focuses attention on equity in healthcare.

The definition of healthcare used in this paper is fairly wide, and includes preventive services (e.g. cancer screening, women’s health clinics), treatments (e.g. prescribing), acute and chronic services, and services provided by a vast

Conclusion

The principles that guide screening have been well described for almost 40 years. For most of this period, ethical debate about the interpretation of these principles has focused on the extent to which screening programs can prevent or reduce the burden of disease. More recently, some screening programs, particularly in prenatal and genetic testing, have been justified in terms of their capacity to enhance personal autonomy. This paper has suggested that neither the preventive nor the autonomy enhancing rationale can be taken at face value. In both cases, arguments about whether a screening program is, indeed, “good” will need to be made on a case by case basis, with careful attention to the circumstances and context of the individual program.

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array of medical, allied health and social care professionals. It is widely recognised in public health, although not uncontroversial, that formal healthcare services may have a limited impact on the health of populations, and that policy and finances should focus on the wider social and economic determinants of health. In these terms, healthcare (as a social system) should be viewed as one of the social determinants of health. Therefore, the equity of healthcare should be contextualised by reference to the equity of access to quality education, the equity of access to clean, safe public spaces, the equity of access to affordable public transport, etc. If we were to take a lead from Social Systems Theory, we would want to explore issues of equity in each of the social systems within society (e.g. legal, economic, medical, political, environmental, etc) in order, firstly to construct a bricolage of inequities and secondly, to understand how we can impact on inequities in different social systems to have a “joined up” approach to the problem.

Inequity, inequality and disparity – taking the mud from the water

The terms “inequality” and “disparity” tend to be used in different geographical contexts, with “inequality” being preferred in Western Europe, whereas “disparity” tends to predominate in the US. Nevertheless, the two terms are very similar in meaning – essentially they are defined by “difference” with no reference to the context, nature or direction of the difference or who may be adversely affected by the difference. In this way, disparities or inequities in healthcare may simply refer to differences in the use, access, availability or quality of healthcare by different groups.

The central ingredient missing from definitions of inequality or disparity is the idea of “social”, “justice” or “fairness.” This is where “equity” becomes particularly useful, since it focuses research, policy and practice on exploring, attending to and monitoring healthcare which is deemed to be “unfair.” There may be differences in healthcare use between various groups, but is it fair? For example, we may find that older people use particular healthcare services more than younger people – but that does not necessarily mean that access to those services are inequitable (i.e. unfair to younger people). It may just be the case that older people are in greater need for the specific services. Indeed, it may actually be the case that the older people are not in fact receiving high enough levels of those services, and therefore, the services may be inequitable in the opposite direction. Nevertheless, “fairness” or “social justice” is the key area of concern.

Defining, measuring and monitoring the equity of healthcare

One of the most important principles of health care systems in the developed world is based around the notion of equity, whereby healthcare services should be provided solely on the basis of clinical need. However, there is a huge research literature demonstrating that access to, quality of, and outcomes from healthcare are inequitable across a number of clinical areas including surgical interventions in coronary care, screening for a variety of cancers, and primary care prescribing for coronary heart disease. These examples would fulfill Julian Tudor-Hart’s notion of the “inverse care law,” whereby the groups with the greatest levels of need receive the lowest levels of service.

There is much literature around how to define, operationalise and measure equity in relation to health care services, although equity is generally taken to mean “fair” or “socially just.” Equity has been generally conceptualised as either horizontal equity or vertical equity. Vertical equity works on the principle that individuals or groups that are “different” should be treated differently, according to their levels of healthcare need. Whilst this is fairly uncontroversial, it is not straightforward to operationalise and monitor in a public health context. Horizontal equity works on the principle of equal treatment for individuals or groups with the same (or similar) levels of healthcare need. For the example of cervical cancer screening, the major determinants of “need” for population-based screening would be age and sex. Therefore, using the framework of horizontal equity, one may expect that the provision, access and uptake of cervical cancer screening services would be similar between a group of 50-60 year old women in one town and a similar group of women in another town. If there were systematic differences in uptake of cervical cancer screening services (i.e. differences in terms of social class, ethnicity, etc), then we could suggest an inequitable uptake.

Equity of healthcare has been divided into three domains: equal access to health care for people in equal need; equal treatment for people in equal need; and equal outcomes for people in equal need. Whilst this is a simplification of the nature of equity, it is useful in delineating the various domains in which inequities may arise. However, implicit in these domains of equity are terms which themselves require definition. For the purposes of this paper, we briefly mention two of these terms – access and need.

In a seminal paper, Aday & Anderson outlined different mechanisms for understanding and defining access. They coined the terms “potential access” and “realised access” to differentiate between providing the mechanisms for people to access services (e.g. culturally appropriate information, adequately located services, appropriate staff mix, etc) and the actual utilisation of those services. Goddard & Smith have built on this definition of access, to provide the following: “the ability to secure a specified range of services, at a specified level of quality, subject to a specified maximum level of personal inconvenience and cost, whilst in possession of a specified level of information” (nb. bold added). This definition begins to make “access” amenable to policy makers, since the word “specified” allows them to shape access in relation to local circumstances (i.e. allow for differences).

