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Review Article

BURDEN OF GYNAECOLOGICAL DISEASE IN DEVELOPING COUNTRIES

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ABSTRACT

While maternal mortality represents a readily identifiable outcome measure for women's health, estimating the burden of gynecological disease is more problematic. However, the importance of including gynecology and care for non-pregnant women within the remit of Primary Health Care has been suggested more than a decade ago. Since then, various studies have used self report in population based morbidity surveys, purposive laboratory studies and "syndromic" approaches to estimate prevalence rates. Routine health facility data, although flawed, represent another complimentary source. For policy development, a critical overview is required to identify firstly the extent of a systematic list of gynecological conditions, and secondly the social burden of these diseases which clearly have an impact on the quality of the lives of women in developing countries. A prototype categorization of gynecological conditions relevant to the developing world is presented.

As examples, menorrhagia is identified as a common but usually non lethal problem with an impact on general health because of associated anemia. Cervical cancer is uncommon but lethal, and potentially amenable to mortality reduction through early case finding or screening interventions. Uterine fibroids and prolapse are of interest as conditions showing marked ethnic variation. We suggest an approach to the application of the above overview, highlighting the extent of the disease burden currently borne by women in the developing world, whose impact is potentially obscured by an exclusive consideration of mortality data. Lack of appropriate categorization and data collection represents a serious barrier to the implementation of policy and services directed towards reproductive health.

INTRODUCTION

16 years ago Rosenfield and Maine put the M back into MCH, giving women's health a new place; worthy of study in its own right (Rosenfield and Maine, 1985). Four years later Bang and colleagues brought gynecological morbidity to international attention by the publication of extremely high prevalence rates in rural India and a call to give more attention to the health of non-pregnant women by including gynecology in Primary Health Care (Bang *et al.,* 1989). This study inspired several subsequent investigations in other developing country settings, all pointing to the low level of met need for health services and the "culture of silence" which prevents women from seeking health care for gynecological problems (Bulut *et al.,* 1995; Younis *et al.,* 1993). However, most of the conditions that can be categorized as "gynecological disease" remain unquantified in the WHO Global Burden of Disease (GBD) calculations for reproductive health (Murray and Lopez, 1998). Moreover, and perhaps more importantly, apart from some notable qualitative studies (Bang and Bang 1994; Oomman, 2000) there are still very few evaluations of the social burden associated with gynecological disease. This aspect of women‟s health and the importance of social contexts and correlates did not go unnoticed by analysts during the last decade with the prevailing emphasis on women's powerlessness and the links with reproductive health (Cairo Plan of Action, 1994). However, health services and health personnel training in developing countries remain poorly attuned to these problems, and maternal mortality remains as the sole indicator of women's reproductive health to be found among the international development targets.

Part of the problem is that list of conditions considered under the heading of gynecological disease is extremely variable. Associated or underlying morbidities are similarly not systematized. Furthermore, an emphasis on studies designed to estimate prevalence has obscured the need also to study determinants and consequences for women - both social and physical. Apart from suffering from a lack of consistent definitions, prevalence estimations have also been undermined by a the variability between testing techniques, inconsistency of physician diagnoses and the poor performance of self report as a tool to predict biomedically defined disease given a disease profile which is often asymptomatic. However, the body of knowledge on instruments for self-reported morbidity is now broad enough for comparative studies to yield useful approaches (Koenig *et al.*, 1998) and the improvement in affordable laboratory diagnostics holds promise for more systematic and influential information to be produced in the near future.

After an initial justification for the pursuit of quantitative as well as qualitative measures of gynecological disease, this paper has three aims:

1. We offer a critique of the DALY approach in relation to gynecological morbidity, criticizing both the methodology as applied to morbidities with a strong social component, and also the omission of some key gynecological conditions from any of the previously calculated disease groups.
2. A summary of findings is presented on physician diagnosis, and self report, syndromic approaches and an update on affordable lab testing appropriate in community studies and also for clinical settings in resource poor areas.
3. As no study ever has the same definition of gynecological disease, we aim to enumerate an exhaustive list based on the International Classification of Diseases. Although this is a predominantly biomedically determined initial approach, we argue that building a consistent list can only begin here - then extensively tested "quality of life" indicators should be used to understand these conditions in relation to the associated physical and mental distress as suffered by women. We therefore advocate a biomedical list built on by a quantitative as well as qualitative assessment of women's loss of quality of life.

