

Chapter 5

Menopause

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Between 1980 and 1998, global average life expectancy increased from 61 to 67 years. The increase, however, was not evenly distributed. For example, high rates of human immunodeficiency virus (HIV) infection in sub-Saharan Africa caused life expectancy to fall to 47 years on average; life expectancy has fallen in 34 countries since 1990 (UNDP, 2003).

In high-income countries, women outlive men by 5–8 years. However, in low-income countries, the differential is reduced to 0–3 years (World Bank, 2006), and in three countries – Nepal, Pakistan and Zimbabwe – women's life expectancy is lower than men's (UNDP, 2003).

In six African countries, women's life expectancy is less than 40 years. These are Malawi (39.1 years), Rwanda (38.7 years), Sierra Leone (35.8 years), Swaziland (39.9 years), Zambia (33.4 years) and Zimbabwe (35.4 years). In high-income developed countries, women's average life expectancy is more than 80 years. These countries include Australia (81.9 years), France (82.6 years), Japan (84.7 years), Spain (82.6 years), Sweden (82.4 years) and Switzerland (82.2 years).

As life expectancy increases, more women are living to the age of menopause and beyond. Even in countries with low average life expectancy, such as those in sub-Saharan Africa, the majority of women not infected by HIV live to menopause and beyond. The marked differences in life expectancy underline the fact that the priority of menopause and its mental health dimensions, as a reproductive health problem, will vary considerably between countries.

Mental health and the perimenopausal period

Menopause is defined retrospectively as the end of menstruation. During the perimenopausal period, women gradually stop menstruating and become unable to conceive and bear children without assisted reproductive technology. In high-income countries, the average age at menopause is around 50 years for nonsmokers. Women who smoke tend to reach menopause approximately 18 months earlier. A low socioeconomic position over the lifetime is also associated with an earlier age at menopause (McKinlay, Brambilla & Posner, 1992; Luoto, Kaprio & Uutela, 1994; Shinberg, 1998; Wise et al., 2002). In low-income countries, an overall earlier age at menopause has been reported. Menopause is earliest among women who have suffered from malnutrition (Khaw, 1992; Leidy, 1994).

Menopause is characterized by simultaneous physical, hormonal, and psychosocial changes. Physically, health status may decline and chronic diseases associated with ageing may appear for the first time. Hormonally, the perimenopausal transition is characterized by declining ovarian follicular activity and hormonal fluctuations that result in vasomotor instability. Symptoms include hot flushes, vaginal dryness and sleep problems.

Dominant views on fertility, ageing and female roles help shape women's expectations of and attitudes towards menopause, and influence the social status accorded to women in midlife. These views inform women's expectations and subjective experiences, and the meanings they attach to menopause (Lock, 1994; McMaster, Pitts &

Poyah, 1997; Boulet et al., 1994). Cultural conceptions of menopause can vary, from its being perceived as a normal and unproblematic part of human development and the female life course to its being seen as a hormone-deficiency disease that gives rise to severe, disabling physical and psychological symptoms requiring medical treatment and surveillance.

A comprehensive review of cross-cultural and comparative research concluded that the majority of women do not find menopause a difficult experience (Lock, 2002). Similar findings on women's attitudes towards natural menopause have been reported in the USA (Avis & McKinlay, 1995). In the longitudinal Massachusetts Women's Health study, the majority of participants did not seek medical help for menopause, and held primarily positive or neutral attitudes towards it (Avis & McKinlay, 1995). Again, few women in the Seattle Midlife Women's Health Survey (Woods & Mitchell, 1997) defined menopause as a time when increased symptoms, disease risk or medical care should be expected. Most women viewed menopause as a normal developmental process.

The prevalence of menopausal symptoms varies considerably, even within countries. For example, Bosworth et al. (2001), in a study of perimenopausal American women (aged 45–54 years) in North Carolina, found high rates of hot flushes (65%), night sweats (56%), difficulty sleeping (45%), mood swings (49%) and memory problems (44%). Conversely, Woods & Mitchell (1997) reported much lower rates of symptoms for women participating in the Seattle Midlife Women's Health Study. In this study only 17% reported hot flushes and night sweats. In contrast, a longitudinal study of Australian women reported an increase in vasomotor symptoms, such as hot flushes, night sweats, breast tenderness and vaginal dryness over the perimenopausal transition (Dennerstein et al., 2000).

Cross-cultural studies have found significant variations between women in different countries in the level and type of menopausal symptoms experienced and the degree of physical and psychological distress associated with them (Punyahotra & Dennerstein, 1997; Fu, Anderson & Courtney, 2003). Women in Japan (Lock, 1994) and other Asian countries, including China (Hong Kong SAR, and Province of Taiwan), Indonesia, Republic of Korea, Malaysia,

the Philippines, and Singapore, tend to report fewer menopausal symptoms than those in the United States (Boulet et al., 1994). Lock (2002) cautions against dismissing reports of fewer symptoms in these societies simply as learned cultural expectations.

Psychosocially, the perimenopausal transition takes place in a context that may be marked by significant life changes and upheavals. Family composition may change through death or divorce, children may leave or return home, and parents may become more dependent. In addition, work status and level of participation in paid work may decline.

While there is a large literature on hormonal treatments for menopause and the effect of such treatments on breast cancer, heart disease, osteoporosis, dementia and depression, this research is not the focus of the current review. First, results from the Women's Health Initiative, the world's largest randomized controlled trial involving more than 16 000 women in the USA, indicated that the combination of estrogen and progestogen, given for treatment of menopause, was associated with significant health risks. This study, begun in 1997, was initially intended to be completed in 2005, but was terminated three years early, because analysis revealed significantly increased health risks. These included increased risks of breast cancer (Chlebowski et al., 2003), heart disease (Pradhan et al., 2002), stroke (Wassertheil-Smoller et al., 2003) and poor cognitive functioning (Rapp et al., 2003). Second, menopause research has been criticized for being carried out primarily in middle- and high-income countries on samples of middle class white women (Standing & Glazer, 1992). Treating menopause in low-income countries carries a high cost and has low public health relevance. Where there are high rates of HIV infection, high maternal mortality rates and low life expectancy for women, other reproductive and mental health issues are of more concern, and require more urgent attention, than treatments for menopause.

This chapter focuses on the relationship between menopause and psychological distress in midlife. It will consider the factors that have been identified as playing a significant role in women's emotional health and well-being at this time, especially those associated with increased rates of depression. The relative contributions of

physical, hormonal and psychosocial changes to depression have received considerable attention from researchers, and evidence on the relationships will be reviewed. Most research has been carried out in high-income countries and the validity of these findings for women in resource-poor settings is largely unknown. Caution in extrapolating findings from high-income countries is especially warranted with regard to studies from the USA, where rates of gynaecological surgery (hysterectomy) and hormone replacement therapy are high, and hence natural menopause is by no means a universal experience.

Menopause: a time of increased risk for poor mental health?

Evidence from national surveys permits comparison of population-based rates of depression over the lifespan. Throughout their reproductive years, women experience significantly higher rates of depression than men, with female:male ratios approximately 2:1 (Astbury & Cabral de Mello, 2000). This difference first emerges in puberty (Wade, Cairney & Pevalin, 2002; Kessler, 2003) and declines from midlife onwards, although evidence on the age when the sex difference ceases to be important varies from one study and one country to another. For Australian women aged between 45 and 54 years, the rate of depression was 7%, considerably lower than that for women aged 18–24 years (11%) (Andrews et al., 1999). Two national surveys in the USA have indicated a U-shaped relationship between age and depression, with the lowest rates occurring in the age group 45–49 years (Kessler et al., 1992). The United Kingdom National Survey of Psychiatric Morbidity found that the sex difference in the prevalence of depression disappeared after the age of 55 years (Bebbington et al., 2003).

Despite the fact that the gender difference in depression is most marked during the reproductive years, experiences related to changes in sex hormones, such as pregnancy, the use of oral contraceptives, hormone replacement therapy and menopause, do not appear to account for this difference (Stephens & Ross, 2002; Kessler, 2003). Large-scale epidemiological surveys of mental health have found no substantial increase in rates of depression among women in midlife. Yet researchers remain interested in identifying the factors that distinguish between women who do

and do not experience depression at this time. These include the role of hormonal changes, menopausal status and menopausal symptoms, such as hot flushes and disturbed sleep, psychosocial, socioeconomic and physical health factors, and a history of depression (Bosworth et al., 2001).

In order to investigate whether menopause has a direct or an indirect effect on depression, it is necessary to clarify through prospective, longitudinal research whether depression is a cause or consequence of high levels of symptoms, including hot flushes, insomnia and vaginal dryness. Over the past decade or so, an increasing number of such studies have been carried out in high-income countries, including Australia, Canada, the United Kingdom, and the United States (Woods & Mitchell, 1997; Avis et al., 2001; Glazer et al., 2002; Kaufert, Gilbert & Tate, 1992; Kuh, Wadsworth & Hardy, 1997; Dennerstein, Lehert & Guthrie, 2002).

Most longitudinal studies have used multidimensional models to investigate why some, but not all, women experience depression during the menopausal transition. These have been designed to assess the contributions of sociocultural factors, attitudes towards and expectations of menopause, health status and health behaviours, and history of depression, as well as the impact of age, menopausal status, and symptoms.

A stress model of depression is congruent with a multidimensional approach to understanding the pathways to depression in midlife (Woods & Mitchell, 1997). Stress, as a highly important mediating factor linked to depression, may arise from a number of different sources: from the menopausal transition itself, because of changes in menstrual patterns and the appearance and persistence of vasomotor symptoms; from the woman's life context, which can have a direct impact on mood but is also influenced by negative socialization experiences and attitudes to menopause and poor health; and from acute or

Do women with negative expectations of menopause have more frequent symptoms and rate these symptoms more negatively than women who hold positive expectations and in turn do such women have more negative experiences of menopause and higher rates of depression?

Three main hypotheses have been proposed regarding the relationship between menopause and depression for women in midlife:

Hypothesis 1. Direct effect

There is a close relationship between hormones and mood, and menopausal change in hormonal status will have direct effects on depression. The specific questions arising from this view include whether lower estrogen levels are associated with increased rates of depression and whether decreases in estrogen bring about neurochemical changes that lead to depression.

Hypothesis 2. Indirect effect

Depression is a consequence of menopausal symptoms (the “domino” hypothesis). The main question related to this hypothesis is whether high rates of menopausal symptoms predict increased depression and reduced emotional well-being.

Hypothesis 3. No effect

Menopause and its associated hormonal changes are largely irrelevant in explaining depression among women in midlife. Depression during menopause can be primarily accounted for by the classical determinants of depression over the life course, and menopausal status and symptoms make no meaningful additional contribution. Implicit in this view is a criticism of other research on menopause that does not include all the previously identified predictors of depression.

The central question is: to what extent do classical determinants of depression, such as low socio-economic status, lack of social support and a confiding relationship with a partner, unemployment, previous history of depression, negative life events and high levels of past or current stress account for depression in midlife?

chronic health conditions and thus the physical and psychological health status and history.

Using this multidimensional framework, researchers have investigated the different contributions of various stressors to depression and troublesome menopausal symptoms. The stressors have included menopausal status, age, life context factors such as psychosocial adversity, negative life events, negative socialization and attitudes towards menopause, as well as general physical health status and health behaviours.

Overall, there is little evidence that menopausal or hormonal status exerts a strong or direct effect on depression. Rather, the evidence supports a “domino” hypothesis that an increased level of distressing symptoms is a cause of depression. Avis et al. (2001), in a longitudinal study, found that depression was positively associated with

symptoms such as hot flushes, night sweats and difficulty sleeping, but not with menopausal status or change in estradiol levels. Estradiol had no direct effect on depression independent of symptoms. Glazer et al. (2002), in the longitudinal Ohio Midlife Women's Study, also found that menopausal status did not significantly predict depression in midlife. Loss of resources and low level of education – both classical determinants of depression – were, however, strongly predictive of depression in this cohort. Anxiety was also predicted by loss of resources but the effectiveness of women's coping strategies and education were important too. The researchers concluded that stress, as indicated by loss of resources, was a better predictor of poor health outcomes than menopausal status.

Bosworth et al. (2001) conducted a cross-sectional study of a random sample of women aged

45–54 years residing in Durham County, North Carolina. Variables included depression (measured by the abbreviated Centre for Epidemiologic Studies – Depression Scale (CES-D), perceived menopausal stage, climacteric symptoms, health behaviour and markers of socioeconomic status. Overall 164 women (28%) were using hormone replacement therapy (HRT), and 236 (41%) reported ever using HRT. Almost one-third (29%) of women in the sample had CES-D scores indicating significant depressive symptoms, but there was no significant difference in menopausal status between depressed and non-depressed women. Depressed women had higher rates of night sweats, hot flushes, insomnia, memory loss/forgetfulness and mood swings. Maartens, Knottnerus & Pop (2002) found that stage of menopausal transition in Dutch women was significantly and independently related to depression, after other risk factors were taken into account. Rates of depression, as measured by the Edinburgh Depression Scale, significantly increased from pre- to perimenopause, and again from peri- to postmenopause. However, other risk factors significantly associated with depression in this study included unemployment, inability to work, financial problems, death of a partner or child, and a previous episode of depression, all of which had higher odds ratios than any stage of the menopausal transition. Two of these – unemployment and the death of a child – conferred particularly high risks of depression in midlife. On the other hand, Dennerstein, Leherter & Guthrie (2002) found that menopausal symptoms exerted no demonstrable effect on women's well-being over time; rather, there was an improvement in well-being from early to late phases of the menopausal transition. Psychosocial variables were most significant in determining this, particularly when a woman formed a new marriage or partnership and experienced increased satisfaction in work.

In population-based longitudinal studies in Massachusetts, USA (Avis et al., 1994) and Manitoba, Canada (Kaufert, Gilbert & Tate, 1992), stressful life events and circumstances were found to be strongly associated with depression persisting or occurring for the first time in midlife. Sources of stress included marital and relationship problems, difficulties with children, and demands from friends and family. Similarly, Woods & Mitchell (1997) reported that a stressful life context and poor health status had significant direct effects on depressed

mood. Stressful life context was significantly associated with having more severe vasomotor symptoms. Women who experienced more menopausal changes tended to have more negative expectations for midlife and poorer health status.

The major explanatory role assigned to attitudes and expectations of menopause in the development of depression presupposes that the majority of women formed these attitudes earlier in life. Avis & McKinlay (1991), in a longitudinal study, found that negative attitudes towards menopause predicted both subsequent symptom reporting during menopause and depression. However, in an interview-based study of more than 500 premenopausal women with a median age of 41 years, participating in the Seattle Midlife Women's Health Study, Woods & Mitchell (1997) found that most were uncertain about their expectations of their own menopause.

Another possible risk factor for depression during menopause is sexual functioning and changes in the frequency of sex or in the level of sexual pleasure and satisfaction. Some studies have reported a decrease in sexual functioning with age, which becomes more marked in midlife (Palacios et al., 1995; Avis, 2000; Dennerstein, Dudley & Burger, 2001). An obvious difficulty for research in this area is separating the effect of increasing age from menopausal status. One longitudinal Swedish study disentangled the effects of these two factors and reported that menopausal status, rather than age, was the important factor for explaining decreased sexual functioning (Hallstrom & Samuelsson, 1990). In addition to age and menopausal status, risk factors for decreased sexual desire included lack of a sexual partner, a poor, non-confiding relationship with the sexual partner, insufficient support, alcohol dependence and the partner's own sexual difficulties. Stressors, employment, negative attitudes towards menopause, previous level of sexual functioning, and poor physical or psychological health also contribute to decreased sexual desire and functioning in midlife (Hallstrom & Samuelsson, 1990; Avis, 2000; Dennerstein, Dudley & Burger, 2001). These factors are also predictive of depression. Difficulties or dissatisfaction with sexual functioning can add to stress during the menopausal transition.

Well-being in midlife and the importance of the life course

In addition to investigating the predictors of depression in midlife, a number of researchers have sought to identify and understand the determinants of positive health and general well-being during this period. Dennerstein, Dudley & Guthrie (2003) noted a small decline in self-rated health with increasing age, but this was not attributable to the effect of the menopausal transition. A decline in self-rated health eight years after enrolment, among women who had initially rated their health as better than average, was associated with only two variables following multivariate analysis: a change in weight and a change in libido and feelings for the partner. Women who reported a decline in self-rated health and were in paid employment were significantly more likely than other women to have had an operation or procedure in the previous year. Kuh, Wadsworth & Hardy (1997) also found that women who were obese had the highest rates of psychological symptoms, while women who were of normal weight had lower levels of self-reported symptoms than women who were under- or overweight.

As these studies illustrate, factors preceding menopause can exert a strong influence on the likelihood of poor mental health at the time of menopause. In general, longitudinal studies of menopause recruit women who are approaching or are already experiencing the perimenopausal transition. This means that potentially important risk factors for depression that have occurred earlier in the life course can only be assessed retrospectively and are therefore susceptible to recall bias. A notable exception is the study by Kuh, Wadsworth & Hardy (1997), who investigated the links between earlier experiences (in childhood, adolescence or earlier adult life) and mental health in midlife. Participants in this research were part of the larger Medical Research Council National Survey of Health and Development (MRCNSHD), a prospective cohort study of a representative sample of the British population born in 1946 and assessed repeatedly over subsequent decades. Data on midlife were collected over a 6-year period when participants were aged between 47 and 52 years. Data were collected on anxiety, depression, irritability, tearfulness and feelings of panic. From these data, researchers calculated an overall psychological score (range 0–12). Risk factors were grouped in

six clusters: family background, characteristics of the child, adult health, adult socioeconomic circumstances, social support, lifestyle and current life stress. Pathways through which risk factors determined psychological distress in midlife included cumulative losses, social adversity, and negative events and experiences over the course of the women's lives. The importance of negative life events, such as adverse changes in family and work life, for mental health was confirmed in this study. No variation was found in psychological symptoms in midlife according to menopausal stage, in keeping with the results of most other studies.

Following multivariate analysis, three significant associations remained between family background variables and symptoms of psychological distress. Women who were psychologically distressed were more likely to have lived in council housing, had parents who divorced, and had mothers who had high scores on a measure of neuroticism. Certain characteristics of the women during childhood and adolescence were significantly associated with adult psychological symptom scores. These included level of neuroticism and antisocial behaviour in adolescence. Women with higher psychological symptom scores in midlife were significantly more likely to have had health problems earlier in adult life. Of particular note were psychological illness between 15 and 32 years, anxiety and depression at 36 years, reported health problems at 36 years and physical disability at 43 years. This study, like many others, found significant relationships between adult circumstances, social relationships, health behaviour and current life stress and high psychological symptom scores.

A significant inverse relationship was found between social class, educational qualifications and psychological symptoms. Women living in households where the income was earned by manual labour, or who were themselves on a low income, had higher symptom scores than those from non-manual-labour households or with higher income. Similarly, divorced or separated women had a higher symptom score than those who were married or single. Although the number of children exercised no effect on symptom scores, the scores were worse in women whose children were teenagers or younger. Higher social support, including emotional support, good social networks and access to help in a crisis were associated with low symptom

scores. However, after simultaneous adjustment of all risk factors, social networks were no longer independently associated with midlife symptoms. Some health risks, such as smoking and weight, were related to symptom scores in midlife. Smokers had the highest symptom scores, lifelong non-smokers the lowest and ex-smokers had intermediate scores. Women of normal weight had lower scores than women who were under- or overweight, while obese women had the highest scores. Alcohol intake and past physical activity were not systematically related to symptom scores.

The researchers concluded that markedly different life course trajectories were associated with psychological distress in midlife, and argued that the relationship between the woman's parents may be even more important than their findings on parental divorce suggested. No measures of parental conflict, parental indifference, or physical, sexual or psychological abuse were included in their study. They commented further that a retrospective question, asked when the women were 42 years old, identified a small number who may have suffered abuse or serious neglect of some kind in childhood. This limited measure of parental maltreatment was strongly associated with midlife psychological distress after adjusting for all other early experiences, and was mediated by mental health status in adult life.

Other research has confirmed the importance of different forms of adversity in childhood, including sexual abuse, for multiple health outcomes in adult life (Felitti et al., 1998). In addition, there is a well documented link between childhood sexual abuse and intimate partner violence in adult life and increased rates of a number of adverse mental health outcomes, including depression, anxiety and post-traumatic stress disorder (Astbury & Cabral de Mello, 2000). Women in the sixth year of follow-up for the Melbourne Women's Midlife Health Project completed a questionnaire on lifetime experience of violence: 28.5% (101/362) reported having experienced some form of domestic violence – physical, sexual or emotional – during their lifetime.

Research into the relationship between depression in midlife and possible risk factors, including menopausal and hormonal status and symptoms, faces a number of methodological challenges. While prospective studies minimize reli-

ance on recall for contemporary events and experiences, bias remains a problem for more distant events and past experiences. Only the life course prospective study by Kuh, Wadsworth & Hardy (1997) avoided recall bias altogether, but such longitudinal studies are extremely costly to run. As a result, the comparison of findings across studies is limited by differences in methodological approach, ranging from the research design, the method of sample selection, differences in recruitment strategies, and choice of instruments for measuring risk factors and outcome variables. Studies also vary in the choice of methods for defining, detecting and measuring outcome variables, such as depression. Some studies have measured symptoms of depression, some have used standardized measures that permit diagnostic criteria to be applied, and others have used non-standardized self-report measures. There are differences in the age groups of women recruited to the studies, not all important covariables are taken into consideration, and most studies do not consider the impact of cultural factors. The sample in a longitudinal study is not necessarily representative of the general population, especially if there is a low response rate to the initial invitation to participate. For example, the response rate to the invitation to participate in the Melbourne Women's Midlife Health Project was only 56% (Dennerstein, Leherter & Guthrie, 2002). As further attrition in prospective samples occurs with time, sample bias is compounded. It may be that those participating in a cross-sectional study, where only one attempt to recruit participants is needed, are more similar to the general population than those who remain in a longitudinal study. However, cross-sectional studies cannot disentangle cause from effect or capture temporal changes. Prospective studies are needed to document time-related changes in indicators of health, including recent hormonal, social and psychological changes. All of these may influence and help to explain variations in menopausal symptoms and depressive symptoms between individual women. In addition, significant social and cultural changes can occur over a single generation. Changes in social organization and gender roles, including increased rates of divorce, decreased fertility rates and increased participation by women in paid work, raise new issues that can affect women's sense of well-being in midlife. Recent cohorts of women might differ from earlier cohorts in the significance they assign to work and personal

achievement in their lives (Woods & Mitchell, 1997).