In terms of defining “need,” we can only scratch the surface here. There is much literature spanning philosophy, social policy, economics and public health, which cover everything from basic human needs through human rights and capabilities, through to health needs assessment.
For our purposes, a useful way of conceptualising healthcare need is the “Taxonomy of Need” which is widely used in healthcare needs assessment. This taxonomy has four domains of need, each of which represents a different dimension of need which can be studied separately. When combined, however, Bradshaw states that we can get somewhere close to understanding overall need. The first domain is “normative need” which is that defined by an “expert”. This “expert” may be in the form of a local GP, school teacher or evidence-based guidelines for the treatment of a particular group of people (e.g. risk factors for those with diabetes). The second domain is “felt need” which is determined by asking people what they feel they need (i.e. akin to “wants”). This domain assumes perfect and equal information across groups in society about what services are available, which is obviously contestable.

The third domain is “expressed need” which may also be conceptualised as “service utilisation”. This may be measured through activity statistics, prescribing data, surgical statistics, etc, although not all “felt need” gets turned into “expressed need” – there will be groups of people who experience unmet need. The fourth domain is “comparative need,” which is akin to horizontal equity. Comparative need is determined by studying the characteristics of differing populations in receipt of differing levels of a service (e.g. differing rates of cervical cancer screening). Using the example of cervical cancer screening, a comparative approach to need would assess the differences in screening rates between population A and population B, weighted to take account of the relevant risk factors in the patient populations. However, it needs to be remembered that this approach is purely comparative. Therefore, if population A is deemed to be in need in comparison to population B, this does not necessarily mean that population B is not in need – the screening rates for population B may not be at an adequate level. This approach merely attempts to assess comparative need (or equity), and makes no judgements about the appropriateness of screening rates.

In summary, understanding the equity of healthcare services requires us to also understand the related concepts of access, need and utilisation of those services. In order to fully understand the equity of cervical cancer screening in South Australia and respond to any areas of inequity, we need to be able to measure and monitor both need for those services and access (potential and realised) to the services.

Data on cervical cancer screening in South Australia – an inequitable pattern?
The National Cervical Screening Program (NCSP), a joint initiative of the Australian and State and Territory governments, aims to reduce mortality and deaths from cervical cancer, in a cost-effective manner through an organised approach to cervical screening. The NCSP has particular guidance:

- Routine screening with Pap smears should be carried out every two years for women who have no symptoms or history suggestive of cervical pathology.
- All women who have ever been sexually active should start having Pap smears between the ages of 18 and 20 years, or one or two years after first having sexual intercourse, whichever is later. In some cases, it may be appropriate to start screening before 18 years of age.
- Pap smears may cease at the age of 70 years for women who have had two normal Pap smears within the last five years. Women over 70 years who have never had a Pap smear, or who request a Pap smear, should be screened.

This policy applies to women with no symptoms and normal Pap smear results who should be screened every two years. It is estimated that approximately 90% of cases of cancer of the cervix could be prevented if all women in the target group were screened biennially.

Inherent in the national policy is the notion that need for screening is a normative need which is determined only by sex, age and the woman having ever been sexually active. If horizontal equity in cervical screening existed, the realised access of participation in the NCSP should be equivalent in sub-groups of women within the target population.

A component of the NCSP is that all Pap smear results are recorded on state/territory based cervical cytology registers. The registers serve a number of functions including being used to remind women and their health care providers when women are overdue for Pap smear tests. Less than 1% of women choose to opt out of having their personal details recorded on the SA register. It is therefore possible to calculate the biennial participation rate in the program from the number of women recorded as having a Pap smear taken within a two year period divided by the Australian Bureau of Statistics (ABS) Estimated female Resident Population for each five year age group. The SA biennial participation rate for women aged 20-69 years for 2003-2004 was 62.7%. Additionally, data collected by the SA Cancer Registry is available to provide information on equity of outcomes for population sub-groups of women.

Access to screening by women living in rural areas is an issue that SA Cervix Screening has monitored over time. Potential access barriers to screening such as limited availability of GPs and more specifically, limited availability of female GPs has been postulated to reduce potential access to Pap smear providers for rural women. In conjunction with local health care providers, the NCSP has incorporated a variety of mechanisms to improve potential access to screening by rural women including funding health promotion projects undertaken by rural Women’s Health Nurses, arranging for visiting female GPs to conduct clinics and, in 2005, two Medicare items (10998 and 10999) were introduced which facilitated Pap smears being taken by practice nurses on behalf of GPs in regional rural and remote areas.
Data from the SA cervical cytology register shows that the biennial participation rate amongst women residing in Metropolitan Health Regions is higher than the rate for rural women overall (see Figure 1). This discrepancy has lessened over recent years, essentially because the screening rate in metropolitan women has fallen over time. When rates of participation are examined in more detail, many rural areas have participation rates which are higher than the SA rate overall, thus it is evident that realised access is variable and not necessarily inequitable in many rural areas. Similarly, for rural women overall, SA Cancer Registry data for the period 1994-2003 does not support inequity of outcome for rural women with annualised rates of cervical cancer per 100,000 women of 10.5 for metro women and 9.3 for rural women for the period 1994-1998, and respective rates of 9.2 and 8.0 for the period 1999-2003.