"Gynecological disease" covers a range of conditions with a wide spectrum of lethality and chronicity and a substantial impact on women‟s quality of life. Racial and geographic variations in disease and social conditions mean that biomedical as well as social science perspectives should come together in providing consistent information for policymakers on this important aspect of women‟s health.

1. Policy Background: Why seek to provide quantitative measures of gynecological disease?

Various studies have sought to quantify the burden of gynecological disease in order to influence policy. Those in India (Bang and Bang, 1994; Bhatia *et al.*, 1997) and the Arab world (Younis *et al.*, 1993, Zurayk *et al.*, 1993) led the field in regions where the "culture of silence" among women was likely to imply high unmet need for services. Despite the array of methodological problems encountered in such studies (Bulut *et al.*, 1995), the evidence is now compelling to suggest high prevalence rates of gynecological disease in developing countries and associated serious impairment in women's quality of life. The second phase of studies should seek to build on the initial research to set gynecological disease in international perspective. Geographical, cultural and also racial characteristics in different parts of the developing world could imply the need for the provision of a range of different and culturally sensitive health services.

Most quantitative assessments of women's health status are still based on maternal health measures.

Indicators such as the Maternal Mortality Ratio (MMR), the proportion of births attended by a skilled attendant, and the percent of women who attend an antenatal check up are now established in the list of International Development Targets (IDTs).

The emphasis on maternity is very appropriate where fertility levels are high and maternal health services are in great need of improvement, which is the case in most developing countries. Indeed the quality of maternal health and family planning services can have a significant impact on gynecological health as well as maternal and child outcomes, through the minimization of iatrogenic transmission of infections (Elias 1996; Wasserheit and Holmes, 1992).

However, the reliance on the MMR as the main indicator of women's health and status within health systems has problems over and above those of measurement, data collection and definition which are commonly cited (Hulton *et al.*, 2000). The focus on mortality ignores the prevalence of many treatable conditions that cause disability and significant distress in women's lives. But also the neglect of non pregnant women, whether in adolescence, between pregnancies, or after menopause, means that women‟s health is conceptualized narrowly in terms of maternity and family planning. The former of these problems is tackled to some extent by the development of "near miss" indicators of severe obstetric morbidity occurring to living women (Stones *et al.*, 1991; Hulton *et al.*, 2000; Fillippi *et al.*, 1998), but these measures still neglect gynecological illness. Thus the lack of appropriate categorization of women's health problems, specifically those relating to gynecological conditions has lead to a policy vacuum in this aspect of reproductive health. There is a commensurate deficit in advocacy and training materials as well as curricula for gynecology. This may be in part because, in contrast to many reproductive health activities, the main focus of gynecological services is curative rather than preventive.

More recently, with the rise of HIV/AIDS, and the establishment of gynecological infection (sometimes asymptomatic) as an important risk factor for HIV in women, there is an added impetus for the more careful investigation of gynecological conditions in women. Moreover, it is clear that the calculation of prevalence rates or the "burden" of these diseases is only the starting point for an understanding of their importance. Determinants and consequences must also be investigated, with due attention to the construction of conceptual frameworks which seek to elucidate linkages between causes and effects of individual gynecological outcomes. The burden of health care falls upon health services worldwide, but currently, the burden of stigma and adverse the social burden is borne, for the main part silently by women. The challenge is for service providers to create more socially attuned facilities, for medical educationalists to underline the importance of gynecology in reproductive health, for policymakers to recognize the significance of gynecology in international perspective, and for researchers to find ways to understand and monitor unreported gynecological ill-health in community and facility studies. To set out the remit of gynecological health and make the list of relevant conditions can form a foundation from which quantification can emerge. The WHO global programme to quantify the burden of reproductive disease has a possible approach to estimating the extent of this problem.

2. Global burden of gynecological disease

Given the desirability of moving away from mortality-based indicators as measures of women's health status, the estimation of disease burden via Disability Adjusted Life Years (DALYs) (Murray *et al.*, 1996) offers a promising alternative. The rationale behind this approach, first developed by the World Health Organization (WHO) for their 1993 World Health Report (WHO, 1993), emphasizes priority setting by selecting health interventions that give the best value for money. It has been suggested that calculating DALYS can help to set priorities within the domain of reproductive health and in relation to other health problems (Vos, 2000).