Overall, therefore, multidimensional models are needed to explain depression in midlife. Depression is more likely to be a consequence of distressing menopausal symptoms than a cause of them. The classical social and contextual determinants of depression, such as unemployment, socioeconomic adversity, negative life events, lack of social support, loss of partner through bereavement or separation, or lack of a confiding relationship with a partner, continue to exercise a powerful influence during menopause. Obesity, smoking and depression in midlife are related. Health promotion programmes that seek to reduce these high-risk behaviours among women in midlife will be successful only if they simultaneously address the causes of depression

Summary

Further research

While there is considerable anthropological literature on the cultural construction of menopause in low- and middle-income countries, and on women's expectations and experiences of it, data on the links between mental health and menopause are more limited. Research on this relationship is needed to provide culturally specific data for decision-making at programme, policy and service-provision levels. In particular, the following questions should be addressed:

1. Are the factors identified in high-income countries as critical to women's mental life in midlife equally important for the mental health and well-being of women in low- and middle-income countries?
2. If not, what other socioeconomic, cultural or interpersonal factors play a significant role?
3. What sources of assistance do women in low- and middle-income countries have for health problems and physically or psychologically distressing symptoms related to menopause?
4. How satisfied are women with these sources? What additional sources of assistance or services would they like to have? Do they think such services should be integrated in existing reproductive health services or stand alone?

Policy

Answers to the above questions are essential to provide data for the development of evidence-based policies on women's health, including their mental health in midlife.

Services

Research to date has the following implications for services and health care providers:

1. It is necessary to look beyond menopausal status, hormone levels and menopausal symptoms to adequately explain depressed mood in women at midlife.
2. A life-course, rather than a cross-sectional, approach is necessary to understand emotional distress in midlife.
3. The "classical" social determinants of depression, as well as the presence of distressing somatic symptoms and decreased sexual functioning and pleasure, are likely to contribute to dysphoria and depression.
4. A history of depression and high levels of psychosocial adversity may be more important than menopausal status in explaining current levels of emotional distress, and should be taken into account.
5. It is important to evaluate the sources and impact of stress, and of social support, on women's emotional well-being. This may include stressful demands from family and friends, who can function as conduits of stress as well as sources of positive social support.

References

- Andrews G et al. (1999) *The mental health of Australia*. Canberra, Commonwealth Department of Health and Aged Care.
- Astbury J, Cabral de Mello M (2000) *Women's mental health: an evidence based review*. Geneva, World Health Organization.
- Avis NE (2000) Sexual function and aging in men and women: community and population-based studies. *Journal of Gender-Specific Medicine*, 3(2): 37-41.
- Avis NE, McKinlay SM (1991) A longitudinal analysis of women's attitudes toward the menopause: results from the Massachusetts Women's Health Study. *Maturitas*, 13(1): 65-79.
- Avis NE, McKinlay SM (1995) The Massachusetts Women's Health Study: an epidemiologic investigation of the menopause. *Journal of the American Medical Women's Association*, 50: 45-49.
- Avis NE et al. (1994) A longitudinal analysis of the association between menopause and depression. *Annals of Epidemiology*, 4: 214-220.
- Avis NE et al. (2001) Longitudinal study of hormone levels and depression among women transitioning through menopause. *Climacteric*, 4: 243-249.
- Bebbington P et al. (2003) The influence of age and sex on the prevalence of depressive conditions: report from the National Survey of Psychiatric Morbidity. *International Review of Psychiatry*, 15: 74-83.
- Bosworth HB et al. (2001) Depressive symptoms, menopausal status, and climacteric symptoms in women at midlife. *Psychosomatic Medicine*, 63: 603-608.
- Boulet MJ et al. (1994) Climacteric and menopause in seven south east Asian countries. *Maturitas*, 19: 157-176.
- Chlebowski RT et al. (2003) Influence of estrogen plus progestin on breast cancer and mammography in health postmenopausal women. *Journal of the American Medical Association*, 289:3243-3253.
- Dennerstein L, Dudley E, Burger H (2001) Are changes in sexual functioning during midlife due to aging or menopause? *Fertility and Sterility*, 76: 456-460.
- Dennerstein L, Dudley E, Guthrie J (2003) Predictors of declining self rated health during the transition to menopause. *Journal of Psychosomatic Research*, 54: 147-153.
- Dennerstein L, Leher P, Guthrie J (2002) The effects of the menopausal transition and biopsychosocial factors on well being. *Archives of Women's Mental Health*, 5: 15-22.
- Dennerstein L et al. (1999) Mood and the menopausal transition. *Journal of Nervous and Mental Disease*, 1187: 685-691.
- Dennerstein L et al. (2000) Life satisfaction, symptoms, and the menopausal transition. *Medscape Women's Health*, 5(4): E4.
- Felitti VJ et al. (1998) Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The Adverse Childhood Experiences (ACE) Study. *American Journal of Preventive Medicine*, 14: 245-258.
- Fu SY, Anderson D, Courtney M (2003) Cross-cultural menopausal experience: comparison of Australian and Taiwanese women. *Nursing and Health Sciences*, 5: 77-84.
- Glazer G et al. (2002) The Ohio Midlife Women's Study. *Health Care for Women International*, 23: 612-630.
- Hallstrom T, Samuelsson S (1990) Changes in women's sexual desire in middle life: the longitudinal study of women in Gothenburg. *Archives of Sexual Behaviour*, 19: 259-268.
- Kaufert PA, Gilbert P, Tate R (1992) The Manitoba Project: a re-examination of the link between menopause and depression. *Maturitas*, 14(2): 157-160.
- Kessler RC (2003) Epidemiology of women and depression. *Journal of Affective Disorders*, 74: 5-13.
- Kessler RC et al. (1992) The relationship between age and depressive symptoms in 2 national surveys. *The Psychology of Ageing*, 7: 119-126.
- Khaw HT (1992) Epidemiology of the menopause. *British Medical Bulletin*, 48: 249-261.
- Kuh D et al. (2002) Lifetime risk factors for women's psychological distress in midlife. *Social Science and Medicine*, 55: 1957-1973.
- Kuh DL, Wadsworth M, Hardy R (1997) Women's health in midlife: the influence of the menopause, social factors and health in earlier life. *British Journal of Obstetrics and Gynaecology*, 104(8): 923-933.
- Leidy LE (1994) Biological aspects of menopause across the lifespan. *Annual Review of Anthropology*, 23: 231-253.
- Lock M (1994) Menopause in cultural context. *Experimental Gerontology*, 29: 307-317.

- Lock M (2002) Symptom reporting at menopause: a review of cross cultural findings. *Journal of the British Menopause Society*, 8: 132-136.
- Luoto R, Kaprio J, Uutela A (1994) Age at menopause and sociodemographic status in Finland. *American Journal of Epidemiology*, 139: 64-76.
- Maartens LW, Knottnerus JA, Pop VJ (2002) Menopausal transition and increased depressive symptomatology: a community based prospective study. *Maturitas*, 42: 195-200.
- Mazza D et al. (2001) The physical, sexual and emotional violence history of middle aged women: a community based prevalence study. *Medical Journal of Australia*, 175: 199-201.
- McKinlay SM, Brambilla DJ, Posner GJ (1992) The normal menopause transition. *Maturitas*, 14(2): 103-115.
- McMaster J, Pitts M, Poyah G (1997) The menopausal experiences of women in a developing country: there is a time for everything, to be a teenager, a mother and granny. *Women and Health*, 26: 1-13.
- Palacios S et al. (1995) Changes in sex behaviour after menopause: effects of tibolone. *Maturitas*, 22 (2): 155-161.
- Pradhan AD et al. (2002) Inflammatory biomarkers, hormone replacement therapy, and incident coronary heart disease. *Journal of the American Medical Association*, 288: 980-987.
- Punyahotra S, Dennerstein L (1997) Menopausal experiences of Thai women. Part 2: The cultural context. *Maturitas*, 26: 9-14.
- Rapp SR et al. (2003) Effect of estrogen plus progestin on global cognitive function in postmenopausal women. The Women's Health Initiative Memory Study: A randomized controlled trial. *Journal of the American Medical Association*, 289: 2663-2672.
- Shinberg D (1998) An event history of age at last menstrual period: Correlates of natural and surgical menopause among midlife Wisconsin women. *Social Science and Medicine*, 46: 1381-1396.
- Standing TS, Glazer G (1992) Attitudes of low income clinic patients toward menopause. *Health Care for Women International*, 13: 271-280.
- Stephens C, Ross N (2002) The relationship between hormone replacement therapy use and psychological symptoms: no effects found in a New Zealand sample. *Health Care for Women International*, 23: 408-414.
- UNDP (2003) *Human Development Report 2003. Millennium Development Goals: A compact among nations to end human poverty*. New York, Oxford, Oxford University Press.
- Wade TJ, Cairney J, Pevalin DJ (2002) Emergence of gender differences in depression during adolescence: national panel results from three countries. *Journal of the American Academy for Child and Adolescent Psychiatry*, 41: 190-198.
- Wassertheil-Smoller S et al. (2003) Effect of estrogen plus progestin on stroke in postmenopausal women. *Journal of the American Medical Association*, 289: 2673-2684.
- Wise LA et al. (2002) Lifetime socioeconomic position in relation to onset of perimenopause. *Journal of Epidemiology and Community Health*, 56: 851-860.
- Woods NF, Mitchell ES (1997) Pathways to depressed mood for midlife women: observations from the Seattle Midlife Women's Health Study. *Research in Nursing and Health*, 20: 119-129.
- Woods NF, Mariella A, Mitchell ES (2002) Patterns of depressed mood across the menopausal transition: approaches to studying patterns in longitudinal data. *Acta Obstetrica Scandinavica*, 81: 623-632.
- World Bank (2006) Women in development. In: *2006 World Development Indicators*, Washington, DC: 34-37.

Chapter 6

Gynaecological conditions

Non-infectious gynaecological conditions – Heather Rowe

Infectious gynaecological conditions – Lenore Manderson & Narelle Warren

Malignant conditions – Lenore Manderson & Narelle Warren

One of the most important aspects of women's health care is the prevention of maternal mortality and the after-effects of injury sustained in pregnancy and childbirth (Wall, 1999). The main focus in this area has, understandably, been on maternal mortality, despite the fact that maternal injury affects substantial numbers of women globally. For every woman who dies from pregnancy-related causes, approximately 30 others incur injury, infection or disability, which, for the most part, remains untreated (Adamson, 1996). Many more women experience other, non-pregnancy-related gynaecological health problems.

Non-infectious gynaecological conditions

The causes of much obstetric and gynaecological morbidity stem from the neglect and abuse associated with the low social position accorded to females in many societies. Malnutrition in childhood and early adulthood, early age at marriage and first pregnancy, and lack of access to obstetric services result in high rates of obstetric morbidity. Myths associated with sex and reproduction result in many women feeling ashamed of their reproductive functions and being blamed for gynaecological infections, injuries and consequent infertility (Adamson, 1996; Miller & Rosenfield, 1996; Wall, 1998). The physical dimensions of these conditions have received little attention, and the mental health implications even less.

The International Conference on Population and Development (ICPD) in 1994 recognized

sexual and reproductive health and rights as fundamental to human rights and development. The ICPD Programme of Action aimed to increase the availability of good quality reproductive health services in developing countries. Too often, such services are of poor quality, with inadequately trained staff and no counselling services. Appropriate provider–patient interactions may be adversely affected by local social hierarchies (Mayhew, 2000), and women have reported disrespectful and abusive treatment by health care providers (Petchesky, 1998). Services are often designed with scant regard for the needs of women with respect to the timing of clinics and the availability of female doctors (Jaswal, 2001). In addition, an emphasis on family planning, and particularly discrimination and coercion in various population programmes, may discourage women from attending. Services should respond to the needs of a wider clientele than is represented in the “unmet need for family planning”, which is narrowly defined as the 100–150 million married women who wish to space or limit births, but are not using contraceptives. Women value services staffed by trusted providers, who are respectful of local beliefs and practices (Toussaint, Mark & Straton, 1998; Hunt & Geia, 2002). Monitoring of progress should include indicators that are of importance to women (Germain, 2000).

Barriers to attendance at reproductive health services are commonly linked to cultural factors. Decisions about seeking treatment, for example, are often in the hands of husbands and mothers-in-law. Other structural factors also inhibit women's use of health services. The low level of literacy and formal education of women in

many countries, their limited opportunities for employment and therefore lack of economic independence, and the poor development of other sectors, such as transport and communication, all inhibit women's access to services and have a negative effect on women's reproductive health (Aoyama, 2001). In addition, policies and services have often been based on the assumption that addressing barriers to physical health is sufficient and that, once this is attained, mental health will follow (Gulcur, 2000).

Studies continue to report high rates of gynaecological health problems in developing countries (Bhatia & Cleland, 2000). Prevalence studies in communities and clinical settings have used a variety of methods of measurement, including interviews to obtain self-reports of symptoms, clinical examinations, and laboratory analysis of specimens. Data derived from representative community-based samples are more generalizable than those from clinic-based studies, as women frequently do not seek treatment for these conditions because of financial and cultural constraints. However, data collected in community settings often underestimate health problems, both because women under-report the conditions and because of the lack of reliable and qualified personnel willing to travel to remote places in adverse conditions to collect information. Women are often reluctant to agree to clinical examination or blood collection, which further undermines the feasibility of community-based epidemiological studies (Bonetti, Erpalding & Pathak, 2002).

There is little consistency in the results of the different studies. Women's own reports, in particular, are influenced by the context of the interview (Bhatia & Cleland, 2000). Frequently, self-reported symptoms do not correspond to medically diagnosed morbidities, although there is no clear evidence-based explanation of the differences (WHO, 2001a). Difficulties in transporting equipment and samples, and the cost of the studies, further limit the evidence base (Bonetti, Erpalding & Pathak, 2002). Finally, very few research studies have addressed the mental health implications of gynaecological or obstetric health problems.

Obstetric fistula

An obstetric fistula is a tract between the bladder and the vagina, or the rectum and the vagina,

which causes urinary or faecal incontinence or both. It is a devastating morbidity of pregnancy, which is prevalent in resource-poor countries. It primarily affects young, poor women with little education and limited social roles, who do not have access to adequate obstetric care (Muleta, 2004). A combination of malnutrition in childhood (which causes growth retardation), early marriage, and pregnancy before pelvic growth is complete results

in cephalopelvic disproportion and obstructed labour – “days of futile contractions repeatedly grinding down the skull of an already asphyxiated baby onto the soft tissues of a pelvis that is just too small” (Adamson, 1996). Prolonged obstructed labour in the absence of emergency obstetric services results in maternal death or, in many of those who survive, “obstructed labour injury complex” – obstetric fistula.

A woman with fistula suffers from constant vaginal wetness, which causes genital ulcerations, frequent infections and terrible odour. Long-term health consequences include skeletal injuries, and a combination of cervical injury, amenorrhoea, vaginal scarring and stenosis, leading to secondary infertility (Wall, 1999). Approximately 20% of women who are in obstructed labour for long enough to develop fistula also develop neurological injuries, including a condition known as “foot drop” which makes walking difficult (Wall, 1999). Most such labours in developing countries end in stillbirth; the typical patient is small and short (less than 44 kg in weight and under 150 cm tall) and married early (average age at marriage, 15.5 years) (Wall et al., 2004).

The fetal death rate in obstructed labour is over 90% (Wall, 1999). Most cases of obstructed labour occur in women having their first baby, who have a high probability of remaining childless thereafter. Amenorrhoea following fistula is common. In a society where childbearing is central to women's status, the loss of both a child and the role of motherhood is especially harsh, and many of these women face stigma. The

While the physical consequences of fistula are disabling, so too are the social consequences: stigmatization, isolation and loss of social support, divorce or separation, worsening poverty, malnutrition and suffering, and ultimately premature death (UNFPA, 2001).

rate of suicide in such women is unknown, but thought to be notable (Adamson, 1996). Social isolation confirms the woman's belief that she is to blame and has brought shame on her family. A study of women with fistula attending a clinic in the United Republic of Tanzania revealed that half of them were not living with their husband; three-quarters of these said that the reason for the separation was the fistula (Bangser, Gumodoka & Berege, 1999).



Women with untreated fistula face a lifetime of disability, pain, humiliation, abandonment, poverty, and malnutrition, often ending in premature death. Because of the shame associated with the condition, it is often hidden. Despite the undoubted psychological consequences of the physical and social burdens endured by women with fistula, there have been no systematic investigations. There are no reliable data on prevalence, but between 500 000 and two million women are estimated to be living with the condition (Adamson, 1996; Donnay & Weil, 2004; UNFPA, 2001). It is thought that, every year, between 50 000 and 100 000 women develop fistula. In sub-Saharan Africa the number of new cases annually is around 33 000 (Vangeenderhuysen, Prual & Ould el Joud, 2001). Most of these go untreated. Lack of services for safe childbirth and timely repair of fistula violates women's internationally recognized human right to reproductive health care (Cook, Dickens & Syed, 2004). There are anecdotal reports that some women with fistula can continue to live a dignified, productive life, but the determinants of apparent individual differences remain uninvestigated (Hilton & Ward, 1998).

Fistula is almost unknown in developed countries, where there is both universal access to high

quality obstetric services and lower rates of teenage pregnancy. Unlike in developing countries, where 90% of fistulae result from obstetric injury, in the United Kingdom over 70% of fistulae follow pelvic surgery (Hilton, 2001). Obstetric fistula is almost entirely preventable and nearly always curable, although repairs can break down and require repeat surgery. Success rates of surgical repair are above 90% among trained surgeons (Bazeed et al., 1995; UNFPA, 2002). Most affected women and girls in developing countries are unable to afford the cost of fistula repair (UNFPA, 2001). However, when the Bugando Medical Centre Project on fistula opened in the United Republic of Tanzania in 1997, with assistance from personnel from the Addis Ababa Fistula Hospital in Ethiopia, women overcame enormous obstacles to attend in large numbers (Bangser, Gumodoka & Berege, 1999).

Timely access to skilled antenatal and intrapartum services is the key to preventing injury in childbirth (Donnay & Weil, 2004). However, in order to reduce the incidence of obstructed labour, two social changes are also needed: girls' nutrition must be improved, to ensure adequate growth of the pelvis; and the average age at first birth must increase. Gender discrimination in household food allocation is common in societies where females are accorded low social status, and is associated with poor access to health care (Messer, 1997). The pelvis continues to grow after menarche and full adult height have been reached, i.e. after the age at which pregnancy can occur (Moerman, 1982). Micronutrient and protein deficiencies in girls and young women compromise this growth and development (Messer, 1997). In Nigeria, maternal and child health education is being introduced into the Koranic school curriculum, with the aim of helping to ensure that young women are better able to have a safe pregnancy and obtain appropriate health care (Ibrahim, Sadiq & Daniel, 2000).

Social changes that promote the value of girls and delay marriage and first birth are potentially powerful agents for reducing the incidence of fistula and other obstetric injuries.

Pelvic organ prolapse

Pelvic organ prolapse is a significant descent of the uterus and vagina, which may protrude partly or completely beyond the vulva. It causes disturbing symptoms, such as pelvic fullness,

back pain, incontinence, vaginal discharge, and bleeding (Aoyama, 2001).

The global prevalence of pelvic organ prolapse is estimated to be between 2% and 20% among women under 45 years (Bonetti, Erpalding & Pathak, 2002). Estimates in developing countries vary widely, from 3.4% in South India (Bhatia et al., 1997) to as high as 56% in Egypt (Younis et al., 1993). Even in developed countries, data on pelvic organ prolapse are inadequate, and there is little agreement on prevalence (Bump & Norton, 1998; Luber, Boero & Choe, 2001). The prevalence is higher in postmenopausal women because of hormonally mediated increases in tissue laxity. In developed countries, pelvic organ prolapse is associated with mature age (Luber, 2001), but in developing countries it occurs in a younger population.

The causes of prolapse are believed to be multifactorial. Multiparity is considered to be the primary predisposing factor, although in one study in Nepal, most women with prolapse had only one child (Bonetti, Erpalding & Pathak, 2002). Chronic health problems that increase abdominal pressure, such as obesity, constipation, chronic coughing and poor nutrition, may contribute to the condition. Heavy manual labour, including lifting and carrying of heavy objects, such as water and wood for cooking, is also a risk factor (Bonetti, Erpalding & Pathak, 2002). Women themselves explain prolapse in terms of difficult first delivery, first birth at a young age, gynaecological surgery, and miscarriage. In turn, women with pelvic organ prolapse are reported to be at a much greater risk of reproductive tract infections (Younis et al., 1993). Symptoms reported by women with prolapse, such as itching and foul-smelling discharge, may in fact be symptoms of other conditions.

Poor medical history-taking appears to result in underdiagnosis of the condition. However, of 227 women with self-reported prolapse in a household survey conducted in north India, 57% had not sought treatment. The majority of those who did seek care consulted a traditional birth attendant, not a doctor. Women reported shyness, lack of cooperation of the husband, and lack of time or money as reasons for not consulting a doctor. Of those who were offered surgery, few took it up (Kumari, Walia & Singh, 2000).

In developed countries, surgery is the principal treatment and over 390 000 repairs are performed annually in the United States of America (Norton et al., 1995). It is estimated that in the USA more than 10% of women will undergo a surgical procedure for symptoms of pelvic organ prolapse, including urinary incontinence, by the age of 80 years (Olsen, 1997), despite the fact that many women with incontinence do not seek medical help (Walters, 2004). There have been few evaluations of the success of surgical treatment, and women and clinicians may disagree on whether surgery has been successful (Hullfish et al., 2002).

Strategies to prevent urinary incontinence, including pelvic floor exercises, are included in antenatal and postnatal education programmes in developed country settings (Mason, 2001). These strategies may also help prevent pelvic organ prolapse. However, they do not address the risk factors for pelvic organ prolapse, such as heavy manual labour.

Little attention has been paid to psychosocial effects and quality of life measures among women with prolapse. Recently validated condition-specific instruments to assess the quality of life of women with pelvic organ prolapse include questions on distress caused by symptoms and their general impact, but there has been no validated assessment of psychological functioning for use pre- or post-surgery (Barber et al., 2001). The impact on women's mental health of progressive, long-term pelvic floor dysfunction remains underinvestigated. In a prospective study conducted in the USA, the pre-surgery goals of a group of 33 predominantly white women were elicited. At 6 and 12 weeks post-surgery, prior to the physician visit, the women were asked about their perceptions of the outcome of surgery. At 6 weeks, women agreed that most of their goals in relation to activity, symptoms, health and appearance had been met, but only by 12 weeks had their goals relating to social interaction and self-image been achieved (Hullfish et al., 2002).

Infectious gynaecological conditions

Reproductive tract infections (RTIs) include all infections of the genital tract in both men and women; some of these, but not all, are sexually transmitted. Environmental conditions, poor general health status and poor personal hygiene can lead to higher rates of reproductive

tract infections that are not sexually transmitted (Whittaker 2002). These infections may have an impact on women's mental health. Research in India highlighted the association between reproductive tract infections and psychological distress (Prasad, Abraham et al. 2003), and demonstrated that presence of a symptom for more than one month – most commonly vaginal discharge – and a history of similar symptoms over the past year were risk factors for the development of common mental disorders, including depression, anxiety and somatization disorders.