Data recorded within the cervical cytology register is limited to information supplied to the testing laboratory on the pathology request form plus results of cytology and histopathology tests. Thus, no information on ethnicity is recorded and it is not possible to calculate the screening participation rates for either Aboriginal or Torres Strait Islander (ATSI) women nor for women from various culturally and linguistically diverse (CALD) communities.

Using SA Cancer Registry data, the cervical cancer incidence rate per 100,000 women for the period 1994-1998 was 12.3 for ATSI women and 8.8 for non-Aboriginal Australian born women. For 1999-2003 these rates were 13.9 and 7.5 respectively. Data on aboriginality/country of birth was missing for 24% of cases and the actual numbers of cases in each period are small, thus, it is necessary to exercise caution in interpretation of these rates. The increased rate for Aboriginal women in the latter period may be a result of Aboriginal women newly participating in the program. However, the fact that the rate in Aboriginal women is 40% higher than in non-Aboriginal women in 1994-1998 and 85% higher in 1999-2003 supports inequity of outcomes, thus, SA Cervix Screening has a Well Women’s Program which aims to increase participation in the screening Program by Aboriginal women. The Well Women’s Program focuses on provision of culturally appropriate health promotion activity and provision of culturally appropriate resources and services for Aboriginal women (refer to Sharon Clarke’s article, later in the Bulletin).

Data on women from CALD communities is limited as previously discussed. However, SA Cancer Registry data for the period 1977-2000 demonstrated that Australian-born women had an incidence about 9% lower than residents born overseas. The difference was particularly pronounced for women born in Germany and Eastern Europe with the incidence in German-born women in SA being approximately twice the rate of Australian-born women. The incidence of cervical cancer in overseas-born South Australians was, in general, much lower than for their parent populations. It is postulated that potential access to Pap smear testing is affected by cultural norms, with many new migrant women not coming from countries with strong preventive health and women’s health programs in place and with cultural beliefs about, for example, modesty and cancer affecting their willingness to participate in the cervical cancer screening program. The SA Cervix Screening Program funds a Senior Project Officer who works collaboratively and holistically with the BreastScreen SA and The Cancer Council SA CALD project officers to reduce barriers to potential and realised access.

There are also women in minority groups such as lesbian women and women with various disabilities who may face potential physical and psychological barriers to cervical cancer screening. Although, the realised access for women in these groups in terms of their participation in the Program is unknown, the NCSP has sought to incorporate measures to address perceived potential barriers into the Program.
These include specific printed resources for lesbian women and women with disabilities and the provision of height adjustable beds to clinics which provide Pap smear.

Figure 2 shows the biennial participation rate for 2003-2004 analysed by socio-economic status (using ABS Socio-Economic Index for Areas Index of Disadvantage quintiles). For all age groups, lower socio-economic status is correlated with lower participation rates. This data is consistent with SA data for previous years. For the period 1999-2003, SA Cancer Registry data indicates that the incidence of cervical cancer correspondingly increased as socio-economic status declined, ranging from an annualised rate of 6.3 cases per 100,000 women in the highest quintile to 11.9 in the lowest quintile. There are often complex barriers for women in low socio-economic areas that prevent them from having a Pap smear. These women are often confronted daily with immediate and urgent life issues including compounding effects of poverty, domestic violence, sole parenting, housing issues and mental and chronic illness. Women in low socio-economic areas may need more support to have regular Pap smears than women from more affluent areas. Research shows that women who don’t have Pap smears say they would be more willing to screen if their health practitioner told them it was important.

Summary
This paper sets the context for research and policy around the equity of healthcare within the broader theoretical framework of Social Systems Theory and the social and economic determinants of health. In other words, striving for a more equitable society means striving for equity within all social systems (e.g. legal, medical, economic, political, etc). The paper also outlines the differences between inequality and inequity and provides a framework for conceptualising, operationalising, measuring and monitoring the equity of healthcare. This paper provides data on both the equity of cervical cancer and participation in cervical cancer screening in South Australia. From the available data, the paper demonstrates higher rates of cervical cancer in ATSI women and in women from lower socio-economic groups, in addition to lower participation rates in cervical cancer screening for women from lower socio-economic groups. Due to data limitations, we were not able to undertake multivariate analyses and therefore these ecological associations require further research.

Notes
(1) Socio-Economic Indexes for Areas 2001 (SEIFA 2001) is a product in which the ABS has developed indexes to allow ranking of regions/areas, providing a method of determining the level of social and economic well-being in that region. The Index of Disadvantage is derived from attributes such as income, educational attainment, unemployment, and dwellings without motor vehicles. In particular it focuses on low income earners, relatively lower educational attainment and high unemployment. Index of disadvantage scores have been grouped into quintiles (highest, high, middle, low, lowest) for analysis. The highest quintile represents the highest 20% of postcode scores (20% of the population) and is the most advantaged areas. The lowest quintile represents the lowest scores and the most disadvantaged areas.

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