The DALY is a single, comparable measure of health outcome designed to quantify both premature mortality and disability from groups of diseases at all ages. More specifically it is a discounted and age-weighted composite indicator of the future stream of life lost due to premature deaths added to the future stream of healthy life foregone due to disabilities caused by disease. Having calculated DALYs lost from a disease or group of diseases, cost effectiveness is then measured in terms of cost of interventions "per DALY saved". The calculation of life years lost due to mortality from disease is reasonably straightforward to calculate, through the use of cause- specific mortality rates and subsequent comparison with "ideal" life table rates such as would be found in modern day Japan. The calculation of the magnitude of disabilities is, however, more problematic. DALYs lost through life lived with a disability are calculated by experts who estimate the incidence of disease, the age of onset, and the duration of disability for each specific disease based on community based data, health facility data or expert judgment. Disability weights are also applied. These are based on subjective opinion of disease experts using person trade off methods which determine the proportion of a year of healthy life deemed “lost” in the presence of disabling disease.

Many criticisms of the DALY approach have been made with respect to the in-built discounting and age weighting assumptions (Williams, 1999; Barendregt *et al.*, 1996; Anand and Hanson, 1997). The use of an idealized life table pattern is also questionable. But these factors are insignificant compared with the debatable nature of the disability weights and the quality of epidemiological estimates of incidence and duration. Particularly in the case of gynecological disease, the application of disability weights is not appropriate. Most gynecological conditions disable women socially, which can be far more crippling, and medical expert opinion will not be able to gauge the extent of such effects. Measurement of distress, or social or mental stress, would be required as well as the estimation of the extent of disability. It is difficult to see how selective decisions about health care spending could be based on such an indicator. It does not capture women’s distress from their own perspective.

Moreover, the DALY calculations that have been carried out in association with reproductive health have excluded key components of gynecology. There are several definitions of reproductive health that DALY analysts have been able to use (Murray and Lopez, 1998), the main four being expressed as follows:

- Consequences of sex in adults.
- Consequences of sex in children and adults.
- Conditions of the reproductive system.
- Conditions managed through reproductive health services.

Important conditions such as fistula, prolapse and menorrhagia are not to be found in any of these lists, which concentrate more on maternal conditions and HIV. It may be a first step towards recognizing the importance of gynecological disease to calculate the DALY burden, but initially there is a need to enumerate all of the possible conditions before data can be brought together. The omission of social distress also implies that measurement tools should also be developed specifically for this element. In addition, there is a need to draw up give a critical overview of the likely mortality, disability and distress of each listed condition worldwide.

In summary, although DALY estimates go some way to recognizing morbidity as well as mortality, they have not, to date, included gynecological disease systematically, and the approach does not provide a sufficient tool by which to capture the nature and extent of gynecological disease. Nor can the estimations help to understand causes and consequences, nor is it easy to set international goals and targets incorporating DALY estimates.

3. Determination of disease status

Classification of disease depends on accurate diagnosis, which is subject to the limitations of particular medical settings and is variably feasible in different circumstances. There are essentially three types of diagnostic method:

1. Obtaining a self report of symptoms. The best example would be a painful condition of the reproductive tract in the absence of an identifiable pathological process, such as primary dysmenorrhoea. Assessment of pain depends entirely on self report and attempts to validate self reported pain by some form of test would be fruitless. Self report pain measures are widely used and have good psychometric reliability in different cultures and settings.
2. History, examination and limited investigations through contact with a health worker.

Many conditions can be diagnosed with reasonable sensitivity and specificity using learned algorithms relating to clinical presentations. This model forms the basis for the bulk of medical practice in both primary and secondary care settings and its learning is increasingly systematized in medical education using curriculum models based on the finite numbers of ways in which disease can manifest (Woloschuk *et al.*, 2000). Similar models have been applied to mid level service provider training. An example might be the diagnosis of incomplete miscarriage based on the history of pain and vaginal bleeding, confirmed by vaginal examination. The most variable aspect of this model is the extent to which investigations are available: in limited resource settings either no tests might be performed or would be limited to haemoglobin estimation, whereas in highly resourced settings ultra sonography might be advised and the patient‟s blood group would be determined to assess her need for anti-D immunoglobulin if rhesus negative. In this example the additional information obtained from ultra sonograhy would be confirmatory rather than essential to the diagnostic process.