Unexplained vaginal discharge

Some reproductive tract infections in women are caused by overgrowth of organisms that are normally present. Itching, irritation, and abnormal but non-bloody vaginal discharge can be distressing, but diagnosis is frequently difficult (Younis et al., 1993; Bhatia & Cleland, 1995; Zurayk et al., 1995; Koenig et al., 1998). Symptoms related to the reproductive tract are extremely common among low-income women, in both developing and developed countries (Jaswal, 2001; Dekker et al., 1993). The prevalence of unexplained vaginal symptoms is difficult to determine, since estimates tend to be based on clinical presentation and laboratory analysis of specimens. There is, however, a low correlation between vaginal discharge and laboratory evidence of infection (Wathne et al., 1994; Zurayk et al., 1995; Patel & Oomman, 1999; Bhatia & Cleland, 2000), and rates of self-reported symptoms are not accurate estimates of the prevalence of gynaecological morbidity (Koenig et al., 1998). In Nepal, for example, laboratory diagnosis indicates low rates of infection in symptomatic women, supporting a cautious approach to symptomatic treatment for RTIs (Bonetti, Erpalding & Pathak, 2002). Similarly, a survey in general practice in the Netherlands found that, in 25% of women presenting with vaginal symptoms, no microbial infection could be diagnosed (Dekker et al., 1993). However, Karaca et al. (2005), in a systematic comparison of microbiological laboratory testing and clinical examination of pregnant women, found that reproductive tract infections were underdiagnosed in settings where laboratory facilities were limited.

Epidemiological data may indicate that reproductive tract infections are not a cause for public health concern. However, women report that the symptoms have a profound effect on their life.

In Asian societies, there is a widespread belief that vaginal discharge is abnormal, depletes vital energy, and causes weakness, fatigue and aches and pains (Chaturvedi et al., 1993; Whittaker, 2002). Women may fear that the symptoms indicate or will lead to serious disease, such as cancer. In other cases, women may be reluctant to seek medical advice because they believe that these conditions are sexually transmitted. Strong cultural taboos and shame may prevent women from seeking professional treatment; they may, instead, try to treat themselves, which in turn may endanger their health (Jaswal, 2001; Boonmongkon, Nichter & Pylypa, 2001; Guo, Wang & Yan, 2002; Whittaker, 2002). In many cultures, women endure vaginal symptoms as an “inevitable” part of womanhood.

The experience of gynaecological symptoms is associated with psychological distress, particularly when no genital tract pathology is diagnosed (Stewart et al., 1990; Patel & Oomman, 1999). The impact on women's mental health of chronic, distressing symptoms, which have no medical explanation and remain unresolved – and by implication, undervalued – has not been fully examined. The symptoms can have deep cultural meanings (Dekker et al., 1993; Trollope-Kumar, 1999), and may in themselves be somatic expression of depression and psychosocial distress (Patel & Oomman, 1999).

Candidiasis

Candidiasis (vaginal thrush or monilia) is one of the most common causes of vaginal discharge and discomfort. Distress is related both to the symptoms and to misunderstanding of their cause. *Candida* yeast is always present in the body. Candidiasis arises when, under certain conditions, the yeast multiplies, leading to an infection characterized by a thick, clumped discharge. The infection can be very debilitating, causing vulval and vaginal itching, discomfort or irritation, redness and/or swelling of the vagina and vulva, and a stinging or burning sensation when urine is passed. The pain, itchiness and general discomfort associated with recurrent candidiasis can cause considerable distress.

The most common causes of candidal overgrowth are antibiotic treatment, oral contraceptives, pregnancy, diabetes, immune system disorders and general illness. Cleaning the anus by wiping towards the vagina can also spread yeast

from the digestive tract. Contemporary products, such as some soaps, antiseptic douches, perfumed sprays, and tight-fitting and synthetic underwear, can also change the local environment in the vagina and may result in overgrowth of yeast. Candidiasis is rarely sexually transmitted. All women are exposed at some time to at least some of the biological factors associated with thrush, and 75% of all women will experience the infection during their life (CDC 2005). Candidiasis is treated as a minor infection and its impact is rarely studied. Because it is often associated with menstruation, pregnancy and the use of oral contraceptives, it is frequently considered trivial by women and their health care providers. However, urination and intercourse during infection can be extremely painful, and lesions may occur as a result of friction with swollen tissue, increasing the woman's risk of acquiring other infections, including human immunodeficiency virus (HIV).

Treatment is usually with an antifungal cream or suppositories, such as miconazole or clotrimazole, although such treatments are rarely available and affordable for women in poor countries. Women may also experiment with natural therapies (e.g. by including yoghurt in their diet) and by applying various herbs topically, but few studies have reported on women's perceptions and self-management of this condition, or on its effects on their mental and emotional health (Bechart 1996).

In a small cross-sectional study of women with chronic vaginal candidiasis, the women reported that recurrent infection seriously interfered with their sexual and emotional relationships (Irving, Miller et al. 1998). The women were significantly more likely than controls to suffer from clinical depression, to be dissatisfied with life, to have low self-esteem, and to perceive their lives as stressful. Similarly, in a small study in the United Kingdom, women reported that thrush had a major adverse impact on their life, making them feel miserable, unable to work, embarrassed, and even stigmatized (Chapple, Hassell et al. 2000). Women of south Asian descent drew attention to the physical discomfort, personal distress and embarrassment, and the impact that infection had on their personal and professional lives; they reported feeling "dirty", embarrassed, depressed and stigmatized (Chapple 2001).

Bacterial vaginosis

Bacterial vaginosis is caused by overgrowth of anaerobic bacteria, and is characterized by vaginal inflammation and discharge. It has serious adverse consequences, in particular an increased risk of premature birth, pelvic inflammatory disease and sexually transmitted infection, including HIV and herpes simplex 2 (Harville, Hatch & Zhang, 2005; Uma et al., 2005). It is thought to be more common in women who have reduced immunity as a result of chronic stress. Ehrstrom et al. (2005) found higher levels of stress hormones in women with recurrent bacterial vaginosis than in age-matched healthy controls. However, Harville, Hatch & Zhang (2005) found that rates of bacterial vaginosis infection were no higher in a sample of 411 African American women with high self-reported life stress than in those without.

Bacterial vaginosis may be more likely to occur in women living in chronic adversity, whose general health status is low. Poor women attending an outpatient clinic in Hyderabad, India, who were seriously undernourished, were more likely to have bacterial vaginosis than those who were adequately fed (Yasodhara et al., 2006). Sex workers are at increased risk of concurrent infection with bacterial vaginosis and sexually transmitted infections (STIs), and it is thought that bacterial vaginosis may increase vulnerability to STI (Kim et al., 2005; Uma et al., 2005).

Sexually transmitted infections of the reproductive tract

Sexually transmitted infections are a major cause of morbidity, disability, psychological suffering and death worldwide. In addition to their direct effects, they can make people more vulnerable to infection with the human immunodeficiency virus and cause infertility.

In both industrialized and poor countries, the prevalence and incidence of sexually transmitted bacterial and viral infections have increased since 1995 (WHO 2001b). In 1999, an estimated 340 million new cases of sexually transmitted bacterial infections (syphilis, gonorrhoea, chlamydial infections and trichomoniasis) occurred in men and women aged 15–49 years; this number has continued to rise (WHO 2001; 2006). Precise global surveillance data on the

prevalence and incidence of sexually transmitted viral infections (other than HIV) are difficult to find, but indicators suggest that 630 million, or two-thirds of people who have ever been sexually active, are infected with a human papillomavirus (Baseman and Koutsky 2005; Pagliusi and Vaccine Research and Development [2001] 2003). The prevalence of genital herpes (herpes simplex virus type 2 (HSV2) and, to a lesser extent, type 1 (HSV1)) varies widely, from 4% in the United Kingdom to up to 80% in sub-Saharan Africa (Paz-Bailey, Ramaswamy et al. 2007). In addition to the primary symptoms, HSV infection increases the likelihood of developing other sexually transmitted infections, such as genital ulcer disease (GUD) and HIV infection (Paz-Bailey, Ramaswamy et al. 2007).

Poverty, low income, urbanization, unemployment and migration are all associated with the incidence and continued transmission of STIs (Holtgrave and Crosby 2003), in particular when condoms are unaffordable or unavailable (Duncan, Tibaux et al. 1997). STI epidemics have been reported from the emerging states of Eastern Europe and other countries experiencing rapid structural, political and social change (Purevdawa, Moon et al. 1997; Axmann 1998; Aral, Lawrence et al. 2003). Marginalized communities are also highly vulnerable. In Australia, for example, indigenous communities have extremely high rates of sexually transmitted infections of all kinds, as well as high rates of sexual violence, and non-sexual physical and mental health problems. In one descriptive study among indigenous Australians, over a quarter of women aged 20–43 years were infertile. Nearly 50% of women in rural northern Australia had been infected with genital chlamydia and there were high rates of previous pelvic inflammatory disease (PID), gonorrhoea and syphilis (Kildea and Bowden 2000). Effective public health interventions are hindered by a history of dispossession, violence and racism, as much as by structural, social and economic barriers to service (Kirk et al., 1998).

Sexually transmitted infections can result in pelvic inflammatory disease, tubal occlusion and consequent infertility, ectopic pregnancy, adverse pregnancy outcomes, genital neoplasia, and neurological complications. Although these infections cause pain, disability and reduced functioning, little research has been conducted into their psychological sequelae, in either de-

veloped or developing country settings. In relative terms, more evidence is available on specific infections for North America and Western Europe.

Diagnosis is universally described as stressful. Being diagnosed with an STI is stigmatizing (1997; Duncan, Hart et al. 2001; Donovan 2004), and carries an implication of one's own or the partner's infidelity. In addition, infection may have implications for reproductive health in the long term; establishing or maintaining a sexual relationship may become problematic; and there may be concerns about preventing recurrence of disease. These psychosocial responses may be exacerbated or compounded if clinic staff have negative attitudes (Connell, McKevitt et al. 2004). Universally, the research literature draws attention to the short- and long-term psychological responses of individuals to STI diagnoses and recurrent infections, the particular emotional, social and mental health costs of these for women, and the lack of systematic responses to meet the mental health needs (Prasad, Abraham et al. 2003).

Infertility in women, as a result of untreated sexually transmitted reproductive tract infections, causes particular distress and hardship, with social and emotional consequences for both men and women, and social stigmatization, particularly of women (Papreen, Sharma et al. 2000).

Various factors impede diagnosis and treatment and contribute to a substantial global underestimate of reproductive tract infections of all kinds. Most women in developing countries have poor access to appropriate, acceptable, gender-sensitive health services. Rural women, in particular, are unfamiliar with reproductive tract infections, confuse sexually and non-sexually transmitted infections, and perceive and experience considerable social stigma on diagnosis (Guo 1999; Go, Quan et al. 2002; 2002). Reproductive tract and sexually transmitted infections are typically associated with sexual freedom, and in much of the world, women's sexuality is tightly controlled. Any symptom of infection may be taken as

Lack of information on reproductive health problems means that women are often unaware that conditions are treatable, and that without treatment many conditions have serious long-term implications.

evidence of infidelity, and this may have serious consequences for women and their children in terms of personal safety and security.

For women whose quality of life is tied to their fertility, reproductive tract and sexually transmitted infections cause short- and long-term problems that affect their economic and domestic life (Walraven, Scherf et al. 2001). Women who are vulnerable and who fear informing their partner about an infection may not accept that they have been infected, because of profound feelings of shame and stigma, as well as fears of intimate partner violence. In Morocco, for example, STIs are viewed as women's illnesses (Manhart, Dialmy et al. 2000); a diagnosis of STI can lead to victimization and stigmatization, by both the male partner and family members. As a result of gender discrimination in sexual health services, women may remain untreated and vulnerable to sequelae of the infection. In Zimbabwe, women's psychological reactions to repeated multiple STIs highlight their lack of power to negotiate safe sex within marriage, their lack of choice in terms of conditions of marriage, and the lack of social support networks for infected women (Pitts, Bowman et al. 1995). Women reported fear or worry about the risk of HIV/AIDS, yet highlighted their feelings of shame, social isolation and stigma; they also related their infections to being unable to trust their husband's sexual behaviours. This finding was supported by data collected from men, most of whom indicated they were unlikely to change their sexual practices (multiple partners, not using condoms) despite the infection. Research in Uganda has also illustrated that psychosocial factors, including gender relations and types of sexual partner, as well as poor quality of health care, discourage women from referring their sexual partner for treatment (Nuwaha, Faxelid et al. 2000). Limited financial resources and a perception that symptoms are not severe discourage women from seeking care. A study in Nairobi, Kenya, demonstrated that women waited longer than men before seeking reproductive and sexual health care (Voeten, O'Hara et al. 2004).

Few studies have documented the social and cultural aspects that lie behind recognition, diagnosis and treatment of reproductive health problems in women. Ethnographic research in north-eastern Thailand highlighted how family life and sexual relations are disrupted by fears of gynae-

cological problems, regardless of the diagnosis. This influences the extent to which women treat themselves, and their concerns about the seriousness of recurrent ailments (Boonmongkon, Nichter et al. 2001; Boonmongkon, Nichter et al. 2002). Women typically minimize their concerns about their gynaecological problems and employ self-management strategies rather than seek medical advice. As the gynaecological problem therefore remains unresolved, these factors result in substantial suffering. Elsewhere in south-east and south Asia, women find reproductive tract symptoms stressful, leading a number of authors to suggest that women over-report vaginal discharge for reasons that are unclear but may be culturally constructed (Bang and Bang 1994; Ramasubban and Rishyasringa 2001; Ross, Laston et al. 2002). Such research highlights how discharge is commonly culturally constructed and therefore perceived by women as being unrelated to sexual contact (Bhatti and Fikree 2002), regardless of its cause. These findings suggest that, while not all discharge is indicative of reproductive tract infection, women may over-report some symptoms and under-report others, because of confusion about their origin. In particular, women who fear the social repercussions of sexually transmitted infections may report somatic symptoms, such as dizziness, backache and weakness, rather than discharge (Trollope-Kumar 2001). As a further complication, women seeking treatment for reproductive tract symptoms may receive unnecessary treatment, especially in areas of high STI prevalence, and may experience fungal infections (candidiasis) as a side-effect of the overprescription of antibiotics (Hawkes, Morison et al.), which compounds rather than reduces their distress.

Sexually transmitted infections are prevalent among women who have experienced sexual violence, compounding effects on their mental health, sexual functioning and social relationships (Holmes 1999; Jewkes 2000; Firestein 2001; Brokaw, Fullerton-Gleason et al. 2002; Upchurch and Kusunoki. 2004). Gender-based violence is associated with STI infection; both are associated with other physical and mental health problems, including mood changes, sleep disturbances, self-harm, and psychosomatic symptoms (Suris, Resnick et al. 1996; Kawsar, Anfield et al. 2004; Plazaola-Castano and Perez 2004).

Young people are at high risk for STIs, because of various social, economic, environmental, psychosocial and behavioural factors (Bishop Townsend 1996). In addition, young women are physiologically at greater risk of lesions during sexual activity, whether intercourse is forced or not. Adolescents may be asymptomatic or unaware of the significance of their symptoms, and not attend for investigation; as a result, STIs may remain undetected and untreated. Risk is higher among young women with multiple partners, or whose partners have multiple partners, who use condoms inconsistently. In many countries, access to condoms and relevant information is limited and they may be completely unavailable to those who are unmarried. Young women typically lack the skills to negotiate with partners regarding the occurrence of sex and the use of condoms.

In various settings other factors may complicate the effect of gender-related variables (Boyer, Shafer et al. 2000). In a study among young people in Lima, Peru, 18% had a history of STI symptoms or diagnosis, but only 11% of those who were heterosexually active reported consistent use of condoms. Those with a history of STI were more likely than others to associate condom use with casual sex, and to report a history of sexual coercion or of having paid or been paid for sex. For women, sex at a young age was a risk factor for STI and unplanned pregnancy (Caceres, Marin et al. 1997). Mental health problems, including depression and low self-esteem, appear to be significantly associated with risky sexual behaviour among young people. In the United States, depressive symptoms are associated with an increased probability of not having used a condom during the last sexual intercourse; for girls, they are associated with a history of STI (Shrier, Harris et al. 2001). Rosenthal & Biro (Rosenthal and Biro 1991) draw attention also to the presence of intrusive or avoidant thoughts in young women following infection, and argue for the need to explore the coping mechanisms of young people with sexually transmitted infections.

Syphilis

Syphilis is highly infectious and was epidemic until the early twentieth century (De Schryver and Meheus 1990; WHO 2001b). Efforts to control it had some success in the 1960s, but prevalence increased in the mid-1980s coincident

with a general increase in STIs. Specific targeted programmes aimed at high-risk populations in some parts of southern Africa have been successful in reducing incidence rates (for example, in Botswana: Creek, Thuku et al. 2005), as have programmes in the Caribbean (Jamaica: Figueroa 2004) and South America (Argentina: Pajaro, Barberis et al. 2001). These declines, largely in developing countries, have contributed to an overall decrease in the global incidence of syphilis (De Schryver and Meheus 1990; Piot and Islam 1994; Gerbase, Rowley et al. 1998; WHO 2001b). Nevertheless, focal epidemics continue to occur in most parts of the world (Finelli, Levine et al. 2001), particularly in rapidly developing and developed countries. Data from South Africa demonstrate that the prevalence of syphilis has increased since 2003 (Department of Health (South Africa) Directorate 2006); similar trends have been observed elsewhere, including central America (Nicaragua: Hoekstra, Riedijk et al. 2006) and Asia (Thirumoothy 1990; Reynolds, Risbud et al. 2006; Chen, Zhang et al. 2007). Syphilis prevalence has increased to critical levels in some populations across Western Europe (Cowan, 2004; Cronin et al., 2004; Marcus, Bremer & Hamouda, 2004; Righarts et al., 2004; Sasse, Defraye & Ducoffre, 2004; Defraye & Sasse, 2005; Lautenschlager, 2005; Oliver & Christensen, 2005; Payne et al., 2005; Simms et al., 2005; Wallace, Winter & Goldberg, 2005; Del Giudice et al., 2006), Eastern Europe (Tichonova, Borisenko et al. 1997; Uuskula, Silm et al. 1997; Ciment 1999; Dencheva, Spirov et al. 2000; Grgic-Vitek, Klavs et al. 2002; Karapetyan, Sokolovsky et al. 2002; Zakoucka, Polanecky et al. 2004; Resl and Kumpova 2005; Yakubovsky, Sokolovsky et al. 2006), the United States (CDC 2006; Kerani, Handsfield et al. 2006) and the Pacific region (Thirumoothy 1990; Mak, Johnson et al. 2004; Azariah 2005; Johnston, Fernando et al. 2005). Prevalence rates are different in men and women; surveillance data from Serbia suggest that the incidence of syphilis has remained fairly stable in women since the mid-1980s, despite significant fluctuations – with a recent surge – in men (Bjekic, Vlajinac et al. 2001). Recent increases, globally, have been attributed to substantial increases in incidence among men who have sex with men (Cowan 2004; Fairley, Hocking et al. 2005; Fenton and Imrie 2005; Wade, Kane et al. 2005; Kerani, Handsfield et al. 2006) and female sex workers (Hernandez-Giron, Cruz-Valdez et al. 1998; Smacchia, Parolin et al. 1998; Uribe-

Salas, Conde-Glez et al. 2003; Nigro, Larocca et al. 2006).

The disease is caused by a bacterium (spirochaete), and can be diagnosed by a blood test. The first symptoms, usually a painless, often isolated ulcer at the site of inoculation, generally appear 10–90 days after infection. Secondary infection can occur in any part of the body, from 6–8 weeks after infection. Symptoms may include fever, a flat red body rash, hair loss, various cutaneous eruptions on the genitals and anus, myalgia, arthralgia and depression. Secondary syphilis is highly contagious, both sexually and transplacentally. Fetuses of infected women may suffer from extreme developmental disorders and often die *in utero* or at birth (Brockmeyer and Reimann 1998). An untreated infected individual can infect others through sexual contact for up to two years. There is then a latency period of 2–10 years followed, in about one-third of untreated individuals, by the development of skin, mucocutaneous and long bone disorders. In some cases, severe complications of the brain and spinal cord may result in progressive paralysis.

Gonorrhoea

Gonorrhoea is a bacterial infection, caused by *Neisseria gonorrhoeae*, the gonococcus. It is usually diagnosed through laboratory testing. In men, infection can cause a burning sensation on passing urine and a yellow discharge from the penis. In women, it is mostly asymptomatic, although some women may have a yellow vaginal discharge, low abdominal pain, or irregular menstrual bleeding. Gonorrhoea is relatively rare in industrialized countries, except in poor groups. In Australia, its prevalence among indigenous Australians is 78 times greater than in the rest of the population (Roche 2001). Gonorrhoea can be treated effectively; if left untreated, the infection can spread to the reproductive organs, causing pelvic inflammatory disease and infertility; it can thus have a major impact on women's quality of life. Psychosocial research related to gonorrhoea has focused on issues relevant to disease control, including barriers to partner referral (Nuwaha, Faxelid et al. 2000; Fortenberry, Brizendine et al. 2002).

There has been virtually no consideration of the mental health factors associated with diagnosis or outcomes of either of these conditions.

Human papillomavirus (HPV) infection

There are a number of human papillomaviruses (HPV), some of which are transmitted through sexual contact. Sexually transmitted HPV infection is common in women, particularly young women. Prevalence rates vary by population group and country of residence: HPV infection has been found in 16% of women in China (Li, Dai et al. 2006), 11–38% in Australia (O'Keefe, Gardner et al. 2006; Posner, Boyle et al. 2006), 51% of women in the United States (Kahn, Slap et al. 2005) and 58% in Brazil (Oliveira, Rosa et al. 2006). Genital HPV infection may be asymptomatic, or may cause genital warts, or genital or cervical intraepithelial neoplasia (often diagnosed by cervical smear tests Tinkle 1990; Stoler 1996; often diagnosed by cervical smear tests Wiley and Masongsong 2006). The association of cervical intraepithelial neoplasia and cervical cancer with HPV has led to increasing interest in testing for HPV during screening for cervical abnormalities. It has also stimulated the development of vaccines against two types of HPV involved in the development of cervical cancer (Frazer and Cox 2006; Leggatt and Frazer 2007); (Wiley and Masongsong 2006). Epidemiological data indicate that genital warts and cervical intraepithelial neoplasia are caused by different HPV types. Thus, the presence of warts does not indicate that a smear test will be abnormal (Ault 2006; Dalstein, Briolat et al. 2006; Wiley and Masongsong 2006). Women's knowledge about the association between HPV, cervical screening and cancer remains limited; in all but one Australian study (Giles and Garland 2006), most women were unaware of any association (Andersson-Ellstrom & Milsom, 2002; Pitts & Clarke, 2002; Gudmundsdottir et al., 2003; Kahn et al., 2005; Klug, Hetzer & Blettner, 2005; McMullin et al., 2005; Philips, Avis & Whyne, 2005).

Diagnosis of HPV infection has a significant psychological impact (Conaglen, Hughes et al. 2001), yet little research has been conducted on the mental health effects of HPV. For a small proportion of women (~3% in an Indian study: Singh, Sehgal et al. 1995), the physical manifestation of HPV is cauliflower-like warts on the labia and in the vagina (due to two specific strains of HPV: Handsfield 1997). Genital warts can provoke a sense of shame, depression, and anxiety (Linnehan and Groce 2000; Cox, Petry et al. 2004; Philips, Avis et al. 2005;

McCaffery, Waller et al. 2006; Friedman and Sheppard 2007), affecting the woman's health behaviour, including her sexual practices and attendance for cervical screening (Ault 2006); this may have consequences subsequently for her physical health. In one of the few studies exploring women's responses to a diagnosis of HPV infection, McCaffery et al. (McCaffery, Waller et al. 2006) argued that it is the diagnosis itself that prompts a range of negative psychosocial responses, which need to be addressed. Specifically, they noted that women often felt distressed, anxious or upset following diagnosis – which often occurred in the context of limited knowledge about HPV – and expressed concerns about their future health, fertility, and cancer risk. In addition, women viewed HPV as a highly stigmatizing condition, which left them feeling “unclean”, “dirty”, or “infectious”; they felt guilty and responsible for the infection, which had significant implications in terms of their sexual relationships (McCaffery, Waller et al. 2006). Such findings suggest that greater attention should be given to psychosocial issues associated with cervical screening and HPV diagnosis (Miller, Mischel et al. 1996; Waller, McCaffery et al. 2004).

Genital herpes

Genital infection with herpes simplex virus type 2 (HSV2) is one of the most common sexually transmitted viral infections in the world. It is incurable and can cause recurrent painful outbreaks. Infants may become infected during birth, and develop serious illness. Infection with HSV2 increases the risk of infection with HIV. Control of HSV2 is a key factor in reducing transmission of HIV in settings where HIV is widespread (del Mar Pujades Rodriguez et al., 2003; Kamali et al., 2003).

Diagnosis of HSV2 infection is associated with a range of psychological responses, including anguish, anger, lowered self-esteem, and hostility towards the person believed to be the source of the infection. Distress may be associated with the diagnosis itself, the adjustment to the infection, the type of social supports available to the person, and the need to decide whether to tell other people (Fraley 2002). Melville et al. (Melville, Sniffen et al. 2003) reported strong emotional and psychosocial responses to a diagnosis of herpes infection, including denial, confusion, distress, disappointment, relief, fear of

telling sexual partners, anger at the source partner, guilt about acquiring or transmitting the infection, and concern about transmitting it to future offspring. Dalkvist et al. (Dalkvist, Wahlin et al. 1995) and Cohen et al. (Cohen, Kemeny et al. 1999) found that persistent stress and anxiety were particularly predictive of recurrence of symptoms, but not transient changes in mood, short-term stressors, life change events, or phase of the menstrual cycle. Chronic elevated stress may result in recurrence of symptoms and, in a cyclical fashion, further worsen mental health and quality of life (Rein 2000; Judlin 2002; Pereira, Antoni et al. 2003). Women experiencing chronic social and economic adversity may therefore be especially likely to experience recurrent outbreaks of herpes.

Depression is common among people diagnosed with genital herpes; it appears to be more severe in women than in men (Mindel 1996; Dibble and Swanson 2000) and in those with a first episode of genital herpes. Ongoing responses include fear of telling future partners, continued concern about transmission, and feeling sexually undesirable and socially stigmatized. Continuing psychological problems include interference with sexual relationships, a sense of despair and low quality of life. People with genital herpes have also been found to use health services more often (Spencer, Leplege et al. 1999; Taboulet, Halioua et al. 1999; Melville, Sniffen et al. 2003).

Despite its global prevalence, little work has been conducted on the mental health impact of herpes outside North America and Western Europe. Psychosocial considerations are important in the management of recurrent genital herpes (Longo and Koehn 1993). Cognitive coping strategies and support from a partner appear to help with adjustment (Mindel 1996). Women with herpes tend to have a more negative self-view and more confusion and stress symptoms than infected men. Gender-specific interventions for young adults with genital herpes have therefore been advocated (Lewis, Rosenthal et al. 1999; Dibble and Swanson 2000).

Overall, herpes infection results in significant psychological stress and psychosexual morbidity, and has a marked negative impact on quality of life (Wild, Patrick et al. 1995; Mindel 1996; Brentjens, Yeung-Yue et al. 2003).

Chlamydia

Chlamydial infection is caused by the bacterium *Chlamydia trachomatis*. It is diagnosed by laboratory testing of swabs collected from the cervix in women or the urethra in men. It can be treated with antibiotics. Untreated chlamydia may spread through the uterus to the fallopian tubes, causing salpingitis, a painful condition, which may result in pelvic inflammatory disease, infertility or ectopic pregnancy. In men, chlamydia can result in infertility through inflammation around the testes. Chlamydial infection is very common, often occurring in young adults, and can be passed from mother to child during birth, causing conjunctivitis or pneumonia.

Most people with chlamydia do not have symptoms and remain unaware of infection. Symptoms in men may include urethritis. In women, infection often starts in the cervix, and symptoms may include vaginal discharge, burning on urination, lower abdominal pain, or pain during sexual intercourse, causing considerable suffering. Little work has been conducted on the mental health effects of the diagnosis, the disease itself, or its long-term effects (France, Thomas et al. 2001). According to one small study in Glasgow, most infected women had not considered that they were at risk of STI; this negatively affected their reactions to diagnosis, and produced anxiety about disclosing their infection to others and about the possible effects on their future reproductive health (Duncan, Hart et al. 2001). Risk factors, other than behavioural factors such as non-use of condoms, are unclear (Williams, Wingood et al. 2002), and there appears to be a complex interaction between geographical location, age, ethnic group, social deprivation and multiple simultaneous sexual partnerships (Potterat, Zimmerman-Rogers et al. 1999; Winter, Sriskandabalan et al. 2000; Connell, McKeivitt et al. 2004). While better population-based data are needed, street youth, sex workers, and individuals with social problems appear to be at high risk of infection in all settings (Paris, Gotuzzo et al. 1999).

Other psychological, behavioural and social factors have yet to be linked to chlamydia (Claman, Toye et al. 1995), but it is often diagnosed in women who have experienced sexual violence (Martin, Matza et al. 1999). The prevalence of chlamydia associated with sexual violence in young people points to the need for services to

appropriately assess and respond to their mental health needs (Kawsar, Anfield et al. 2004). There is evidence from the USA that young people diagnosed with conditions such as chlamydia subsequently felt less comfortable during sex, had negative feelings about themselves, and felt angry after sex (Whitten, Rein et al. 2003). This points to the emotional costs of such diagnoses and the need for readily available mental health services and interventions targeted to specific subgroups, particularly young people or women who have experienced sexual violence.

Malignant conditions

Cervical cancer

Cervical cancer is associated with infection with human papillomavirus, a sexually transmitted virus. It is the second most common cancer in women after breast cancer (Lambley, 1993; (Parkin, Bray et al. 2005), accounting for approximately 15% of all cancers in women. Its incidence is increasing: each year, worldwide, approximately 500 000 new cases of cervical cancer are diagnosed and some 270 000 women die of the disease (WHO, 2004 (Parkin, Bray et al. 2005). The incidence of cervical cancer is higher in developing than in developed countries, and 78% of all new cases occur in developing countries (Parkin 1994; Parkin, Bray et al. 2005). In developing countries, the burden of disease from cervical cancer is higher than that from breast cancer; approximately 80% of women who die from the disease are in these countries (Parkin, Pisani et al. 1999; Rohan et al., 2003; WHO, 2004). The highest incidence rates – over 30 per 100 000 women per year – occur in Melanesia, Central and South America, and eastern and southern Africa (WHO, 2004). The lowest incidences are found in Europe, North America, east Asia and the western Pacific (Parkin, Pisani et al. 1999). Cervical cancer rates are higher in countries in which there is a general lack of awareness of the disease, lack of recognition of premalignant cervical changes, lack of screening programmes, and limited treatment services (WHO, 2004). Death rates from cervical cancer are highest among women aged over 50 years, who may be less likely than women of reproductive age to attend gynaecological services (WHO, 2004).

The difference in incidence and mortality rates between developing and developed countries re-

flects differences in both stage of disease at diagnosis and availability of effective treatment. The Papanicolaou cytological test (Pap smear), which can detect premalignant changes in cervical cells, is recommended by WHO for population screening. Early intervention among those found positive can reduce cervical cancer mortality by at least 80% (Van Til, MacQuarrie & Herbert, 2003; WHO, 2004). Effective screening, however, places high demands on resources, and is not common in poor countries, where visual inspection of the cervix is often the only method available to detect cervical dysplasia (WHO, 2004). In developing countries, diagnosis of cervical cancer typically occurs at an advanced stage, and the 5-year survival rate is around 48% (ranging from 41% in Eastern Europe to 49% across the African continent) ((Parkin, Pisani et al. 1999). The only treatments for cervical cancer are radiotherapy and surgery, which are costly and often unavailable to women in developing countries. Prevention therefore offers the most effective strategy for controlling the disease (WHO, 2004).

Individual, social, cultural, logistic, practical, and economic factors associated with participation in cervical screening services have been investigated, in particular to learn about barriers to accessing screening, with the ultimate aim of encouraging women to attend these services. Screening programmes in developed countries have led to improved survival rates, but there are still groups of women who are not adequately screened, and are diagnosed when disease is advanced (IARC, 2004). Members of minority ethnic groups and immigrants are less likely to present for screening than other women and subsequently experience higher cervical cancer incidence and mortality rates. Women may be reluctant to attend for screening because it involves an intimate vaginal examination, especially if they have inadequate knowledge about the causes and development of cervical cancer.

Relatively little research has been conducted outside the United States on the mental health aspects of cervical cancer and knowledge of the wider psychological and social factors associated with it is limited. Studies in the USA have found that: women with disabilities have low utilization rates of cervical screening services (Havercamp, Scandlin & Roth, 2004); African-American women are more likely to be diagnosed with late stage cervical cancer than other women born

in the USA (Schwartz et al., 2003); and Asian immigrants have higher rates of cervical cancer mortality (Singh & Miller, 2004). American-born and immigrant Vietnamese women are five times more likely to be diagnosed with the disease than white women born in the USA (Taylor et al., 2004), and cervical cancer incidence and mortality rates in Latin American immigrants are more than double those of white women (Scarinci et al., 2003). These authors interpret the findings as indicating that poor, marginalized and immigrant women in the USA have a poor understanding of cervical cancer etiology, prevention, and symptoms, and therefore do not attend existing services (Perez-Stable et al., 1992; Suarez et al., 1997a; 1997b; Phipps et al., 1999).

In Canada, women of low socioeconomic status are less compliant with screening recommendations and more likely to be identified when pre-cancerous tissue is already present (Gupta et al., 2003). Screening rates are low in Hong Kong, China, which has been found to be related to cost, low knowledge about risk factors, lack of education about the importance of early detection, cultural values related to modesty, and embarrassment. Consequently the incidence of cervical cancer is relatively high (Holyroyd, Twinn & Adab, 2004). Women with a history of sexual abuse are also less likely to attend for screening, and these women appear also to be at higher risk of developing cervical cancer (Coker et al., 2000; Farley, Golding & Minkoff, 2002).

Many women experience anxiety and uncertainty when attending for screening. Ambivalence is generated by the tension between the reassurance potentially offered by screening and the possibility of diagnosing an abnormality. Uncertainty may also derive from a lack of knowledge about whether screening involves a Pap smear, colposcopy or visual examination. Although it is promoted as a preventive measure, many women see screening as a way of detecting cancer (Howson, 2001). Intimate screening examinations are invasive, may be physically uncomfortable and can arouse anxiety. Even when women present for cervical screening, they may doubt that there is an effective treatment for any abnormalities detected (Gregg & Curry, 1994; Temple-Smith et al., 1995; Kirk et al., 1998; Manderson, Kirk & Hoban, 2001). The situation is more complicated in developing countries. Women in one Thai province understood the Pap smear as a

way of diagnosing all gynaecological problems, rather than a way of screening for precancer (Boonmongkon et al., 2002). Thai women are familiar with some risk factors for cervical cancer, such as a history of sexually transmitted infections or multiple sexual partners, but attributed its occurrence also to poor vaginal and perineal hygiene, fertility control and *karma* (the negative effects of past action) (Boonmongkon, Nichter & Pylypa, 2001; Jirojwong & Manderson, 2001; Boonmongkon et al., 2002).

Testing blood for the presence of HPV antibodies has been suggested as an additional or alternative screening technique to the Pap smear. It is less invasive than other screening methods, would reduce demands on resources and is likely to improve access for older women and hard-to-reach populations (Rohan, Burk & France, 2003). Maissi et al. (2005) compared groups of women with normal or abnormal Pap smear results, who had or had not been tested for HPV infection. While there were no differences in mood or quality of life between the four groups six months after the test, specific anxiety about abnormal test results remained and was highest in the group not tested for HPV. Among the HPV-positive women in this study, those who were younger, perceived themselves to be at high risk of cancer, and who had difficulty understanding the test results were most distressed (Maissi et al., 2004).

However, the association of HPV infection and cervical cell abnormalities can discourage women from attending for screening. Kavanagh & Broom (1998) found that women who had an abnormal Pap smear result rejected the explanation that their own sexual behaviour could have caused their condition, and indicated that they were afraid that their personal morality would be judged. McCaffrey et al. (2004) surveyed 428 adult women following routine cervical screening in London, England, and found that those who were HPV-positive were more anxious than those who tested negative; the women were especially concerned about the impact on future sexual relationships. Indigenous Australian and South African women also associate cervical cancer with promiscuity, linking sexuality, dirt and disease (Wood, Jewkes & Abrahams, 1997; Manderson, Kirk & Hoban, 2001).

For some women, any gynaecological symptoms are alarming indicators of possible cervical can-

cer. Kavanagh & Broom (1997, 1998) and Karasz, McKee & Roybal (2003) found that women believed that vaginal itching and discharge could be indicators of cervical cancer and lead to an abnormal smear result. Women in north-east Thailand, with recurrent symptoms of abdominal or lower back pain, and vaginal discharge, itching or odours, also believed that these could develop into cervical cancer (Boonmongkon et al., 2002). Misunderstandings about risk generate high levels of fear. In Thailand, women's fear and worry about their cervical cancer risk led to psychological symptoms, including anxiety, insomnia, and increased stress (Boonmongkon et al., 2002).

Women who have dysplasia (abnormal cervical cell changes) or cervical cancer may have no symptoms and generally feel well. Signs of cervical cancer include irregular vaginal bleeding, unusual vaginal discharge, postcoital discomfort or bleeding, pelvic pain, excessive fatigue, swollen legs and backache. However, these signs may also indicate other conditions. Lack of knowledge about the implications of an abnormal smear test often exacerbates women's confusion, fear and anxiety following a positive result (Kavanagh & Broom, 1997; Karasz, McKee & Roybal, 2003). Limited knowledge about the natural history of cervical cancer may also contribute to women's confusion regarding medical responses to a cervical abnormality (Karasz, McKee & Roybal, 2003). The detailed physical investigations that follow an abnormal screening result are sometimes unexpected and can be emotionally disruptive; they have been described as intense and traumatic (Howson, 2001) and as having an adverse impact on day-to-day psychological functioning (Forss et al., 2004).

Relatively little is known about women's mental health once cervical cancer has been diagnosed. Studies have tended to focus on women's need for support, with less attention being paid to other aspects of psychological functioning. In general, women of low socioeconomic status and members of minority ethnic groups have been found to be more pessimistic about their prognosis than other women. While this may be realistic, because the disease is detected at a more advanced stage, it is also a result of misinformation and poor education about the progression and implications of the condition (Rodney et al., 2002). Diagnoses of cancer commonly arouse fears of illness, infirmity and death, and are of-

ten associated in the short term with elevated rates of anxiety and depression.

Women's reactions to the diagnosis, treatment and prognosis of cervical cancer have been described in general terms and include: difficulty adjusting to side-effects of treatment, including nausea, loss of weight, and hair loss; concern about the impact on relationships; and fear of recurrence of cancer after treatment. These reactions affect confidence, self-esteem and general quality of life. Some studies have indicated that women who survive cervical cancer may experience anger and frustration that they can no longer have children (Basen-Engquist et al., 2003). Others have found reduced sexual interest and higher levels of sexual dysfunction than among survivors of other cancers, including problems with arousal, genital pain and altered sexual self-concept (Lagana et al., 2001; Jensen et al., 2004). A recent study with poor Latin American immigrants in the United States identified high levels of self-reported depression related to having cancer (Meyerowitz et al., 2000). Zulu women patients in South Africa also had high levels of psychiatric morbidity (Nair, 2000). In the long term, cervical cancer has a more severe adverse effect than other chronic conditions on women's quality of life; psychologically informed cancer support services are needed by all (Lalos & Eisemann, 1999; Li, Samsioe & Iosif, 1999; Klee, Thranov & Machin, 2000).

Ovarian, endometrial and other gynaecological cancers

Globally, ovarian cancer is most common among older, socioeconomically advantaged women in highly industrialized countries. Among American women, it is the fifth most common cancer and the leading cause of death from all gynaecological cancers. Although the cause is as yet unknown, the risk of developing ovarian cancer is increased in women who carry mutations of the BRCA1 and BRCA2 genes. Endometrial cancer appears to be associated with early age at menarche, late age of menopause and nulliparity, as well as infertility, obesity, diabetes and hypertension. However, many cases occur in women without any known risk factors (Holschneider & Berek, 2000; Loman et al., 2001; Purdie & Green, 2001; Runnebaum & Stickeler, 2001). Mental health research has focused on effective communication regarding familial risk and decision-making about prophylactic oophorectomy.

Mutations in BRCA genes can now be identified through DNA testing, which is available in most rich countries. The psychological impact of this testing is complex and has been examined in survey and interview studies. In a twelve-month post-investigation comparison of tested women who were and were not found to carry the mutation, those carrying mutations and who had not undergone prophylactic oophorectomy were the most distressed. Non-clinical distress, specific to cancer, was apparent in all carriers (Claes et al., 2005). Anxieties related to development of disease were persistent in carriers of genetic mutations (Watson et al., 2004), but there was a general reduction in distress after screening (Tiffen, Sharp & O'Toole, 2005). The alternative to prophylactic oophorectomy is regular gynaecological screening and women using one or other of these approaches were compared prospectively by Madalinska et al. (2005). Women who had surgery had fewer cancer-specific anxieties and a more optimistic view of the future, but worse sexual functioning and more menopausal symptoms. The authors concluded that these risks need to be weighed against the benefits of surgery in the clinical care of individual women. In a systematic review, Nelson et al. (2005) found that cancer risk assessment and genetic testing did not have adverse psychological sequelae, but that counselling and expert advice were needed to help women interpret the risk assessment. While professional support is beneficial for all those who screen positive (Hopwood, 2005), individual reactions are influenced by personality factors, in particular whether the person has an active or avoidant coping style; counselling needs to take this into account (Aziz et al., 2005; Hopkins et al., 2005).

In common with all those diagnosed as having cancer, women with ovarian cancer often try to make sense of their illness by seeking a cause. Unfortunately, with ovarian cancer, no direct cause can usually be identified. In Canada, women with ovarian cancer believed they had developed the disease because of a wide variety of factors, including stress, genetic factors, environmental pollution, hormones, sexual practices and smoking (Stewart et al., 2001). Awareness of cancer is generally related to age, access to information and economic status (Perez-Stable et al., 1992; Dyck, 1995; Suarez et al., 1997a; DiGiacomo, 1999; Phipps et al., 1999).

Ovarian cancer commonly presents with non-specific abdominal symptoms. Accurate diagnosis may be delayed, and women report considerable frustration regarding their experiences in seeking help, as doctors dismiss complaints such as back pain and discomfort (Markovic, Manderson et al. 2006). In women who are members of minority groups, disease is usually detected at a more advanced stage, because of delays in seeking treatment; as a result, these women have higher mortality and morbidity rates. Delays in diagnosis influence both survival and mental health status.

Length of survival depends on age at diagnosis, cancer stage and the type of tumour. The physical effects of surgery and adjuvant treatment affect quality of life and emotional well-being. Depression can occur in response to both the disease and its treatment, including to post-surgical pain, nausea, hair loss, weight loss, uncertain prognosis and the prospect of premature death. Delays in diagnosis, the high mortality rate and lack of curative treatments have an adverse impact on mental health, which should always be taken into account in routine care. Many women with ovarian cancer experience a pervasive diminution in quality of life, with preoccupation about risk of recurrence and life purpose, and gradual social withdrawal (Ferrell et al., 2005). Distress is worse in those who are younger and poor, and have a personal history of cancer or a family history of breast or ovarian cancer (Halbert et al., 2005; Geirdal et al., 2005). Social support assists adjustment following chemotherapy for ovarian cancer (Hipkins et al., 2004), but there is significant psychological morbidity during treatment and more than one-third of patients have clinically significant depression and anxiety.

Other gynaecological cancers, including vulval and vaginal cancers and teratomas, are rare. As a result, women who develop these diseases often feel isolated and distressed, linked to an inadequate general understanding of their disease and inaccurate beliefs about their causes. Treatment may involve surgical excision of the vulva, which is deeply traumatic and adversely affects body image, self-esteem, social confidence and sexual life. Its impact on mood and interpersonal relationships has not yet been systematically investigated (Andersen & Vanderdoes, 1994; Andersen, 1999a, 1999b; Barton, 2003).

Overall, poor gynaecological health has direct effects on women's mental health and psychological functioning, which need to be considered during routine health care.

Summary

Future research

1. The psychosocial consequences of obstetric injury, reproductive tract morbidity and cancers in women need to be considered and included in all research into these conditions.
2. Primary prevention programmes for gynaecological morbidity need to be designed and evaluated.
3. The specific needs of women in culturally diverse settings for advice, support and counselling during treatment and rehabilitation for gynaecological conditions should be systematically ascertained.

Policy

1. Policy and service delivery need to address both prevention and treatment of obstetric injury and gynaecological morbidity.
2. Where women's access to health services is constrained by social and cultural factors, strategies to reduce obstetric injury and gynaecological morbidity should be accompanied by efforts to improve women's social position.
3. Obstetric injuries and consequent gynaecological morbidity can be reduced by: encouraging social changes that promote the value of girls and delay marriage and first birth; ensuring rapid access to trained personnel during labour and childbirth; and ensuring that women do not return to hard manual labour shortly after childbirth.

Services

1. Gynaecological and obstetric health services need to be accessible, affordable and appropriate to women's needs.
2. The staff of such services should be trained to manage sensitively gynaecological morbidity and obstetric injury; they should try to change cultural practices that reduce women's self-determination and to identify psychological distress and anxiety.
3. Health service staff should offer non-judgemental, empathic care, which encourages women to talk about their reproductive health concerns. They should also be capable of providing support to minimize the mental health impact associated with treatment and care.
4. Gynaecological and cancer screening services should recognize that women may be fearful, embarrassed or ashamed of tests, treatment and possible disease, and should ensure that they understand the nature of screening.