3. Definitive laboratory studies or imaging. While some lab studies with high sensitivity and specificity can be undertaken in limited resource primary care settings such as a gram stain of a cervical mucus sample for gonorrhea , diagnosis of some gynecological conditions requires laboratory or imaging facilities which are of limited availability in the developing world, but essential for effective provision of services. An example is carcinoma of the cervix: while women may present to health workers with suggestive symptoms such as post coital bleeding, or be identified in case finding programmes on the basis of inspection of the cervix during an internal examination, histological confirmation of the diagnosis is required, as many suspected cancers will not be confirmed as such. A programme requiring cytological screening of Pap smears for the detection of the pre- malignant phase of the disease is entirely dependent on the availability and quality of laboratory staff, notwithstanding the complex service organizational issues relating to screening in developed as well as developing countries. The concept of “syndromic” diagnosis has been used to apply the principles of clinical presentation and prior probability to the presumptive diagnosis of reproductive tract infection. This has been shown to be an appropriate and useful approach for some conditions but not others: in a study in Cote d’Ivoire (La Ruche *et al.*, 2000) reports of female genital ulcer were very consistent between 30 clinics offering syndromic diagnosis, but diagnosis of vaginal discharge in the same clinics was highly variable indicating a lack of sensitivity and specificity.

In a setting of low STI prevalence the syndromic approach was found to have a low specificity even when incorporating a vaginal speculum examination and extension of this strategy to the health service would have resulted in large scale over-treatment (Hawkes *et al.*, 1999). Rapid and cheap immunodiagnostic tests for reproductive tract infections may become available, as major research effort is currently being invested in this area. However, there are considerable technical problems to be overcome.

The current policy implications for service delivery in relation to women were summarized as:

1. Maintain syndromic management approach and treat for vaginitis and genital ulcers
2. Do nothing for women with vaginal discharge
3. Promote trials of rapid cheap tests
4. Screen pregnant women for syphilis (Askew and Maggwa, 2001)

After 10 years of community surveys on gynecological disease in developing countries, self report techniques have improved. A recent overview (Koenig *et al.*, 1998) assessing the results of seven recent surveys has highlighted the key issues in applying self-report strategies to gynecological problems. Close interaction with the community is important when conducting studies to avoid misunderstandings and omission of important population groups. As well as questionnaires, in depth qualitative studies are required in order to ensure that local terminology for illness and disease is correctly understood. Under-reporting of illness is a consistent problem in developing country settings, especially in the more disadvantaged groups who paradoxically report less morbidity than better off Sections of society. This has been cited as a reason for not utilizing self report quality of life data at all in studies of disease burden (Murray *et al.*, 1996). However, as indicated above to ignore self - report data would be to overlook a considerable burden of illness. In well-designed field studies, probing and consideration of severity can improve validity of self-report measures which would go some way to overcome the problem. A further challenge for investigators is the avoidance of sample loss arising from unwillingness to participate in studies. This applies especially in relation to gynecologic conditions where open discussion of intimate matters may not be culturally or personally acceptable. It may be necessary to limit the areas and depth of questioning in response to what is acceptable to women in the setting, which again requires careful qualitative study at the design stage. Finally, as indicated above there are very significant variations in clinical definitions in relation to gynecological disease depending on both the available diagnostic modalities and on expert consensus that will influence the interpretation of data obtained both by self-report and from healthcare facilities.

1. Using international classifications of disease as a basis for a revised approach

Of the recent studies in gynecological conditions, there is little consensus on which conditions to include. Jejeebhoy and Koenig (forthcoming) categorize conditions into four types as follows:

- Sexually transmitted infections (Chlamydial infection, gonorrhoea, trichomoniasis, syphilis, chancroid, genital herpes, genital warts and HIV)
- Endogenous infections (bacterial vaginosis, candidiasis)
- Iatrogenic infections e.g. poor delivery or abortion practices
- “Other factors” e.g. prolapse, menstrual disturbances, fistulae and dyspareunia and urinary tract disorders.

While especially useful in conceptualizing the distinction between sexually transmitted, endogeneous and iatrogenic infections, this classification has a massive proportion of conditions listed together as “other”. An exhaustive listing based on the International Classification of Diseases (World Health Organization, 1992) has the advantage of not omitting significant conditions through grouping. Although this is a predominantly biomedically determined initial approach, we argue that building a consistent list can only begin here - then extensively tested quality of life indicators should be used to understand these conditions in relation to the associated physical and mental distress as suffered by women. We advocate a biomedical list, built on by quantitative as well as qualitative assessment of women loss of quality of life. ICD-10 represents a practically useful starting point for this endeavor, and the initial task is to identify the classification items that should be included ICD-10 categories making up “gynecological disease”.

Conditions identified in ICD-10 are listed in Table 2. Inflammatory conditions are classified in terms of the affected organs in the first table below (a), and may or may not cross reference to specific infective causes listed in the second table (b). ICD-10 cross refers to specific pathologies with the symbol *, and a cross reference from pathological states to syndromes are identified with the symbol j. The major advantage of this approach is that it allows for the realities of diagnosis in different settings: data from community surveys or primary health facilities can be classified in terms of clinical presentation without pathological confirmation. Where laboratory data exist these can be tabulated, for example to derive sentinel estimates of disease prevalence. Even with optimal laboratory resources in Western countries a large proportion of clinical presentations do not result in a definitive pathological diagnosis, which reflects the inherent mismatch between illness as experienced by the patient and disease as reflected by a demonstrable pathological process. A classification system based exclusively on pathological diagnosis would seriously underestimate the disease (or illness) burden both in developing country settings where laboratory and imaging facilities are limited but also in Western countries. Conversely, in the course of investigation pathology is sometimes identified as a coincidental feature without any relevance to the patient‟s illness. Examples in gynecologic practice include asymptomatic uterine fibroids and intraperitoneal adhesions. Adhesions are often suspected to be a cause of pain but are actually present equally in women presenting with sub fertility in the absence of pain (Rapkin, 1986). Uterovaginal prolapse may be identified at the time of gynecological examination and as a result has been highlighted in a study incorporating vaginal examination (Younis *et al.*, 1993). In this instance the resulting prevalence estimate was probably too high as many participants in the study would have been asymptomatic and treatment would not have been appropriate.

It may be important to identify potentially hazardous organisms or pathologies in the population even in the absence of overt illness: for example, in some populations chlamydia is detectable in women in the absence of symptoms, but its potential to cause pelvic inflammatory disease means that a high prevalence in asymptomatic patients would have implications for service delivery, specifically that appropriate antibiotic prophylaxis should be used during invasive procedures such as termination of pregnancy.

ICD-10 and GBD have used the broad primary groupings of “inflammatory disorders” and “noninflammatory disorders” which has some face validity in distinguishing between the developed and developing world and reflects notions of health transition. However, this distinction is of limited overall utility in the context of gynecological disease, especially given the important contribution of early pregnancy complications to disease burden and the inherent problems of relating symptoms to disease. For example, in a patient presenting with lower abdominal pain the detection of chlamydia would lead to classification under “Inflammatory disorders” A 56, whereas in the absence of laboratory facilities the patient might be classified on clinical grounds as either N74 “Female PID” or R10.2 “Pelvic pain”, the latter category being listed among the “Non-inflammatory conditions”. Both clinical categories are useful and might reflect the degree to which the patient manifested signs of infection or the chronicity of her pain, but neither is specific for chlamydial infection. Thus, the value of the ICD-10 categories lies in their inclusiveness and flexibility but it would not be useful to concatenate gynecological diseases in terms of the inflammatory/ non inflammatory division.

A grouping of “other important categories” taken from ICD-10 is included below. It could be argued that rape is not a specifically gynecologic problem: however, women who have experienced sexual assault will be subject to immediate problems of genital tract trauma, potential infection, risk of pregnancy and later potential problems of psychological harm, impact on sexual relationships, and social ostracism. Reproductive health services have a responsibility to address those aspects that can be addressed through service provision, and where sexual assault is a common occurrence the burden in the population needs to be identified because of its special significance for human rights and the collective self-respect of communities and nations as well as for the suffering of individuals.