References

- Adamson P (1996) Commentary: a failure of imagination. In: *The progress of nations 1996*. New York, UNICEF (<http://www.unicef.org/pon96/womfail.htm>).
- Andersen BL (1999a) Sexual self concept (schema) and adjustment following cancer. *Psychosomatic Medicine*, 61(1): 130.
- Andersen BL (1999b) Surviving cancer: the importance of sexual self-concept. *Medical and Pediatric Oncology*, 33(1): 15-23.
- Andersen BL, Vanderdoes J (1994) Surviving gynecologic cancer and coping with sexual morbidity – an international problem. *International Journal of Gynecological Cancer*, 4(4): 225-240.
- Aoyama A (2001) *Reproductive health in the Middle East and North Africa: well-being for all*. Washington, World Bank.
- Aral SO et al. (2003) The social organization of commercial sex work in Moscow, Russia. *Sexually Transmitted Diseases* 30(1): 39-45.
- Ault KA (2006). Epidemiology and natural history of human papillomavirus infections in the female genital tract. *Infectious Diseases in Obstetrics Gynecology* 14(1): 40-47.
- Axmann A (1998) Eastern Europe and community of independent states. *International Migration*, 36 (4): 587-607.
- Azariah S (2005) Is syphilis resurgent in New Zealand in the 21st century? A case series of infectious syphilis presenting to the Auckland Sexual Health Service. *New Zealand Medical Journal* 118(1211): U1349.
- Bang R, Bang A (1994) Women's perceptions of white vaginal discharge: Ethnographic data from rural Maharashtra. *Listening to Women Talk About their Health: Issues and Evidence from India*. Gittlesohn J, Bentley ME, Pelto PJ et al. New Dehli, Ford Foundation, Har-Anand Publishers.
- Bangser M, Gumodoka B, Berege Z (1999) A comprehensive approach to vesico-vaginal fistula: a project in Mwanza, Tanzania. In: Berer M, Sundari Ravindran T, eds., *Safe motherhood: critical issues*, London, Blackwell Science: 157-165.
- Barber M et al. (2001) Psychometric evaluation of two comprehensive condition-specific quality of life instruments for women with pelvic floor disorders. *American Journal of Obstetrics and Gynecology*, 185: 1388-1395.

- Baseman JG, LA Koutsky (2005) The epidemiology of human papillomavirus infections. *Journal of Clinical Virology* 32 Suppl 1: S16-24.
- Bazeed M et al. (1995) Urovaginal fistulae: 20 years' experience. *European Urology*, 27(1): 34-38.
- Bechart E (1996) Recurrent vaginal candidiasis. Reflections of a psychosomatic gynecologist. *Contraception, Fertilite, Sexualite* 24(3): 233-7.
- Bhatti LI, Fikree FF (2002) Health-seeking behavior of Karachi women with reproductive tract infections. *Social Science & Medicine* 54(1): 105-117.
- Bhatia J, Cleland J (1995) Self-reported symptoms of gynecological morbidity and their treatment in South India. *Studies in Family Planning*, 26(4): 203-216.
- Bhatia J, Cleland J (2000) Methodological issues in community-based studies of gynecological morbidity. *Studies in Family Planning*, 31(4): 267-277.
- Bhatia J et al. (1997) Levels and determinants of gynecological morbidity in a district of South India. *Studies in Family Planning*, 28(2): 95-103.
- Bishop Townsend V (1996) STDs: Screening, therapy, and long-term implications for the adolescent patient. *International Journal of Fertility and Menopausal Studies* 41(2): 109-114.
- Bjekic M, Vlajinac H et al. (2001) Trends of gonorrhoea and early syphilis in Belgrade, 1985-99. *Sexually Transmitted Infections* 77: 387-389.
- Bonetti T, Erpelding A, Pathak L (2002) *Reproductive morbidity – a neglected issue? A report of a clinic-based study held in Far-Western Nepal*. Kathmandu, Nepal Ministry of Health, GTZ, UNFPA.
- Boonmongkon PM, Nichter et al. (2001) Mot Luuk problems in northeast Thailand: why women's own health concerns matter as much as disease rates. *Social Science & Medicine* 53(8): 1095-1112.
- Boonmongkon P, Nichter M et al. (2002) Women's health in northeast Thailand: Working at the interface between the local and the global. *Women & Health* 35(4): 59-80.
- Boyer CB, Shafer MA et al. (2000) Associations of sociodemographic, psychosocial, and behavioral factors with sexual risk and sexually transmitted diseases in teen clinic patients. *Journal of Adolescent Health* 27(2): 102-111.
- Brentjens MH, Yeung-Yue KA et al. (2003) Recurrent genital herpes treatments and their impact on quality of life. *Pharmacoeconomics* 21(12): 853-863.
- Brockmeyer NH, Reimann G (1998) Syphilis - clinical aspects, diagnosis and therapy. Part 1 - clinical aspects. *Medizinische Welt* 49(12): 618-623.
- Brokaw J, Fullerton-Gleason L et al. (2002) Health status and intimate partner violence: A cross-sectional study. *Annals of Emergency Medicine* 39(1): 31-38.
- Bump R, Norton P (1998) Epidemiology and natural history of pelvic floor dysfunction. *Obstetrics and Gynecology Clinics of North America*, 25: 723-746.
- Caceres CF, Marin BV et al. (1997) Young people and the structure of sexual risks in Lima. *AIDS* 11: S67-S77.
- CDC, C. f. D. C. a. P. (2005) Genital Candidiasis (Vulvovaginal Candidiasis (VVC), vaginal yeast infections). *Candidiasis*. D. o. B. a. M. D. Coordinating Center for Infectious Diseases. Atlanta, GA, CDC. 2007.
- CDC, C. f. D. C. a. P. (2006) Primary and secondary syphilis--United States, 2003-2004. *Morbidity and Mortality Weekly Report* 55(10): 269-73.
- Chapple A (2001) Vaginal thrush: perceptions and experiences of women of south Asian descent. *Health Education and Research* 16(1): 9-19.
- Chapple A, Hassell K et al. (2000) You don't really feel you can function normally: women's perceptions and personal management of vaginal thrush. *Journal of Reproductive and Infant Psychology* 18(4): 309-319.
- Chaturvedi S et al. (1993) Somatization misattributed to non-pathological vaginal discharge. *Journal of Psychosomatic Research*, 37(6): 575-579.
- Chen ZQ, Zhang GC, et al. (2007) Syphilis in China: results of a national surveillance programme. *Lancet* 369(9556): 132-8.
- Ciment J (1999) Health situation in former communist bloc is dire, says Unicef. *BMJ* 319(7221): 1324.
- Claman P, Toye B et al. (1995) Serologic Evidence of Chlamydia-Trachomatis Infection and Risk of Preterm Birth. *Canadian Medical Association Journal* 153(3): 259-262.
- Cohen F, Kemeny ME, et al. (1999) Persistent stress as a predictor of genital herpes recurrence. *Archives of Internal Medicine* 159(20): 2430-2436.

- Conaglen HM, Hughes R et al. (2001) A prospective study of the psychological impact on patients of first diagnosis of human papillomavirus. *International Journal of STD & AIDS* 12(10): 651-658.
- Connell P, McKevitt C et al. (2004) Investigating ethnic differences in sexual health: focus groups with young people. *Sexually Transmitted Infections* 80(4): 300-305.
- Cook RJ, Dickens BM, Syed S (2004) Obstetric fistula: the challenge to human rights. *International Journal of Gynaecology & Obstetrics*, 87(1):72-77.
- Cowan S (2004) Syphilis in Denmark-Outbreak among MSM in Copenhagen, 2003-2004. *European Surveillance* 9(12): 25-7.
- Cox JT, Petry KU et al. (2004) Using imiquimod for genital warts in female patients. *Journal of Womens Health* 13(3): 265-271.
- Creek TL, Thuku H et al. (2005) Declining syphilis prevalence among pregnant women in northern Botswana: an encouraging sign for the HIV epidemic? *Sexually Transmitted Infections* 81(6): 453-455.
- Dalkvist J, Wahlin TBR et al. (1995) Herpes-Simplex and Mood - a Prospective-Study. *Psychosomatic Medicine* 57(2): 127-137.
- Dalstein V, Briolat J et al. (2006) The epidemiology of genital human papillomavirus infections. *Review of Practice* 56(17): 1877-81.
- De Schryver A, Meheus A (1990) Epidemiology of sexually transmitted diseases: the global picture. *Bulletin of the World Health Organization* 68(5): 639-54.
- Dekker JH et al. (1993) Vaginal symptoms of unknown aetiology: a study in Dutch general practice. *British Journal of General Practice*, 43(371): 239-244.
- Dencheva R, Spirov G et al. (2000) Epidemiology of syphilis in Bulgaria, 1990-1998. *International Journal of STD and AIDS* 11(12): 819-22.
- Department of Health (South Africa) Directorate, E. a. S. (2006) *National HIV and syphilis antenatal sero-prevalence survey in South Africa, 2005*. Pretoria, National Department of Health: 20.
- Dibble SL, Swanson JM (2000) Gender differences for the predictors of depression in young adults with genital herpes. *Public Health Nursing* 17(3): 187-194.
- Donnay F, Weil L (2004) Obstetric fistula: the international response. *Lancet*, 363(9402): 71-72.
- Donovan B (2004) Sexually Transmitted infections other than HIV. *Lancet* 363(9408): 545-556.
- Duncan B, Hart G et al. (2001) Qualitative analysis of psychosocial impact of diagnosis of Chlamydia trachomatis: implications for screening. *British Medical Journal* 322(7280): 195-199.
- Duncan ME, Tibaux G et al. (1997) STDs in women attending family planning clinics: A case study in Addis Ababa. *Social Science & Medicine* 44(4): 441-454.
- Dyck I (1995) Hidden geographies: the changing lifeworlds of women with multiple sclerosis. *Social Science & Medicine*, 40(3): 307-320
- Fairley CK, Hocking JS et al. (2005) Syphilis: back on the rise, but not unstoppable. *Medical Journal of Australia* 183(4): 172-173.
- Fenton KA, Imrie J (2005) Increasing rates of sexually transmitted diseases in homosexual men in Western europe and the United States: why? *Infectious Diseases Clinics of North America* 19(2): 311-31.
- Figueroa JP (2004). An overview of HIV/AIDS in Jamaica: strengthening the response. *West Indian Medical Journal* 53(5): 277-82.
- Finelli L, Levine WC et al. (2001) Syphilis outbreak assessment. *Sexually Transmitted Diseases* 28 (3): 131-135.
- Firestein BA (2001) Beyond STD prevention: Implications of the new view of women's sexual problems. *Women & Therapy* 24(1-2): 27-31.
- Fortenberry JD, Brizendine E et al. (2002) The role of self-efficacy and relationship quality in partner notification by adolescents with sexually transmitted infections. *Archives of Pediatrics & Adolescent Medicine* 156(11): 1133-1137.
- Fraley SS (2002) Psychosocial outcomes in individuals living with genital herpes. *Journal of Obstetric Gynecologic and Neonatal Nursing* 31 (5): 508-513.
- France C, Thomas K et al. (2001) Psychosocial impacts of chlamydia testing are important. *British Medical Journal* 322(7296): 1245.
- Frazer IH, Cox J (2006) Finding a vaccine for human papillomavirus. *Lancet* 367(9528): 2058-9.
- Friedman AL, Sheppard H (2007) Exploring the Knowledge, Attitudes, Beliefs, and Communication Preferences of the General Public Regarding HPV: Findings from CDC Focus Group Research and Implications for Practice. *Health Education and Behaviour*.

- Gerbase AC, Rowley JT et al. (1998) Global prevalence and incidence estimates of selected curable STDs. *Sexually Transmitted Infections* 74 Suppl 1: S12-6.
- Germain A (2000) Population and reproductive health: where do we go next? *American Journal of Public Health*, 90(12): 1845-1847.
- Giles M, Garland S (2006) A study of women's knowledge regarding human papillomavirus infection, cervical cancer and human papillomavirus vaccines. *Australian and New Zealand Journal of Obstetrics and Gynaecology* 46(4): 311-5.
- Go VF, Quan VM et al. (2002) Barriers to reproductive tract infection (RTI) care among Vietnamese women - Implications for RTI control programs. *Sexually Transmitted Diseases* 29(4): 201-206.
- Grgic-Vitek M, Klavs I et al. (2002) Syphilis epidemic in Slovenia influenced by syphilis epidemic in the Russian Federation and other newly independent states. *International Journal of STD and AIDS* 13 Suppl 2: 2-4.
- Gulcur L (2000) Evaluating the role of gender inequalities and rights violations in women's mental health. *Health and Human Rights*, 5(1): 46-66.
- Gupta S et al. (2003) Delivering equitable care: comparing preventive services in Manitoba. *American Journal of Public Health*, 93(12): 2086-2092.
- Guo SF (1999) Cultural and personal behavioral factors and women's reproductive tract infections. *Chinese Medical Journal* 112(11): 1044-1048.
- Guo SF, Wang LH et al. (2002) Health service needs of women with reproductive tract infections in selected areas of China. *Chinese Medical Journal* 115(8): 1253-1256.
- Handsfield HH (1997) Clinical presentation and natural course of anogenital warts. *American Journal of Medicine* 102(5A): 16-20.
- Havercamp S, Scandlin D, Roth M (2004) Health disparities among adults with developmental disabilities, adults with other disabilities, and adults not reporting disability in North Carolina. *Public Health Report*, 119(4): 418-426.
- Hawkes S, Morison L et al. (1999) Reproductive-tract infections in women in low-income, low-prevalence situations: assessment of syndromic management in Matlab, Bangladesh. *Lancet* 354(9192): 1776-1781.
- Hernandez-Giron CA, Cruz-Valdez A et al. (1998) Prevalence and risk factors associated with syphilis in women. *Review Saude Publica* 32(6): 579-86.
- Hilton P (2001) Vesico-vaginal fistula: new perspectives. *Current Opinion in Obstetrics and Gynecology*, 13: 513-520.
- Hilton P, Ward A (1998) Epidemiological and surgical aspects of urogenital fistula: a review of 25 years experience in south-east Nigeria. *International Urogynecology Journal and Pelvic Floor Dysfunction*, 9: 189-194.
- Hoekstra, CEL, Riedijk M et al. (2006) Prevalence of HIV and syphilis in pregnant women in Leon, Nicaragua. *American Journal of Tropical Medicine and Hygiene* 75(3): 522-525.
- Holmes M (1999). Sexually transmitted infections in female rape victims. *AIDS, Patient Care and STDS* 13(12): 703-708.
- Holtgrave DR, Crosby RA (2003) Social capital, poverty, and income inequality as predictors of gonorrhoea, syphilis, chlamydia and AIDS case rates in the United States. *Sexually Transmitted Infections* 79(1): 62-64.
- Hunt J, Geia L (2002) Can we better meet the healthcare needs of Aboriginal and Torres Strait Islander women? *Medical Journal of Australia*, 177(18 November): 533-534.
- Ibrahim T, Sadiq A, Daniel S (2000) Characteristics of vesico-vaginal fistula patients as seen at the specialist hospital Sokoto, Nigeria. *West African Medical Journal*, 19: 59-63.
- Irving, G, Miller D et al. (1998) Psychological factors associated with recurrent vaginal candidiasis: a preliminary study. *Sexually Transmitted Infections* 74(5): 334-8.
- Jaswal S (2001) Gynaecological morbidity and common mental disorders in low-income urban women in Mumbai. In: Davar B, ed., *Mental health from a gender perspective*, New Delhi, Sage Publications: 138-154.
- Jewkes R (2000) Violence against women: an emerging health problem. *International Clinical Psychopharmacology* 15: S37-S45.
- Johnston A, Fernando D et al. (2005) Sexually transmitted infections in New Zealand in 2003. *New Zealand Medical Journal* 118(1211): U1347.
- Judlin PG (2002) Genital herpes and health-related quality of life. *Pathologie Biologie* 50(8): 493-495.
- Kahn JA, Slap GB et al. (2005) Psychological, behavioral, and interpersonal impact of human papillomavirus and Pap test results. *Journal of Womens Health* 14(7): 650-9.

- Karapetyan AF, Sokolovsky YV et al. (2002) Syphilis among intravenous drug-using population: epidemiological situation in St Petersburg, Russia. *International Journal of STD and AIDS* 13(9): 618-23.
- Kawsar M, Anfield A et al. (2004) Prevalence of sexually transmitted infections and mental health needs of female child and adolescent survivors of rape and sexual assault attending a specialist clinic. *Sexually Transmitted Infections* 80(2): 138-141.
- Kerani RP, Handsfield HH et al. (2006) Rising Rates of Syphilis in the Era of Syphilis Elimination. *Sexually Transmitted Diseases*.
- Kildea S, Bowden FJ (2000) Reproductive health, infertility and sexually transmitted infections in Indigenous women in a remote community in the Northern Territory. *Australian and New Zealand Journal of Public Health* 24 (4): 382-386.
- Koenig M et al. (1998) Investigating women's gynaecological morbidity in India: not just another KAP survey. *Reproductive Health Matters*, 6(11): 84-96.
- Kumari S, Walia I, Singh A (2000) Self-reported uterine prolapse in a resettlement colony of North India. *Journal of Midwifery and Women's Health*, 45(4): 343-350.
- Leggatt GR, Frazer IH (2007) HPV vaccines: the beginning of the end for cervical cancer. *Current Opinions in Immunology*.
- Lewis LM, Rosenthal SL et al. (1999) College students' knowledge and perceptions of genital herpes. *International Journal of STD & AIDS* 10(11): 703-708.
- Li LK, Dai M et al. (2006) Human papillomavirus infection in Shenyang City, People's Republic of China: A population-based study. *British Journal of Cancer* 95(11): 1593-7.
- Linnehan M, Groce NE (2000) Counseling and educational interventions for women with genital human papillomavirus infection. *AIDS Patient Care and STDs* 14(8): 439-445.
- Longo D, Koehn K (1993) Psychosocial Factors and Recurrent Genital Herpes - a Review of Prediction and Psychiatric-Treatment Studies. *International Journal of Psychiatry in Medicine* 23(2): 99-117.
- Luber K, Boero M, Choe J (2001) The demographics of pelvic floor disorders: current observations and future projections. *American Journal of Obstetrics and Gynaecology*, 184(7): 1496-1503.
- Mak DB, Johnson GH et al. (2004) A syphilis outbreak in remote Australia: epidemiology and strategies for control. *Epidemiology of Infections* 132(5): 805-12.
- Manhart LE, Dialmy A et al. (2000) Sexually transmitted diseases in Morocco: gender influences on prevention and health care seeking behavior. *Social Science & Medicine* 50 (10): 1369-1383.
- Markovic M, Manderson L et al. (2006) Treatment decisions: A qualitative study with women with gynaecological cancer. *Australian & New Zealand Journal of Obstetrics & Gynaecology* 46(1): 46-48.
- Martin SL, Matza LS et al. (1999) Domestic violence and sexually transmitted diseases: The experience of prenatal care patients. *Public Health Reports* 114(3): 262-268.
- Mason L (2001) Evidence-based midwifery in action. Guidelines on the teaching of pelvic floor exercises. *British Journal of Midwifery*, 9(10): 608-611.
- McCaffery K, Waller J et al. (2006) Social and psychological impact of HPV testing in cervical screening: a qualitative study. *Sexually Transmitted Infections* 82(2): 169-74.
- Melville J, Sniffen S et al. (2003) Psychosocial impact of serological diagnosis of herpes simplex virus type 2: a qualitative assessment. *Sexually Transmitted Infections* 79(4): 280-285.
- Messer E (1997) Intra-household allocation of food and health care: current findings and understandings-introduction. *Social Science and Medicine*, 44(11): 1675-1684.
- Miller SM, Mischel W et al. (1996) From human papillomavirus (HPV) to cervical cancer: Psychosocial processes in infection, detection, and control. *Annals of Behavioral Medicine* 18(4): 219-228.
- Miller K, Rosenfield A (1996) Population and women's reproductive health: an international perspective. *Annual Review of Public Health*, 17: 359-382.
- Mindel A (1996) Psychological and psychosexual implications of herpes simplex virus infections. *Scandinavian Journal of Infectious Diseases* 100: 27-32.
- Moerman M (1982) Growth of the birth canal in adolescent girls. *American Journal of Obstetrics and Gynecology*, 143(5): 528-532.
- Muleta M (2004) Socio-demographic profile and obstetric experience of fistula patients managed at the Addis Ababa Fistula Hospital. *Ethiopian Medical Journal*, 42(1): 9-16.

- Nigro L, Larocca L et al. (2006) Prevalence of HIV and other sexually transmitted diseases among Colombian and Dominican female sex workers living in Catania, Eastern Sicily. *Journal of Immigrant and Minority Health* 8(4): 319-23.
- Norton P et al. (1995) Genitourinary prolapse and joint hypermobility in women. *Obstetrics and Gynecology*, 85: 225-228.
- Nuwaha F, Faxelid E et al. (2000) Psychosocial determinants for sexual partner referral in Uganda: qualitative results. *International Journal of STD & AIDS* 11(3): 156-161.
- O'Keefe EJ, Gardner A et al. (2006) Prevalence of genital human papillomavirus DNA in a sample of senior school-aged women in the Australian Capital Territory. *Sex Health* 3(2): 91-4.
- Oliveira LH, Rosa ML et al. (2006) Human papillomavirus status and cervical abnormalities in women from public and private health care in Rio de Janeiro State, Brazil. *Review Institute of Medicine Tropica Sao Paulo* 48(5): 279-85.
- Olsen A et al. (1997) Epidemiology of surgically managed pelvic organ prolapse and urinary incontinence. *Obstetrics and Gynecology*, 89: 501-506.
- Pagliusi S. Vaccine Research and Development ([2001] 2003) *Vaccines against human papillomavirus*. Geneva, World Health Organization. 2007.
- Pajaro MC, Barberis IL et al. (2001) Epidemiology of sexually transmitted diseases in Rio Cuarto, Argentina. *Review Latinoam Microbiology* 43(4): 157-60.
- Papreen N, Sharma A et al. (2000) Living with infertility: Experiences among urban slum populations in Bangladesh. *Reproductive Health Matters* 8(15): 33-44.
- Paris M, Gotuzzo E et al. (1999) Prevalence of gonococcal and chlamydial infections in commercial sex workers in a Peruvian Amazon city. *Sexually Transmitted Diseases* 26(2): 103-107.
- Parkin DM (1994) Cancer in developing countries. *Cancer Survey* 19-20: 519-61.
- Parkin DM, Bray F et al. (2005) Global Cancer Statistics, 2002. *Cancer Journal Clinics* 55(2): 74-108.
- Parkin DM, Pisani P et al. (1999) Global cancer statistics. *Cancer Journal Clinics* 49(1): 33-64.
- Patel V, Oomman N (1999) Mental health matters too: gynaecological symptoms and depression in South Asia. *Reproductive Health Matters*, 7(14): 30-38.
- Patel V et al. (1999) Women, poverty and common mental disorders in four restructuring societies. *Social Science and Medicine*, 49: 1461-1471.
- Paz-Bailey G, Ramaswamy M et al. (2007) Herpes simplex virus type 2: epidemiology and management options in developing countries. *Sexually Transmitted Infections* 83(1): 16-22.
- Pereira DB, Antoni MH et al. (2003) Stress as a predictor of symptomatic genital herpes virus recurrence in women with human immunodeficiency virus. *Journal of Psychosomatic Research* 54(3): 237-244.
- Petchesky R (1998) Cross-country comparisons and political visions. In: Petchesky R, Judd K, eds., *Negotiating reproductive rights. Women's perspectives across countries and cultures*, London, Zed Books: 295-323.
- Philips Z, Avis M et al. (2005) Knowledge of cervical cancer and screening among women in east-central England. *International Journal of Gynecological Cancer* 15(4): 639-45.
- Piot P, Islam MQ (1994) Sexually transmitted diseases in the 1990s. Global epidemiology and challenges for control. *Sexually Transmitted Diseases* 21(2 Suppl): S7-13.
- Pitts M, Bowman M et al. (1995) Reactions to Repeated STD Infections - Psychosocial-Aspects and Gender Issues in Zimbabwe. *Social Science & Medicine* 40(9): 1299-1304.
- Plazaola-Castano J, Perez IR (2004) Intimate partner violence and physical and mental health consequences. *Medicina Clinica* 122(12): 461-467.
- Posner TN, Boyle FM et al. (2006) Prevalence and risk factors for lifetime exposure to Pap smear abnormalities in the Australian community. *Sex Health* 3(4): 275-9.
- Potterat JJ, Zimmerman-Rogers H et al. (1999) Chlamydia transmission: Concurrency, reproduction number, and the epidemic trajectory. *American Journal of Epidemiology* 150 (12): 1331-1339.
- Prasad J, Abraham S et al. (2003) Symptoms related to the reproductive tract and mental health among women in rural southern India. *National Medical Journal of India* 16(6): 303-308.
- Purevdawa E, Moon TD et al. (1997) Rise in sexually transmitted diseases during democratization and economic crisis in Mongolia. *International Journal of STD & AIDS* 8(6): 398-401.

- Ramasubban R, Rishyasringa B (2001) Weakness ('ashaktapana') and reproductive health among women in a slum population in Mumbai. *Cultural Perspectives on Reproductive Health*. C. M. Obermeyer. Oxford, Oxford University Press.
- Rein M (2000) Stress and genital herpes recurrences in women. *Journal of the American Medical Association* 283(11): 1394.
- Resl V, Kumpova M (2005) Interaction of legislation and prevalence of sexually transmitted diseases with focus on syphilis and gonorrhoea in the Czech Republic - review to year 2003. *Journal of European Academy of Dermatology and Venereology* 19(6): 692-5.
- Reynolds SJ, Risbud AR et al. (2006) High rates of syphilis among STI patients are contributing to the spread of HIV-1 in India. *Sexually Transmitted Infections* 82(2): 121-6.
- Roche P et al (2001) Australia's notifiable disease status, 1999: annual report of the National Notifiable Diseases Surveillance System. *Communicable Diseases Intelligence* 25 (4): 7pp.
- Rosenthal SL, Biro FM (1991) A Preliminary Investigation of the Psychological Impact of Sexually-Transmitted Diseases in Adolescent Females. *Adolescent and Pediatric Gynecology* 4(4): 198-201.
- Ross JL, Laston SL et al. (2002) Exploring explanatory models of women's reproductive health in rural Bangladesh. *Culture Health & Sexuality* 4(2): 173-190.
- Shrier LA, Harris SK et al. (2001) Associations of depression, self-esteem, and substance use with sexual risk among adolescents. *Preventive Medicine* 33(3): 179-189.
- Singh V, Sehgal A et al. (1995) Clinical presentation of gynecologic infections among Indian women. *Obstetrics and Gynecology* 85(2): 215-9.
- Smacchia C, Parolin A et al. (1998) Syphilis in prostitutes from Eastern Europe. *Lancet* 351(9102): 572.
- Spencer B, Leplege A et al. (1999) Recurrent genital herpes and quality of life in France. *Quality of Life Research* 8(4): 365-371.
- Stewart DE et al. (1990) Psychosocial aspects of chronic, clinically unconfirmed vulvovaginitis. *Obstetrics and Gynecology*, 75: 852-856.
- Stoler MH (1996) A brief synopsis of the role of human papillomaviruses in cervical carcinogenesis. *American Journal of Obstetrics and Gynecology* 175(4 Pt 2): 1091-8.
- Sundari Ravindran T, Savitri R, Bhavani A (1999) Women's experiences of utero-vaginal prolapse: a qualitative study from Tamil Nadu, India. In: Berer M, Sundari Ravindran T, eds., *Safe motherhood: critical issues*, London, Blackwell Science: 166-172.
- Suris JC, Resnick MD et al. (1996) Sexual behavior of adolescents with chronic disease and disability. *Journal of Adolescent Health* 19(2): 124-131.
- Taboulet F, Halioua B et al. (1999) Quality of life and use of health care among people with genital herpes in France. *Acta Dermato-Venereologica* 79(5): 380-384.
- Thirumoorthy T (1990) The epidemiology of sexually transmitted diseases in Southeast Asia and the western Pacific. *Seminars Dermatology* 9(2): 102-4.
- Tichonova L, Borisenko K et al. (1997) Epidemics of syphilis in the Russian Federation: trends, origins, and priorities for control. *Lancet* 350(9072): 210-3.
- Tinkle MB (1990) Genital human papillomavirus infection. A growing health risk. *Journal of Obstetric Gynecological and Neonatal Nursing* 19(6): 501-7.
- Trollope-Kumar K (2001) Cultural and biomedical meanings of the complaint of leukorrhea in South Asian women. *Tropical Medicine & International Health* 6(4): 260-266.
- Upchurch DM, Kusunoki Y (2004) Associations between forced sex, sexual and protective practices, and sexually transmitted diseases among a national sample of adolescent girls. *Women's Health Issues* 14(3): 75-84.
- UNFPA. (2001) *Report on the meeting for the prevention and treatment of obstetric fistula*. London. New York, United Nations Population Fund.
- UNFPA. (2002) *Mending torn lives: initiatives against obstetric fistula*. New York, United Nations Population Fund (<http://www.unfpa.org/mothers/fistula/index.htm>).
- Uribe-Salas F, Conde-Glez CJ et al. (2003) Sociodemographic dynamics and sexually transmitted infections in female sex workers at the Mexican-Guatemalan border. *Sexually Transmitted Diseases* 30(3): 266-71.
- Uuskula A, Silm H et al. (1997) Sexually transmitted diseases in Estonia: past and present. *International Journal of STD and AIDS* 8(7): 446-50.

- Vangeenderhuysen C, Prual A, Ould el Joud D (2001) Obstetric fistulae: incidence estimates for sub-Saharan Africa. *International Journal of Gynecology and Obstetrics*, 73: 65-66.
- Voeten H, O'Hara HB et al. (2004) Gender differences in health care-seeking behavior for sexually transmitted diseases - A population-based study in Nairobi, Kenya. *Sexually Transmitted Diseases* 31(5): 265-272.
- Wade AS, Kane CT et al. (2005) HIV infection and sexually transmitted infections among men who have sex with men in Senegal. *Aids* 19(18): 2133-40.
- Wall L (1999) Birth trauma and the pelvic floor: lessons from the developing world. *Journal of Women's Health*, 8(2): 149-155.
- Wall L et al. (2004) The obstetric vesicovaginal fistula: characteristics of 899 patients from Jos, Nigeria. *American Journal of Obstetrics and Gynecology*, 190(4):1011-1019.
- Waller J, McCaffery K et al. (2004) Beliefs about the risk factors for cervical cancer in a British population sample. *Preventive Medicine* 38(6): 745-53.
- Walraven G et al. (2001) The burden of reproductive-organ disease in rural women in The Gambia, West Africa. *Lancet*, 357(9263): 1161-1167.
- Walraven G, Scherf C et al. (2001) The burden of reproductive-organ disease in rural women in The Gambia, West Africa. *Lancet* 357(9263): 1161-1167.
- Walters MD (2004) Pelvic floor disorders in women: an overview. *Revista de Medicina de la Universidad de Navarra*, 48(4): 9-12.
- Wathne B et al. (1994) Vaginal discharge: comparison of clinical, laboratory and microbiological findings. *Acta Obstetrica et Gynecologica Scandinavica*, 73(10): 802-808.
- Whittaker M (2002) Negotiating care: Reproductive tract infections in Vietnam. *Women & Health* 35(4): 43-57.
- Whitten KL, Rein MF et al. (2003) The emotional experience of intercourse and sexually transmitted diseases - A decision-tree analysis. *Sexually Transmitted Diseases* 30(4): 348-356.
- World Health Organization (WHO) (2001) *Progress in Reproductive Health Research*, No. 57. Geneva, World Health Organization.
- WHO, (2001) *Global Prevalence and Incidence of Selected Curable Sexually Transmitted Infections: Overview and Estimates*. Geneva, Department of Communicable Disease Surveillance and Response, WHO.
- WHO, (2006) *Prevention and control of sexually transmitted infections: draft global strategy*. Secretariat. Geneva, World Health Organization: 67.
- Wild D, Patrick D et al. (1995) Measuring health-related quality of life in persons with genital herpes. *Quality of Life Research* 4(6): 532-539.
- Wiley D, Masongsong E (2006) Human papillomavirus: the burden of infection. *Obstetric and Gynecological Survey* 61(6 Suppl 1): S3-14.
- Williams KM, Wingood GM et al. (2002) Prevalence and correlates of Chlamydia trachomatis among sexually active African-American adolescent females. *Preventive Medicine* 35(6): 593-600.
- Winter AJ, Sriskandabalan P et al. (2000) Sociodemography of genital Chlamydia trachomatis in Coventry, UK, 1992-6. *Sexually Transmitted Infections* 76(2): 103-109.
- Yakubovsky A, Sokolovsky E et al. (2006) Syphilis management in St. Petersburg, Russia: 1995-2001. *Sexually Transmitted Diseases* 33(4): 244-9.
- Zakoucka H, Polanecky V et al. (2004) Syphilis and gonorrhoea in the Czech Republic. *European Surveillance* 9(12): 18-20.
- Zurayk H et al. (1995) Comparing women's reports with medical diagnoses of reproductive morbidity conditions in rural Egypt. *Studies in Family Planning*, 26(1): 14-21.

Chapter 7

Women's mental health in the context of HIV/AIDS

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The epidemic of human immunodeficiency virus (HIV) infection and acquired immunodeficiency syndrome (AIDS) is a major international public health problem, especially in contexts where access to health services is difficult and social inequalities are marked. The patterns of transmission of HIV and development of AIDS reflect the socioeconomic context of infection and disease: disproportionately, the populations affected are poor, marginalized, ethnic minorities, and people living in resource-poor settings and countries (Dodds et al., 2000; Tiamson, 2002). Worldwide, the number of women living with HIV is the highest it has been in the history of the epidemic (UNAIDS, 2006b). Poverty is a major factor in risk of infection, and in the impact of infection on a person's general health. At the same time, the increase in the extent and severity of poverty that occurs with AIDS is felt most acutely by women. Rights violations, economic dependence, lack of decision-making power, conflicting gender roles, disproportionate domestic responsibilities, and gender-based violence are also closely linked to, and contribute to, reproductive and mental health problems for women (Gulcur, 2000). There is, however, a marked lack of evidence on women's mental health and how it interacts with vulnerability, risk of HIV infection, response to diagnosis, and subsequent health care (Patel & Oomman, 1999). Most research on HIV/AIDS and its effects on mental health has been conducted in the United States; there is some from other rich countries, but very little from developing countries.

Gender and the risk of contracting HIV/AIDS

Since the HIV epidemic began, more than 60 million people have been infected with the virus, and globally 39.5 million people are currently living with HIV/AIDS. In 2006, there were 4.3 million new infections, and 2.9 million deaths from HIV/AIDS, making it the fourth leading cause of death in the world (UNAIDS, 2006b). The AIDS epidemic is highly concentrated in Africa, with especially high prevalence in the sub-Saharan region. In 2006, 63% of people living with HIV and 72% of all deaths from AIDS occurred in sub-Saharan Africa.

Worldwide, at the end of December 2006, 17.7 million adult women (aged 15 years and over) were living with HIV, an increase from 16.5 million in 2004 and 17.3 million in 2005 (UNAIDS, 2006a, 2006b). In 2006, worldwide, 48% of all HIV-infected adults were women; this rate reaches almost 60% in sub-Saharan Africa. Three-quarters of all HIV-positive women live in sub-Saharan Africa. One-third of pregnant women visiting clinics for antenatal checkups are HIV-positive (UNAIDS, 2006a).

HIV/AIDS has spread particularly rapidly among women because of entrenched and pervasive gender inequality. Clinical research has shown that women who contract HIV/AIDS have shorter survival times than men do because they tend to seek treatment later, if at all (Bury, Morrison & McLachlan, 1992). Studies of women's particular vulnerability to various infections, including HIV, have until recently concentrated on clinical and physiological aspects, while the psy-

chological and mental health ramifications have received less research attention. There have been few investigations of the social epidemiology of HIV infection and its interaction with mental health in women, particularly in resource-poor settings. However, there appears to be an intricate relationship between mental health and disease progression, quality of life and disease outcome. Clark (1998), in a review of the literature on the emotional impact of HIV/AIDS, described qualitative differences between women and men in terms of grief, shame, and depression. In addition, women experienced gender-specific social stigma, a greater sense of isolation, and oppression related to gender, stigma, ethnicity, poverty, and route of infection.



Worldwide in 2006, 2.3 million children under 12 years of age were infected with HIV, two million of them in sub-Saharan Africa (UNAIDS, 2006a). In 2005, half of all new adult HIV infections were in young people between the ages of 15 and 24 years (UNAIDS, 2006b). In particular, the incidence of HIV among female adolescents is increasing steadily, affecting their life circumstances and potential by predisposing them to poor physical and mental health (Brady et al., 2002). Young women are particularly vulnerable to HIV infection, because their vaginal wall is thinner than that of older women, and they have a higher risk of epithelial lesions through which infection can occur. Girls and women are often dependent on men for financial security, and the combination of dependence and subordination makes it difficult for them to insist on safe sex

(even from their partner or husband), or to end relationships that increase their risk of infection (UNAIDS, 2002a, 2002b; UNIFEM, 2001). Young women are also more at risk of HIV infection for social and economic reasons, including poor access to education, information, employment, and health care. For example, in northern Thailand, commercial sex work is the "choice" of many young women in the face of family debt, landlessness and poverty, or as a way of escaping from unhappy or abusive relationships. These young women may risk assault if they insist on condom use, and may be dependent on drugs and alcohol to deal with the circumstances of their work (Bond, Celentano & Yaddhanaphuti, 1996).

In cultures where early marriage is common, young married women often have a higher risk of HIV infection, because of its association with early sexual debut, high frequency of intercourse, low condom use, and women's limited right to refuse sex. Recent research in urban settings in Kenya and Zambia, which sought to explain the higher rates of HIV infection in young married women than in single women, found that their husbands were three times more likely to be HIV-positive than the boyfriends of the single women (Clarke, 2004). Ulin, Cayemittes & Gringle (1996) reported that between 80% and 90% of HIV-infected Haitian women attending antenatal clinics had "no possible source of infection other than their own husbands" (WHO, 2001). While women have the right, in theory, to refuse sex, in reality their partners might not recognize this right; alternatively, they may turn to sex workers, where they risk contracting the virus and bringing it back to infect their wife. "Women tend to agree that refusing sex amounts to little less than a death warrant for themselves." "People say that when you like the skin, you should like the seed. In these times – with AIDS on the streets – you have to accept when your husband says, 'Let's make love'" (Ulin, Cayemittes & Gringle, 1996).

Women may also be subject to reprisals if they refuse sex, such as the withdrawal of financial support or domestic violence: (Ulin, Cayemittes & Gringle, 1996). A history of trauma has also been found to be a general risk factor for HIV in women (Jones et al., 2001; Wyatt et al., 2002).

Sociocultural, economic and educational barriers impede effective communication between

partners (Gupta, Weiss & Mane, 1996). Lack of information about reproductive anatomy may also contribute to fears and pressures experienced by women: one review revealed that women from several countries, including Brazil, India, Jamaica and South Africa, did not like using condoms because they feared the condom might fall off inside the vagina and harm them (Gupta, Weiss & Mane, 1996).

Gender-based violence and HIV/AIDS

Gender-based violence can be both a contributor to, and a consequence of, HIV infection. Sexual violence and abuse are now recognized as a significant public health concern, placing women at high risk of sexually transmitted infections (STIs), including HIV, and a range of post-traumatic stress disorders, with adverse effects on physical and mental health (Carballo, Grocutt & Hadzihasanovic, 1996; McMahon, Goodwin & Stringer, 2000; Fikree & Bhatti, 1999). Reproductive tract infections, including STIs and HIV, contribute to a significant level of ill-health in women of reproductive age, and continue to pose a threat beyond the menopause (Sadik, 1997). The best predictors of HIV risk for women are limited material resources, previous exposure to violence, and high-risk sexual behaviour (Wyatt et al., 2002).

In December 1998, a young South African woman, Gugu Dlamini, was beaten to death by members of her community after disclosing her HIV status, because she was seen to be a disgrace to the community (Vetten & Bhana, 2001). Recently, an Indian women's rights group investigated the death of a woman with HIV/AIDS in Andhra Pradesh, India, and concluded that she had been stoned after being turned out of her family home. The National Commission for Women said they had not been able to determine the exact cause of death, but there were suggestions that she had been burned alive. However, the National AIDS Control Authority said that she had died of natural causes (BBC, 2003).

Sexual violence by men against women and girls of all ages is found in all societies. Violence and sexual exploitation increase women's and girls' exposure to, and risk of, multiple infections, including HIV, and have serious implications for women's ability to protect themselves from HIV infection (Institute of Development Studies, 2002). Women and girls are extremely vulnerable in coercive situations, where they have little power to insist on condom use or otherwise control the terms on which sex takes place. Several studies from South Africa, for example, have found that more than one in four women report that their first sexual encounter was forced (Astbury, 2002). Furthermore, in a study involving 48 countries, WHO found that 10–69% of women had been abused by an intimate partner (WHO, 2002).

The HIV pandemic has reinforced gender-based violence, stigmatization and discrimination against women. Women who are HIV-positive, or who are perceived to be HIV-positive, may be subject to discriminatory treatment, abandoned and shunned by their families and communities, dismissed from employment, assaulted, and even killed if their husband or partner dies. Women are more likely than men to be blamed for spreading the disease and stigmatized as promiscuous (UNIFEM, 2001).

HIV-positive women experience high rates of sexual and physical violence (Gielen et al., 2000; Vlahov et al., 1998; Zierler, Witbeck & Mayer, 1996), often have inadequate social support (Catalan et al., 1996; Linn et al., 1996), and express concerns about stigma, discrimination and hopelessness (Gielen et al., 1997; Pizzi, 1992; Quinn, 1993; Sowell et al., 1997). A study by Kimerling, Armistead & Forehand (1999) found that HIV-positive women were more likely to report a violent victimization experience, and had higher levels of psychological distress, depressive symptoms, and distress regarding physical symptoms (see also Linn et al., 1996).

Various studies have reported that women and girls living with HIV/AIDS are significantly more likely to have experienced traumatic life events, such as incest, sexual assault, significant physical abuse, and substance abuse (Brady et al., 2002; Emlet & Gusz, 1998; Moser, Sowell & Phillips, 2001). Wyatt et al. (2002), in their investigation of HIV-related risk factors in a community sample in the United States, found

that HIV-positive women had had more sexual partners and more sexually transmitted infections, and had suffered more severe abuse than HIV-negative women. Sexual abuse, incidents of rape and attempted rape since the age of 18, and physical abuse in childhood and adulthood increase the risk of HIV infection. Several other factors are also linked to HIV risk, including racial or ethnic group affiliation, socioeconomic status, overall health, sexual risk-taking, and prevalence of sexually transmitted infections (Newcomb et al., 1998; Wyatt, Forge & Guthrie, 1998; Wyatt et al., 1999). Women who report early and chronic sexual abuse have a sevenfold higher prevalence of HIV-related risk behaviour and markers of risk than women with no history of abuse (Allers et al., 1993; Arnow et al., 1999; Bensley, Van Eenwyk & Simmons, 2000; Parillo et al., 2001; Thompson et al., 1997; Zierler et al., 1991). The associations between child sexual abuse and HIV-related risks in adulthood have been well documented (Allers et al., 1993; Heise, Moore & Toubia, 1995; Zierler et al., 1991).

In war and conflict situations, the risk and incidence of violence against women escalate, because of breakdown of law and order, large-scale population movements, particularly of women and children, rape of young girls and women by opposing forces, and increased "survival sex", as women try to survive the loss of income, home and family (Institute of Development Studies, 2002). These factors all have an immense impact on women's psychological well-being and coping mechanisms.

Women who have sex in exchange for goods, services, security or money are at an especially increased risk of infection. Some employers may also try to exact sexual services in exchange for job security (Gordon & Crehan, 1999; Institute of Development Studies, 2002; UNAIDS, 2002a, 2002b; UNIFEM, 2001). In resource-poor settings, the context of most sex work and sexual transactions is poverty-driven, and the priority for many women is to make money to keep themselves and their families alive, rather than avoiding becoming infected.

In addition, in many countries, women have little access to treatment, and post-exposure prophylaxis (PEP) is not available. PEP is the administration of antiretroviral medication after a high-risk exposure in order to reduce the likelihood of HIV infection. Theoretically, PEP may prevent

establishment of infection (Anderson, 2000). Currently, in most countries, PEP is available only to health care professionals, and is not available to women, children and men who have been sexually assaulted or raped. Recommendations have recently been developed for PEP after non-occupational exposure to HIV. So far, limited data are available regarding the type of exposures for which PEP is prescribed, and little is known about the population most likely to seek PEP (Kwong et al., 1999). Even when PEP is available (e.g. in the industrialized countries), many women have no knowledge or information about it and no means of accessing it.

Domestic violence is also associated with increased HIV-related risks (Kimerling, Armistead & Forehand, 1999; Wingood & DiClemente, 1997a, 1997b). Women in violent relationships tend to have more partners, are less able to negotiate sexual decisions, and are more at risk of HIV infection (Amaro, 1995; Wyatt et al., 2002). Kalichman et al. (2002), in a study in the USA, found that 68% of women and 35% of men living with HIV/AIDS reported having been sexually assaulted since the age of 15. They reported greater anxiety, depression, and symptoms of borderline personality disorder, and were more likely to have unprotected intercourse and to have traded sex than HIV-negative subjects. Women with HIV/AIDS who had been sexually assaulted reported more symptoms of trauma, depression, emotional distress, HIV symptoms, opportunistic infections and AIDS-defining conditions than HIV-infected women who had not been sexually assaulted (Kimerling, Armistead & Forehand, 1999; Simoni & Ng, 2000). Similar conclusions were drawn by Gielen et al. (2001), although they also found that a supportive social network was associated with better mental health and overall quality of life.