Faecal incontinence arises from poorly conducted deliveries with inadequate repair of lacerations. Although not life threatening, it is associated with extreme loss of quality of life. Its identification could lead to improved service provision, such as training of midwives and doctors in primary repair of anal sphincter injury sustained during childbirth, as well as tertiary level services for long standing anal sphincter injuries following the service model that has been used for fistula surgery. Urinary incontinence is common during and after childbirth: in a careful prospective questionnaire study of women during and after their first birth the prevalence of urinary incontinence rose from 3.6% before to 43.7% during pregnancy, with 14.6% symptomatic three months postpartum. There was no clear relationship to obstetric variables such as length of labour or mode of delivery (Chaliha *et al.*, 1999). There are important racial differences in susceptibility to urinary stress incontinence (and also uterovaginal prolapse) that need to be considered in estimating disease burden.

The inclusion of “contraceptive management” and gynecological examination for other purposes reflects the reality that many contacts with reproductive health services are in the context of prevention rather than in response to illness: it will be important to identify women consulting in this mode in order to cross reference illness and disease identified incidentally during such contacts, for example screening for anemia or STIs. It is very likely that the prevalence of specific conditions will be different in those seeking services compared to those who do not, and in the context of the reproductive health agenda (as opposed to an exclusive focus on birth control) health workers need to be alert to the fact that many women will find it easier to discuss health problems while accessing contraceptive services. While information on health contacts for screening or contraceptive purposes cannot be considered to contribute to disease burden, their inclusion within records of health service activity is essential. It should be noted that screening interventions are not without morbidity: in particular, the stress and anxiety associated with cervical screening is well documented in Western countries (Wilkinson *et al.,* 1990), and the likely over-diagnosis of sexually transmitted infection using syndromic approaches has the potential for serious adverse consequences in the community (Hawkes *et al.,* 1999) .

We believe that iron deficiency anemia (D50) should be included in a listing of gynecological conditions. Its primary or secondary importance will vary depending on the prevalence of hookworm infestation and nutritional iron deficiency. Among well-nourished women in the reproductive years excessive menstrual loss represents the major primary cause of iron deficiency anemia; in association with hookworm related blood loss or nutritional iron deficiency co-existing menorrhagia would exacerbate the problem. Anemia arising from or exacerbated by heavy menstrual loss is potentially influenced by local contraceptive prevalence and method choice, beneficially through use of the combined oral contraceptive pill, or adversely by the use of an IUD.

Available "burden of disease" estimates for gynecological conditions:

Table 3 indicates those conditions for which some identifiable Burden of Disease data are available. It will be noted that the bulk of the conditions listed earlier are not identifiable within GBD.

6. Experience of gynecological illness and disease: quality of life

The developers of the Global Burden of Disease methodology specifically rejected incorporation of self report or quality of life questionnaire material (Murray *et al.,* 1996) on the basis that such material is subjective and correlates poorly with disease as recognized in terms of pathological processes. Furthermore, self reports are highly sensitive to socio cultural factors such that the poor or less educated tend to report less morbidity. The discussion above have highlighted the limitations of the "pathology only" approach to estimating disease burden, such limitations being especially relevant where the mismatch between pathological states and clinical illness is extensive, as is the case with many gynecological conditions. The failure of syndromic algorithms to capture the appropriate patients or diseases has been reviewed above, and this failure has prompted renewed interest in the potential incorporation of quality of life measures into assessment of gynecological morbidity (Bhatia and Cleland, 2000).

Quality of life instruments have been developed for a number of purposes, which may be summarized as:

1. Enabling comparisons to be made of the impact of different diseases to inform health economic cost utility analyses;
2. Use in clinical trials to assess quality of life outcomes of treatment interventions;
3. Identifying disease impact where functional impairment predominates over pathological features in the natural history of the disease.

A further distinction is between disease specific and generic instruments; a generic instrument would of course be required to achieve the first of the above purposes, whereas the second and third applications would typically require a combination of generic and disease specific tools. A widely used generic instrument geared to health economic applications is EuroQol (EuroQol Group, 1990) which evolved as an application of the quality-adjusted life year (Rosser and Kind, 1978) based on a two dimensional grid of disability and distress. An advantage of the EuroQol is that a single numeric assessment of health status is derived; clearly this advantage is at the price of detail and meaning. The Short Form-36 (SF-36) (Ware and Snow, 1993) is probably the most widely applied generic quality of life instrument, with an extensive literature covering numerous diseases and validated versions for a number of countries and languages, unfortunately none of them in the developing world. The 36 items of the questionnaire load to eight domains relating physical and mental functioning, for which a score on a 0-100 scale is obtained. Normative data in relation to age, gender, social class and disease states are available as are numerous reports of applications to specific conditions. A methodology has been described for distillation of the eight subscales into two summary dimensions, a mental and a physical component score, in both the North American (Ware and Kosinski, 1994) and UK (Jenkinson *et* *al.*, 1996) versions. In respect of gynecological conditions, examples of the validation and use of SF-36 include menorrhagia (Jenkinson *et al.*, 1996) and chronic pelvic pain (Stones *et al.*, 2000), (Zondervan *et al.*, 2001). A special consideration for assessing the quality of life impact of gynecological conditions is the inclusion of items addressing sexual function. These may be problematic in many countries and settings; an example of a relatively non intrusive and acceptable instrument developed in the UK is the Sexual Activity Questionnaire (Thirlaway *et al.*, 1996).

The product of a multicountry effort to design a generic quality of life instrument is the WHOQOL (Power *et al.*, 1998) which at the pilot stage incorporated 236 questions plus 41 further items rating the importance of each facet. An important feature of this development process for the present discussion has been the inclusion of investigators in India and Zimbabwe, although the majority of contributions were from developed countries. Further evolution of this instrument is anticipated; the number of items has recently been reduced to 100 (Power *et al.*, 1999).

The use of quality of life data remains problematic because of the range of different instruments used in the published studies, and the very limited number of such studies that have been undertaken in developing countries. A combination of approaches will be required, such as the development of new "cross cultural" instruments such as the WHOQOL, but also the validation of existing measures such as SF-36 in as many settings as possible so that existing data relating quality of life to disease states can be utilized. Finally, exploration of "reproductive health related quality of life" as a construct valid for women's lives and experience, rather than a policy aim, could lead to the formulation of an instrument able to capture this dimension.

7. The burden of gynecological illness and disease: future strategies

We have indicated the challenges inherent in conceptualizing the burden of gynecological disease and assembling the available data to result in meaningful estimates. The first and vital step has been to identify the relevant conditions using diagnostic criteria sufficiently flexible to accommodate syndromic, clinical and pathological diagnostic methods, and to cross reference data from different sources. Classification systems need to be able to accommodate the link between, for example, menorrhagia and the apparently non-gynecological result, i.e. anemia. Secondly, measurement tools are required so as to derive estimates of incidence, prevalence, mortality and duration. New approaches will be required to incorporate meaningful dimensions of quality of life: at present GBD methodology uses a single weighting value for years lived with disease (YLD) which does not have face validity. In contrast to quality of life measures, the sensitivity of current GBD estimates to interventions is unknown.

Our proposed approach is to use the ICD-10 classification as clinical and administrative basis for tabulation, to use health facilities for data collection according to such tabulations so as to derive incidence and prevalence estimates, and to allow for regional and ethnic variations in gynecological conditions. Descriptive expert opinions are required for estimates of duration of morbidity, the affected age profile and the sociological aspects of quality of life impact. An appropriate range of conditions can be investigated using community surveys, with due regard for cultural sensitivity, and community based methods would also indicate the health seeking behavior associated with different conditions. Table 4 indicates examples of the type of overview that could result from the application of this strategy.

CONCLUSION

This paper has presented an approach to the current challenge of adequately conceptualizing gynecological disease to the stage where meaningful data can be assembled from institutional and community survey sources, taking into account the major quality of life impact of many gynecological conditions even when not life threatening. We believe this approach would go some way to counteracting the omission of a significant group of illnesses and diseases from epidemiological scrutiny and policy formulation. The extent of the disease burden currently borne by women in the developing world is otherwise obscured by an exclusive consideration of mortality data and concatenation of important morbidities to broad groupings. This represents a barrier to the implementation of policy and services directed towards reproductive health.

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