Research by Wyatt et al. (2002) showed that being HIV-positive is associated with significantly lower income for women of all ethnic groups. Regardless of ethnicity, women who are seropositive are more likely to report being victims of adult sexual abuse and to report a more severe history of trauma than other women. Women who had had more sexual partners, were unemployed, had had more STIs, had a history of more severe trauma, or were less educated were also more likely to be HIV-positive.

Low socioeconomic resources, exposure to violence, and risky sexual behaviour increase vulnerability to infection (Wyatt et al., 2002). In most societies, racial and ethnic minorities are marginalized and underprivileged, have less access to education, information and knowledge, have fewer economic resources, live in poorer sections of the society, engage in high-risk behaviour or engage in transactional sex for survival, and have unaddressed psychosocial problems. Indirectly, therefore, HIV/AIDS risk is a function of race and ethnicity.

Inability to access socioeconomic resources, especially employment and education, may be more important than income in increasing risk of HIV infection (Schiffrin, 2001). A growing number of women are being diagnosed as having both HIV infection and substance abuse problems, particularly in industrialized countries (Moser, Sowell & Phillips, 2001); substance abuse is classified as a psychiatric disorder.

Sexual and physical abuse are frequently associated with physical and psychological co-morbidities. For example, Wingood, DiClemente & Raj (2000) found that women experiencing both sexual and physical abuse were more likely to have a history of multiple STIs, be worried about being infected with HIV, use marijuana and alcohol to cope, attempt suicide, feel as though they had no control in their relationships, and experience more episodes of physical abuse. Such traumatic life experiences are often associated with high rates of psychiatric co-morbidity, clinical depression or anxiety, substance abuse, and possible non-compliance with recommended health care and treatment (Brady et al., 2002; Weingourt et al., 2001).



Other studies on violence and its relationship to mental health have come to similar conclusions, particularly that women exposed to physical and sexual abuse are more likely to have a high level of depressive symptoms and psychiatric disorders (Hall et al., 1993; Mullen et al., 1988). Roberts et al. (1998a, 1998b) found that women in Australia who experienced abuse as adults had elevated rates of mental disorders compared with non-abused women; women who had experienced abuse both in childhood and as adults had still higher rates. Women who reported sexual abuse in adulthood had increased rates of anxiety, dysthymia, depression, phobias, harmful alcohol consumption and psychoactive drug dependence. Doubly abused women (as a child and as an adult) also had a significantly higher risk of harmful alcohol consumption and drug dependence.

A recent study investigating violence among HIV-infected women in Zambia found three major problems; domestic violence, symptoms of depression, and alcohol abuse (Murray et al., 2006). The authors highlighted the important overlap between violence and HIV infection, and identified the potential for a cyclical pattern to materialize, in which exposure to violence in childhood leads to risky sexual behaviour, which leads to increased risk of HIV infection, which leads back to the initial risk of violence related to HIV status (Murray et al., 2006).

Migration and HIV/AIDS

Globally, each year, nearly 95 million women migrate, comprising almost 50% of all international migrants (UNFPA, 2006). Social and economic factors play a major role in migration (Institute of Development Studies, 2002). In many cases, women dominate migration flows, because female migration has increased as a survival strategy for families (Wolffers & Fernandez, 1999). The governments of a number of developing countries, e.g. Bangladesh, Indonesia, the Philippines, and Sri Lanka, help their people to migrate (Fernandez, 1998).

Most migrant workers travel without their sexual partners. They often have to deal with the disruption of social support, poor living conditions and poor provision of care for their health needs (Bandyopadhyay & Thomas, 2002; Fernandez, 1998; UNAIDS, 1998). Migrant women face double problems, as women and as migrants (Long & Ankrah, 1996; Lukalo, 1998). Being a migrant

is not in itself a risk factor for infections, but circumstances can lead to increased personal risk. Two quite different sources of risk may be present in a migrant's life: stress, and sexual abuse and exploitation. In these situations, stress is associated with low wages, poor working and housing conditions and lack of autonomy. Unwelcome sexual attention and sexual abuse by employers are often reported (Bandyopadhyay & Thomas, 2002; Institute of Development Studies, 2002; Singhanetra-Renard, 1997).



Sexual abuse and exploitation are under-acknowledged features of the working environment, particularly for women working in the entertainment industry, as domestic servants, or in the sex industry. Women are particularly vulnerable in work situations involving isolation and low levels of social support. Their low status, low pay, and isolation from family and social support networks make them vulnerable to abuse and infection, and increase their dependence on others for survival. Migrant women are regularly confronted with sexual harassment, discrimination and exploitation. They are often trapped in situations where they cannot refuse to provide sexual services (Fernandez, 1998). They may have few negotiation skills and little or no bargaining power. During the initial period of adaptation, migrants are particularly vulnerable to STIs and HIV infection. Migrant workers are generally concerned first with their livelihood and survival, rather than HIV risk (Bandyopadhyay & Thomas, 2002). Stress often

contributes to the greater vulnerability of migrants to STIs and HIV/AIDS, as well as to emotional and mental health problems.

Mental health and HIV/AIDS

The mental health problems experienced by women who have HIV infection are considerable and have multiple causes (Tostes, 2004; Murray, 2004). A study in Bangkok, Thailand, documented the profound negative impact of HIV infection on women who had given birth and their families (Manopaiboon et al., 1998). The women experienced depressive symptoms and anxiety, primarily related to being HIV-infected, but also to their children's and partner's health. Other adverse family impacts that women faced were reduced income, separation from or death of partner, shifting child care responsibilities, and family migration.

An estimated one in four women newly infected with HIV is between 35 and 44 years of age, (Kalichman, Heckman & Kochman, 2000). Little is known about the impact of HIV/AIDS on these women and their partners and families. However, VanDevanter et al. (1999), in a study on the impact of a diagnosis of HIV on serodiscordant heterosexual couples, identified four major sets of issues: (1) the emotional and sexual impact on the relationship; (2) reproductive decisions; (3) the future of children and the non-infected partner; and (4) disclosure of the infection to friends and family. Specific links have been found between stigma, disclosure and the mental health status of women. Comer et al. (2000) studied the relationship between disclosure of infection and mental health among an ethnically diverse group of 176 women with mean age 36.5 years. They found that disclosure made a small but independent contribution to mental health status. In stigmatized groups, disclosure was predictive of poorer mental health status. The researchers also explored an alternative model, that poor mental health might predict lower levels of disclosure. They looked at one particular study of Hispanic women in the United States, where greater disclosure was related to higher levels of depression, psychological distress, and reported pain (although this finding did not hold up for African-American or European women) (Comer et al., 2000).

Throughout their lives, women may face a variety of challenges: fear of unwanted pregnancy, part-

ner infidelity, HIV infection, family rejection, loss of economic support and domestic violence. Married women often face considerable difficulty in attempting to assert their reproductive rights. If they request their partner to use a condom as a preventive measure, they may be seen as promiscuous or unfaithful (Long & Ankrah, 1996). On the other hand, if they contract HIV, they face being accused of causing it. "My wife at home cannot ask me to use condoms, but sometimes you sleep with a young girl. This young girl can ask you, because she doesn't want to get pregnant and have problems with her parents" (Ulin, Cayemittes & Gringle, 1996).

Women's disclosure of their HIV infection often triggers a downward spiral to destitution. In addition to the physical effects of the infection, women often lose their jobs and the support of their husbands, and are forced to turn to prostitution to feed, clothe, and educate their children. The multiple difficulties, including loss of physical and financial independence, discrimination, and other HIV-related problems, can often lead to significant distress and a risk of suicide (Heckman et al., 1999). Suicide is one of the ten leading causes of death for women aged 35–44 years, and the risk of suicide is significantly higher among those with HIV infection (Kalichman, Heckman & Kochman, 2000).

A emerging trend has been the increase in HIV infection among people aged over 50 years, reaching approximately 2.8 million cases in 2005 (UNAIDS, 2006a). The dominant risk factor for older women is heterosexual sex. Older women are particularly vulnerable, both because of the sexual behaviour of their husband or partner, and because of physiological changes that occur during menopause, such as thinning of the vaginal wall and reduced lubrication. A study of HIV-positive women over 45 years of age identified five risk factors for contracting HIV: poor mental health, substance abuse, ignorance of the earlier HIV risk behaviour of sexual partners, risk-taking in order to preserve the relationship, and lack of information on HIV prevention (Neundorfer, 2005). Mental health issues, often related to childhood or domestic abuse, were found to contribute to an increased risk of HIV. In many societies, multiple partner relationships are condoned for men, further increasing women's vulnerability to STIs, including HIV (Institute of Development Studies, 2002; Kalichman, Heckman & Kochman, 2000).

Globally, HIV/AIDS still carries a stigma, and discrimination and religious and other forms of social condemnation and sanctions persist. Depression is common among those who are infected, and is associated with a variety of other problems, including lowered immune response, disease progression to AIDS, shorter survival time, increased disability, and a lower quality of life (Chesney et al., 1996; Leserman et al., 2000; Sambamoorthi et al., 2000). Generally, patients are more likely to develop depression at two specific times: when they are diagnosed and when the first symptoms appear. HIV patients with untreated depression have higher medical costs than those treated with antidepressants.

HIV-infected patients also experience varying levels of anxiety, ranging from mild unease to full-blown panic. Inability to cope, altered body image, isolation and grief may trigger feelings of anger, despair and frustration. As a result, the patient may develop chronic generalized anxiety disorder, acute anxiety attacks, insomnia, hypochondria, major depression or brief psychosis. Dementia may be prominent, with manifestations ranging from mild forgetfulness to severe disorientation. Delirium too can be caused by a variety of organic disorders, as well as by mental distress (Abrams, Parket-Martin & Unger, 1989; Nichols, 1985; Perry, Jacobsberg & Fishman, 1990; WHO, 1987). A study in the United States found that half of HIV-positive adults had symptoms of mental disorder, including major depression, dysthymia, generalized anxiety disorder and panic attacks. A large number of these patients visited mental health specialists, participated in group treatment, used psychotherapeutic medication and discussed their emotional problems with their medical practitioners. However, few of those with low income, with little education, or from an ethnic minority attended mental health outpatient services (Bing, 2001).

Symptoms of depression are common, not only in those with HIV infection (Kalichman, Heckman & Kochman, 2000; Kalichman, Rompa & Cage, 2000), but also in people close to them (Sikkema et al., 2000). Biggar & Firehand (1998), for example, found more symptoms of depression in HIV-infected mothers and their children than in non-infected mothers and their children. People with HIV infection, particularly in small towns and rural areas, may face barriers that prevent them from receiving important care services, resulting in anxiety and depression (Heckman et

al., 1998). A study on access to and use of antenatal care by HIV-infected women reported that barriers included the unexpected and unplanned nature of the pregnancy, and mental health issues related to HIV infection, poverty, periodic homelessness, substance dependence, and lack of social support. Seropositive women perceived the health care system as threatening, and feared discrimination and breach of confidentiality. Women were mostly concerned with their mental health and well-being (Napravnik et al., 2000).

In a study of the physical and mental health of African-American mothers with a seropositive infant, the women reported infections, difficulty thinking and remembering, low energy, and gynaecological problems (Miles, Gillespie & Holditch-Davis, 2001). Women reported moderate levels of perceived stigma and high levels of depressive symptoms. Significant correlations between depressive symptoms and physical health status were found, suggesting a clear link between mental and physical health. Bennetts et al. (1999) found evidence of depressive symptoms and HIV-related worry among HIV-infected mothers in Bangkok, Thailand, at 18–24 months postpartum. Women who were no longer with their partner were at greater risk of depression; women whose babies were HIV-infected had greater worries, as did those who had not disclosed their HIV status to others and who reported that their family would be ashamed about their HIV infection. Similar observations were made by Comer et al. (2000), who found that one of the main concerns of seropositive men and women was disclosure; this led to greater stress because of the stigma surrounding HIV infection (Armistead & Forehand, 1995; Demas et al., 1995; Semple et al., 1993).

HIV symptoms are likely to have a negative impact on functioning and well-being, thereby increasing psychological distress and anxiety. Moreover, the presence of multiple HIV-related symptoms is predictive of psychiatric disorder (Bing, 2001; Bing et al., 2001). A study of 2864 HIV-positive adults found that the probability of screening positive for anxiety and depression was related to the number of HIV symptoms present (Tsao, 2004). As the disease progresses, there may be further psychiatric problems. AIDS dementia complex (ADC), a neurological dysfunction, has been found in 25–90% of AIDS patients and in 30–40% of HIV-infected patients; in some cases, it is the only mani-

festation of AIDS (Adams, 1997). Depression has a serious impact on the course of disease. For example, a study in the USA found that depression was associated with reduced quality of life and poor adherence to HIV treatment regimens (Tate et al., 2003). Despite this, women in one study (Ciambrone, 2001) did not consider HIV to be the most devastating event in their lives. Despite initial disruption, many women infected with HIV regarded family violence, drug use, or separation from their children as more significantly disruptive elements in their lives. Demi et al. (1998) studied a number of variables in women with HIV infection, such as health status, depressive mood, family cohesion and perceived stigma. They found that suicidal thoughts and suicide attempts were quite common among women with HIV infection, and those who reported suicidal thoughts had more HIV-related symptoms. Chibnall (2002) found “death distress” (death-related depression and anxiety) among younger patients with specific, diagnosable life-threatening conditions; the experience of death distress was associated with the psychosocial and spiritual dimensions of the patient's life. These psychosocial ramifications are especially relevant to patients living with AIDS.

HIV/AIDS and depression

Recent studies have tended to concentrate on the overall health and well-being of people with HIV (Brady et al., 2002; Dodds et al., 2000; Moser, Sowell & Phillips, 2001; Napravnik et al., 2000; Wingood, DiClemente & Raj, 2000). Women's health is frequently linked to inequality and generalized oppression (Travis & Compton, 2001). Women's sexual health is a direct reflection of their low status and lack of sexual autonomy, which increase the risk of sexual health problems and make it difficult for them to obtain appropriate treatment and support. This is evident in the HIV/AIDS epidemic, in which women's vulnerability is increased by male-controlled sexual decision-making, partner violence, and sexual assault (Amaro, Raj & Reed, 2001; Farmer, Connors & Simmons, 1996; WHO, 1993). Additionally, psychosocial stress may be greater in patients with AIDS than in those with other chronic diseases (WHO, 1987). Most research on psychosocial stress in HIV infection has focused on homosexual white males (Chesney, Folkman & Chambers, 1996; Chuang et al., 1989; Folkman et al., 1996; Leserman et al., 2000; Rabkin et al., 1997; Sambamoorthi et al., 2000; Williams et al., 1991). In particular,

there has been little research on the psychosocial problems faced by women with HIV infection and the related issues of childbearing and parenting (Perry, Jacobsberg & Fishman, 1990).

A 2004 study of 1716 HIV positive women found that AIDS-related deaths were more common among those with depression, and that use of mental health services was associated with lower mortality rates (Cook et al., 2004). A study among female injecting drug users found similar results: those with chronic depression were 1.7 times more likely to die from AIDS-related causes than those without (James, 2004). Again, those who used mental health services were less likely to die than those who did not use such services.

A number of studies have investigated the impact of depressive symptoms on adherence to HIV treatment. Some studies have found depression to be one of the primary reasons for poor adherence to antiretroviral treatment (Bogart, 2000; Starace 2002). A study in 2006 examined the relationship between treated or untreated depression and adherence to antiretroviral therapy in HIV-positive women (Cook et al., 2006). Those given antidepressants in addition to psychotherapy were more likely to adhere to antiretroviral therapy than those not receiving any treatment for depression. Similar findings have been found in various HIV-positive groups, including injecting drug users. In a study of 5073 HIV-positive injecting drug users, women were less adherent to antiretroviral therapy than men, and were more likely to be diagnosed with depression (Turner et al., 2003). However, a study published in 2006 found that mental health disorders, such as substance abuse and affective disorders (including depression), were not associated with decreased adherence to antiretroviral therapy or with reduced survival. In fact, mental illness was positively associated with increased use of health care services and adherence to antiretroviral therapy (Mijch et al., 2006).

Conclusion

Factors associated with psychosocial stress among patients with HIV infection and AIDS include lack of family support, fear of discrimination, loss of friends, uncertainty about the course of the illness, and concerns about sexual activity and transmitting the disease (Sadvosky, 1991). Depression is the most common mental health

problem in women, and is closely linked to the stressful life events associated with being female (Patel et al., 1999). For example, women are more likely to be victims of violence, both within and outside their home; they are more likely to be denied educational and employment opportunities; and they are more likely to have difficulties accessing health care, receiving quality care, accessing information, and satisfying their nutritional needs (Das Gupta, 1987, 1989; Patel et al., 1999). The prevalence of depression in HIV-infected clinic populations in the United States has been found to range from 22% to 32%, 2–3 times that in the general community (Brown et al., 1992; Evans et al., 1998; Ferrando et al., 1998; Rabkin et al., 1997; Williams et al., 1991). Neuropsychiatric syndromes, including dementia, delirium and depression, occur in 40–70% of AIDS patients during the later stages of the disease (Abrams, Parket-Martin & Unger, 1989; Sadvosky, 1991).

Summary

Future research

1. There have been few reports on the psychological problems of new mothers with HIV infection, in either developed or developing countries. Further research is required to complement the strong biomedical efforts to reduce mother-to-child transmission of HIV. This needs to consider the psychosocial aspects of being HIV positive and breastfeeding and of decisions about HIV treatment during the antenatal and postnatal periods.
2. Studies of distress and anxiety in HIV-positive women regarding the fate of their children are extremely rare. An estimated 14 million children have lost one or both parents to AIDS, and it is predicted that by 2010 one-third of all children in southern Africa will be orphans.
3. The impact on the mental health of girls orphaned as a result of AIDS has barely been studied; the predicted increase in their number indicates an urgent need for such research.
4. There are significant gaps in the literature on the mental health of migrant and refugee women, and its interaction with reproductive functioning. These women continue to be vulnerable to STIs, including HIV. The mental health problems of these highly vulnerable groups are either sidelined or disre-

garded at present. Next to nothing is known about how the vulnerability of these women affects their overall reproductive health, mental health and emotional well-being.

5. Another under-researched aspect of the mental health impact of the HIV epidemic on women relates to the fact that the burden of care falls primarily on them. Women may adopt or care for orphaned children of friends or relatives who have died of AIDS. In addition, women often care for partners with AIDS, regardless of their own health status. How they fulfil this responsibility, care for others, and maintain their own health is an important area for future research.

Implications for policy

1. Policies and strategies to identify psychosocial problems in HIV-infected girls and women, and mechanisms to provide support to them through integrated reproductive health services, need to be put in place.
2. Policies and strategies to help halt the widespread sexual exploitation of children, including orphaned children, are critical.
3. Protection of vulnerable girls and women, including widows, migrants and refugees, needs to be built into legal frameworks.
4. Laws to reduce prejudice, stigma and violence against girls and women are needed.

Services

1. The need for mental health care and support of girls, women and orphans in communities affected by AIDS must be ascertained and addressed at all levels of routine care.
2. Victims of domestic and sexual violence and coercion should have access to confidential care and quality psychosocial support at all levels.
3. The special needs of vulnerable children and orphans for psychosocial support and protection must be sensitively addressed through all service points.
4. Health care workers at all levels, including in the community, should receive training in counselling and psychosocial support techniques.

References

- Adams MA, Ferraro FR (1997) Acquired immunodeficiency syndrome dementia complex. *Journal of Clinical Psychology*, 53(7): 767-778.
- Abrams DI, Paret-Martin J, Unger KW (1989) Psychosocial aspects of terminal AIDS. *Patient Care*, 23(19): 41-60.
- Allers CT et al. (1993) HIV vulnerability and the adult survivor of childhood sexual abuse. *Child Abuse and Neglect*, 17(2): 291-298.
- Amaro H (1995) Love, sex, and power: considering women's realities in HIV prevention. *American Psychologist*, 5(6): 437-447.
- Amaro H, Raj A, Reed E (2001) Women's sexual health: the need for feminist analyses in public health in the decade of behaviour. *Psychology of Women Quarterly*, 25(4): 324-334.
- Anderson J, ed. (2000) *A guide to the clinical care of HIV+ women*. Rockville, MD, Womenscare.
- Armistead L, Forehand R (1995) For whom the bell tolls: parenting decisions and challenges faced by mothers who are HIV seropositive. *Clinical Psychology: Science and Practice*, 2: 239-249.
- Arnold BA et al. (1999) Childhood sexual abuse, psychological distress, and medical use among women. *Psychosomatic Medicine*, 61(6): 762-770.
- Astbury J (2002) Intimate partner violence finally a "legitimate" public health issue. *Australian and New Zealand Journal of Public Health*, 26(5): 409-411.
- Bandyopadhyay M, Thomas J (2002) Women migrant workers' vulnerability to HIV infection in Hong Kong. *AIDS care*, 14(4): 509-521.
- Bogart LM et al. (2000) Impact of medical and non medical factors on physician decision making for HIV/AIDS antiretroviral treatment. *Journal of Acquired Immune Deficiency Syndrome*, 23: 396-404.
- BBC (2003) *Mystery death of Indian AIDS woman*. London, British Broadcasting Corporation.
- Bennetts A et al. (1999) Determinants of depression and HIV related worry among HIV positive women who have recently given birth, Bangkok, Thailand. *Social Science and Medicine*, 49(6): 737-749.
- Bensley LS, Van Eenwyk J, Simmons KW (2000) Self-reported childhood sexual and physical abuse and adult HIV-risk behaviors and heavy drinking. *American Journal of Preventive Medicine*, 18(2): 151-158.

- Biggar H, Firehand R (1998) The relationship between maternal HIV status and child depressive symptoms: Do maternal depressive syndromes play a role? *Behavior Therapy*, 29(3): 409-421.
- Bing EG (2001) Psychiatric disorders and drug use among human immunodeficiency virus infected adults in the US. *Journal of the American Medical Association*, 286(20): 2524.
- Bing EG et al. (2001) Psychiatric disorders and drug use among human immunodeficiency virus infected adults in the United States. *Archives of General Psychiatry*, 58(8): 721.
- Bond KC, Celentano DD, Yaddhanaphuti C (1996) "I'm not afraid of life or death": Women in brothels in Northern Thailand. In: Long LD, Ankrah EM, eds, *Women's experiences with HIV/AIDS: an international perspective*, New York, Columbia University Press: 123-149.
- Brady S et al. (2002) Physical and sexual abuse in the lives of HIV-positive women enrolled in a primary medicine health maintenance organization. *AIDS Patient Care and Standards*, 16(3): 121-125.
- Brown GR et al. (1992) Prevalence of psychiatric disorders in early stages of HIV infection. *Psychosomatic Medicine*, 54(5): 588-601.
- Bury J, Morrison V, McLachlan S (1992) *Working with women and AIDS: medical, social, and counseling issues*. London, Routledge.
- Carballo M, Grocutt M, Hadzihanovic A (1996) Women and migration: a public health issue. *World Health Statistics Quarterly*, 49(2): 158-164.
- Catalan J et al. (1996) Women and HIV infection: investigation of its psychosocial consequences. *Journal of Psychosomatic Research*, 41(1): 39-47.
- Chesney M, Folkman S, Chambers D (1996) Coping effectiveness training for men living with HIV: preliminary findings. *International Journal of STD and AIDS*, 7 (Suppl 2): 75-82.
- Ciambrone D (2001) Illness and other assaults on self: the relative impact of HIV/AIDS on women's lives. *Sociology of Health and Illness*, 23(4): 517-540.
- Chibnall JT et al. (2002) Psychosocial-spiritual correlates of death distress in patients with life-threatening medical conditions. *Palliative Medicine*, 16(4): 331-338.
- Chuang HT et al. (1989) Psychosocial distress and well-being among gay and bisexual men with human immunodeficiency virus infection. *American Journal of Psychiatry*, 146(7): 876-880.
- Clark AS (1998) HIV/AIDS: The emotional effects and psychotherapeutic implications for women. *Dissertation Abstracts International: Section B: The Sciences & Engineering*, 59(5-B): 2414.
- Clark S (2004) Early marriage and HIV rates in sub-Saharan Africa. *Studies in Family Planning*, 35(3): 149-160.
- Comer LK et al. (2000) Illness disclosure and mental health among women with HIV/AIDS. *Journal of Community and Applied Social Psychology*, 10(6): 449-464.
- Cook J, Nygren-Krug H (2001) *Health and the Fifty-Seventh Session of the United Nations Commission on Human Rights*, Geneva, Palais des Nations. Geneva, United Nations.
- Cook J et al (2004) Depressive symptoms and AIDS related mortality among a multisite cohort of HIV positive women. *American Journal of Public Health*, 94(7): 1133-1140.
- Cook J et al (2006) Effects of treated and untreated depressive symptoms on highly active antiretroviral therapy use in a US multi-site cohort of HIV positive women. *AIDS Care*, 18(2): 93-100.
- Das Gupta M (1987) Selective discrimination against female children in rural Punjab, India. *Population and Development Review*, 13(1): 257-270.
- Das Gupta M (1989) *The effects of discrimination on health and mortality*. New Delhi, International Union for the Scientific Study of Population.
- Demas P et al. (1995) Stress, coping, and attitudes toward HIV treatment in injecting drug users: a qualitative study. *AIDS Education and Prevention*, 7(5): 429-442.
- Demi A et al. (1998) Suicidal thoughts of women with HIV infection: Effect of stressors and moderating effects of family cohesion. *Journal of Family Psychology*, 12(3): 344.
- Dodds S et al. (2000) Integrating mental health services into primary care for HIV-infected pregnant and non-pregnant women: whole life. A theoretically derived model for clinical care and outcomes assessment. *General Hospital Psychiatry*, 22: 251-260.
- Emlet CA, Gusz SS (1998) Service use patterns in HIV/AIDS case management: a five-year study. *Journal of Case Management*, 7(1): 3-9.
- Evans S et al. (1998) Pain and depression in HIV illness. *Psychosomatics*, 39(6): 528-535.

- Farmer P, Connors M, Simmons J, eds. (1996) *Women, poverty and AIDS: sex, drugs and structural violence*. Health and Social Justice, Monroe, Maine, Common Courage Press.
- Fernandez I (1998) Migration and HIV/AIDS vulnerability in South East Asia. *Paper presented at the 12th World AIDS Conference, June 28-July 3 Geneva*.
- Ferrando S et al. (1998) Fatigue in HIV illness: relationship to depression, physical limitations and disability. *Psychosomatic Medicine*, 60(6): 759-764.
- Fikree FF, Bhatti LI (1999) Domestic violence and health of Pakistani women. *International Journal of Gynaecology and Obstetrics*, 65(2): 195-201.
- Folkman S et al. (1996) Post-bereavement depressive mood and its prebereavement predictors in HIV+ and HIV- gay men. *Journal of Personality and Social Psychology*, 70(2): 336-348.
- Gielen AC et al. (2000) Women living with HIV: disclosure, violence, and social support. *Journal of Urban Health*, 77(3): 480-491.
- Gielen AC et al. (1997) Women's disclosure of HIV status: experiences of mistreatment and violence in an urban setting. *Women and Health*, 25(3): 19-31.
- Gielen AC et al. (2001) Quality of life among women living with HIV: the importance of violence, social support, and self care behaviours. *Social Science and Medicine*, 52(2): 315-322.
- Gordon P, Crehan K (1999) *Dying of sadness: gender, sexual violence and the HIV epidemic*. Geneva, United Nations Development Programme.
- Gulcur L (2000) Evaluating the role of gender inequalities and rights violations in women's mental health. *Health and Human Rights*, 5(1): 46-66.
- Gupta GR, Weiss E, Mane P (1996) Talking about sex: a prerequisite for AIDS prevention. In: Long LD, Ankrah EM, eds, *Women's experiences with HIV/AIDS: an international perspective*. New York, Columbia University Press: 333-350.
- Hall LA et al. (1993) Childhood physical and sexual abuse: their relationship with depressive symptoms in adulthood. *Image – The Journal of Nursing Scholarship*, 25(4): 317-323.
- Heckman TG et al. (1999) Depressive symptomatology, daily stressors, and ways of coping among middle-age and older adults living with HIV disease. *Journal of Mental Health Aging*, 5: 311-322.
- Heckman TG et al. (1998) Barriers to care among persons living with HIV/AIDS in urban and rural areas. *AIDS Care*, 10(3): 365-375.
- Heise L, Moore K, Toubia N (1995) *Sexual coercion and reproductive health: a focus on research*. New York, The Population Council.
- Institute of Development Studies (2002) *Gender and HIV/AIDS: Raising awareness among policy makers and practitioners*. Brighton (Bridge Brief No 11).
- James J (2004) Chronically depressed women with HIV twice as likely as others to die from AIDS related causes; those with mental health services had half the death rate of those without. *AIDS Treatment News*, 403: 2-3.
- Jones DJ et al. (2001) Disease status in African American single mothers with HIV: The role of depressive symptoms. *Health Psychology*, 20(6): 417-423.
- Kalichman SC, Heckman TG, Kochman A (2000) Depression and thoughts of suicide among middle-aged and older persons living with HIV/AIDS. *Psychiatric Services*, 51(7): 903-907.
- Kalichman SC, Rompa D, Cage M (2000) Distinguishing between overlapping somatic symptoms of depression and HIV disease in people living with HIV/AIDS. *Journal of Nervous and Mental Disease*, 188(10): 662-670.
- Kalichman SC et al. (2002) Emotional adjustment in survivors of sexual assault living with HIV/AIDS. *Journal of Traumatic Stress*, 15(4): 289-296.
- Kimerling R, Armistead L, Forehand R (1999) Victimization experiences and HIV infection in women: associations with serostatus, psychological symptoms, and health status. *Journal of Traumatic Stress*, 12(1): 41-58.
- Kwong J et al. (1999) Non-occupational HIV post-exposure prophylaxis at a Boston community health centre. *Paper presented at the 1999 National HIV Prevention Conference, Atlanta, GA*.
- Leserman J et al. (2000) Impact of stressful life events, depression, social support, coping and cortisol on progression to AIDS. *American Journal of Psychiatry*, 157(8): 1221-1228.
- Linn JG et al. (1996) Perceived health, HIV illness, and mental distress in African American clients of AIDS counseling centers. *Journal of the Association of Nurses in AIDS Care*, 7: 43-51.
- Long LD, Ankrah EM, ed. (1996) *Women's experiences with HIV/AIDS: an international perspective*. New York, Columbia University Press.

- Lukalo R (1998) *People on the move fuel HIV/AIDS*. Geneva, PANOS.
- Manopaiboon C et al. (1998) Impact of HIV on families of recently delivered HIV-infected women, Bangkok, Thailand. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology*, 18: 54-63.
- McMahon PM, Goodwin MM, Stringer G (2000) Sexual violence and reproductive health. *Maternal and Child Health Journal*, 4(2): 121-124.
- Miles MS, Gillespie JV, Holditch-Davis D (2001) Physical and mental health in African American mothers with HIV. *Journal of the Association of Nurses in AIDS Care*, 12(4): 42-50.
- Mijch A et al (2006) Increased health care utilization and increased antiretroviral use in HIV-infected individuals with mental health disorders. *HIV Medicine*, 7: 205-212.
- Moser KM, Sowell RL, Phillips KD (2001) Issues of women dually diagnosed with HIV infection and substance use problems in the Carolinas. *Issues in Mental Health Nursing*, 22(1): 23-49.
- Mukoyogo MC, Williams G (1991) *AIDS orphans: a community perspective in Tanzania*. Actionaid.
- Mullen PE et al. (1988) Impact of sexual and physical abuse on women's mental health. *Lancet*, 1(8590): 841-845.
- Murray LK et al. (2006) Violence and abuse among HIV-infected women and their children in Zambia: a qualitative study. *Journal of Nervous and Mental Disease*, 194(8): 610-615.
- Napravnik S et al. (2000) HIV-1 infected women and prenatal care utilization: barriers and facilitators. *AIDS Patient Care and Standards*, 14(8): 411-420.
- Neundorfer M et al. (2005) HIV-risk factors for midlife and older women. *The Gerontologist*, 45(5): 617-625.
- Newcomb MD et al. (1998) Acculturation, sexual risk taking and HIV health promotion among Latinas. *Journal of Counselling Psychology*, 45(4): 454-467.
- Nichols SE (1985) Psychosocial reactions of persons with the acquired immunodeficiency syndrome. *Annals of Internal Medicine*, 103(5): 765-767.
- Parillo KM et al. (2001) Association between early sexual abuse and adult HIV-risky sexual behaviors among community-recruited women. *Child Abuse and Neglect*, 25(3): 335-346.
- Patel V, Oomman N (1999) Mental health matters too: gynaecological symptoms and depression in South Asia. *Reproductive Health Matters*, 7(14): 30-38.
- Patel V et al. (1999) Women, poverty and common mental disorders in four restructuring societies. *Social Science and Medicine*, 49: 1461-1471.
- Perry S, Jacobsberg I, Fishman B (1990) Relationships between CD4 lymphocytes and psychosocial variables among HIV seropositive adults. *Paper presented at Sixth International Conference on AIDS, San Francisco*.
- Pizzi M (1992) Women, HIV infection, and AIDS: tapestries of life, death, and empowerment. *American Journal of Occupational Therapy*, 46(11): 1021-1027.
- Quinn SC (1993) AIDS and the African American woman: the triple burden of race, class, and gender. *Health Education Quarterly*, 20: 305-320.
- Rabkin JG et al. (1997) Stability of mood despite HIV illness progression in a group of homosexual men. *American Journal of Psychiatry*, 154(2): 231-238.
- Reid JB (1998) HIV/AIDS: the emotional impact on two young women whose mothers are HIV-infected. *Dissertation Abstracts International Section A: Humanities and Social Sciences*, 59(3-A): 0971.
- Roberts GL et al. (1998a) The impact of domestic violence on women's mental health. *Australian and New Zealand Journal of Public Health*, 22(7): 796-801.
- Roberts GL et al. (1998b) How does domestic violence affect women's mental health? *Women and Health*, 28(1): 117-129.
- Sadik N (1997) Reproductive health/family planning and the health of infants, girls and women. *Indian Journal of Pediatrics*, 64(6): 739-744.
- Sambamoorthi U et al. (2000) Antidepressant treatment and health services utilisation among HIV-infected Medicaid patients diagnosed with depression. *Journal of General Internal Medicine*, 15(5): 311-320.
- Schiffrin E (2001) An overview of women's health issues in the United States and United Kingdom. *Womens Health Issues*, 11(4): 261-281.
- Sample S et al. (1993) Identification of psychobiological stressors among HIV-positive women. *Women and Health*, 20(4): 15-36.
- Sikkema KJ et al. (2000) Coping strategies and emotional wellbeing among HIV infected men and women experiencing AIDS related bereavement. *AIDS Care*, 12(15): 613-624.

- Simoni JM, Ng MT (2000) Trauma, coping, and depression among women with HIV/AIDS in New York City. *AIDS Care*, 12(5): 567-580.
- Singhanetra-Renard A (1997) Population movement and the AIDS epidemic in Thailand. In: Herdt G, ed., *Sexual cultures and migration in the era of AIDS*. Oxford, Clarendon Press.
- Sowell RL et al. (1997) Quality of life in HIV-infected women in the Southeastern United States. *AIDS Care*, 9(5): 501-512.
- Starace F et al (2002) Depression is a risk factor for suboptimal adherence to highly active antiretroviral therapy. *Journal of Acquired Immune Deficiency Syndrome*, 31:S136-S139.
- Tate D et al. (2003) The impact of apathy and depression on quality of life in patients infected with HIV. *AIDS Patient Care and STDs*, 17(3): 115-120.
- Human Rights Watch (2002) *Suffering in silence: human rights abuse and HIV transmission to girls in Zambia*. New York.
- Thompson NJ et al. (1997) The relationship of sexual abuse and HIV risk behaviors among heterosexual adult female STD patients. *Child Abuse and Neglect*, 21(2): 149-156.
- Tiamson ML (2002) Challenges in the management of the HIV patient in the third decade of AIDS. *Psychiatric Quarterly*, 73(1): 51-58.
- Travis CB, Compton JD (2001) Feminism and health in the decade of behaviour. *Psychology of Women Quarterly*, 25(4): 312-323.
- Tsao JCI et al. (2004) Stability of anxiety and depression in a national sample of adults with human immunodeficiency virus. *Journal of Nervous and Mental Disease*, 192(2): 111-118.
- Turner BJ et al. (2003) Relationships of gender, depression, and health care delivery with antiretroviral adherence in HIV-infected drug users. *Journal of General Internal Medicine*, 18:248-257.
- Ulin PR, Cayemittes M, Gringle R (1996) Bargaining for life: women and the AIDS epidemic in Haiti. In: Long LD, Ankrah EM, eds, *Women's experiences with HIV/AIDS: an international perspective*. New York, Columbia University Press: 91-111.
- UNAIDS (1998) *Migration and HIV/AIDS*. New Delhi, Joint United Nations Programme on HIV/AIDS.
- UNAIDS (2002a) *AIDS epidemic update*. Geneva, Joint United Nations Programme on HIV/AIDS.
- UNAIDS (2002b) *Report on the global HIV/AIDS epidemic*. Geneva, Joint United Nations Programme on HIV/AIDS.
- UNAIDS (2006a) *Report on the global AIDS epidemic*. Geneva, Joint United Nations Programme on HIV/AIDS.
- UNAIDS (2006b) *AIDS epidemic update 2006*. Geneva, Joint United Nations Programme on HIV/AIDS, World Health Organization.
- UNICEF (2002) *The state of the world's children*. New York, United Nations Children's Fund.
- UNIFEM (2001) *Turning the tide: CEDAW and the gender dimension of the HIV/AIDS pandemic*. New York, United Nations Development Fund for Women.
- UNFPA (2006) *The State of World Population 2006. A passage to hope: women and international migration*. New York, United Nations Population Fund.
- VanDevanter N et al. (1999) Heterosexual couples confronting the challenges of HIV infection. *AIDS Care*, 11(2): 181-193.
- Vetten L, Bhana K (2001) *Violence, vengeance and gender: a preliminary investigation into the links between violence against women and HIV/AIDS in South Africa*. Johannesburg and Cape Town, Centre for the Study of Violence and Reconciliation.
- Vlahov D et al. (1998) Violence among women with or at risk for HIV infection. *AIDS and Behaviour*, 2(1): 53-60.
- Weingourt R et al. (2001) Domestic violence and women's mental health in Japan. *International Nursing Review*, 48: 102-108.
- WHO (1987) *Report from consultation on psychosocial research needs in HIV infection and AIDS*. Geneva, World Health Organization.
- WHO (1993) *Psychosocial and mental health aspects of women's health*. Geneva, World Health Organization.
- WHO (2001) *Integration of the human rights of women and the gender perspective*. Geneva, World Health Organization.
- WHO (2002) *World report on violence and health*. Geneva, World Health Organization.
- Williams JB et al. (1991) Multidisciplinary baseline assessment of homosexual men with and without human immunodeficiency virus infection, II: Standardized clinical assessment of current and lifetime psychopathology. *Archives of General Psychiatry*, 48(2): 124-130.

- Wingood GM, DiClemente RJ (1997a) Child sexual abuse, HIV sexual risk, and gender relations of African-American women. *American Journal of Preventive Medicine*, 13(5): 380-384.
- Wingood GM, DiClemente RJ (1997b) The effects of an abusive primary partner on the condom use and sexual negotiation practices of African-American women. *American Journal of Public Health*, 87(6): 1016-1018.
- Wingood GM, DiClemente RJ, Raj A (2000) Adverse consequences of intimate partner abuse among women in non-urban domestic violence shelters. *American Journal of Preventive Medicine*, 19(4): 270-275.
- Wolffers I, Fernandez J (1999) *Female migrants from Bangladesh: two studies, one from Bangladesh and one from Malaysia*. Kuala Lumpur: Coordination of Action Research on AIDS and Mobility (CARAM)
- Wyatt GE, Forge NG, Guthrie D (1998) Family constellation and ethnicity: current and lifetime HIV-related risk taking. *Journal of Family Psychology*. 12(1): 93-101.
- Wyatt GE et al. (1999) The prevalence and circumstances of child sexual abuse: changes across a decade. *Child Abuse and Neglect*, 23(1): 45-60.
- Wyatt GE et al. (2002) Does a history of trauma contribute to HIV risk for women of color? Implications for prevention and policy. *The American Journal of Public Health*, 92(4): 660-665.
- Zierler S et al. (1991) Adult survivors of childhood sexual abuse and subsequent risk of HIV infection. *American Journal of Public Health*, 81(5): 572-575.
- Zierler S, Witbeck B, Mayer K (1996) Sexual violence against women living with or at risk for HIV infection. *American Journal of Preventive Medicine*, 12(5): 304-310.

Chapter 8

Infertility and assisted reproduction

Jane Fisher

Estimating the prevalence of fertility difficulties, infertility or involuntary childlessness is hampered by variations in the definitions of these conditions (Schmidt & Munster, 1995; Kols & Nguyen, 1997). The central difficulty is in defining both the population with compromised fertility and the appropriate comparison population. The former may be conceptualized as either individuals or couples who are unable to conceive after a specified period of regular unprotected sexual intercourse or those seeking medical assistance in order to conceive. The specified time of trying to conceive has varied from 12 months to more than 24 months. Some studies have included people with primary infertility (the inability to conceive at all), secondary infertility (those who have at least one living child but are unable to conceive again), and sub-fecundity (the capacity to conceive but not to sustain a pregnancy to term). The comparison populations have sometimes included those who have never tried to conceive and large groups of young women who may not yet have tried to conceive.

The definition of infertility has a significant impact on clinical outcomes, including those reported in research studies. Definitions vary in terms of whether the condition is identified by self-report, or based on a life calendar of reproductive events, a physician consultation or a physician diagnosis. Infertility can be regarded as a heterogeneous group of health problems, influenced by a range of risk factors (Marchbanks et al., 1989).

It has been estimated, on the basis of investigations in several clinical services, that 8–12% of

women in North America are unable to conceive spontaneously (Beral et al., 1994). Postal surveys of a national sample in Australia suggest that the equivalent figure there is 15% (Australian Bureau of Statistics, 2004). Kols & Nguyen (1997) summarized the available estimates of infertility in developing countries, and found wide variations, e.g. 11–20% in sub-Saharan Africa and 14–32% in Namibia. There have been relatively few population-based investigations of the prevalence of fertility difficulties in developing countries. While this reflects local research capacity, it is also argued that it reflects predominant concerns about overpopulation and the costs of unrestrained fertility in these areas (Inhorn & Buss, 1994). Most women with infertility live in the developing world, and have limited access to diagnostic tests or treatment and, often, no access to assisted reproductive technologies (Fathalla, 1992; Vayena, Rowe & Griffin, 2002). A population survey in Gambia, using randomly selected census areas, found that primary infertility was relatively uncommon (3%), but secondary infertility following the birth of at least one child was more common (6%) (Sundby, Mbogé & Sonko, 1998). Half of those affected had not sought treatment and both investigative testing and treatment were limited. Larsen (2000) used linked population census data, which included childbirth history, to examine infertility in 28 African countries. Primary infertility was assumed in those who had been married for at least seven years without having a child, and secondary infertility in those aged 20–44 years whose most recent birth was more than five years ago. Primary infertility was low (less than 3% in the countries surveyed), but there was a wide range in secondary infertility (5–23%). In

a survey using random sampling in a rural community in Nigeria, the prevalence of primary infertility was 9.2% and of secondary infertility 21.1% (Adetoro & Ebomoyi, 1991). In a single survey of one urban region in Viet Nam, 5.7% of couples were reported to be infertile (Thwaites, 2002). In countries where treatment for reproductive tract infections is not widely available, more than 30% of women develop secondary infertility caused by tubal occlusion resulting from infection (Vayena, Rowe & Peterson, 2002).

In reviewing prevalence surveys, Schmidt & Munster (1995) found that current and lifetime prevalence of infertility ranged from 3.6% to 32.6%. They concluded that, overall, about 24% of the global population experiences either primary or secondary infertility, and that about 15% of the population of reproductive age will seek medical assistance to conceive.



Causes of infertility

Male and female factors are each believed to account for 40% of cases of infertility; the remaining 20% are either unexplained – so-called idiopathic infertility – or of shared etiology. In women, the most common causes of fertility difficulties are obstructed fallopian tubes and ovulation dysfunction, while in men low sperm viability and dysfunction of sperm motility are most common (Johnson & Everitt, 2000). It has been suggested that 5% of infertility is caused by constitutional problems, including genetic conditions, anatomical defects, and endocrinological or immunological dysfunction (Kols & Nguyen, 1997). The balance is attributable to infection, unhygienic health care practices, particularly in obstetrics, and exposure to environmental toxins. Reproductive tract infections, especially sexually transmitted infections, are the predominant cause of infertility, leading to the

formation of scar tissue which obstructs the fallopian tubes (Kols & Nguyen, 1997). In a case-control study of 60 women with infertility and 53 matched controls in Ile-Ife, Nigeria (Okonofua et al., 1997), the infertile group had higher rates of *Neisseria gonorrhoeae* antibodies and of a history of other sexually transmitted infections than the controls. Infections secondary to abortion or childbirth are also implicated (Kols & Nguyen, 1997; Sundby, Mboge & Sonko, 1998). In a comparison of consecutive women presenting with fertility problems and female hospital workers in Nigeria, Aghanwa et al. (1999) found that the patients were significantly more likely to be married to polygamous men and to have had an abortion. It has also been suggested that inappropriate treatment of undiagnosed conditions, including curettage in Gambia (Sundby, Mboge & Sonko, 1998) and cervical electrocauterization in Egypt (Inhorn & Buss, 1994) may contribute to infertility. Female fertility may be reduced following genital mutilation, as a result of chronic pelvic infections leading to obstruction of the fallopian tubes, or because narrowing of the introitus may lead to the anus or urethra being used for intercourse (Ng, 2000). Normal vaginal intercourse may be impossible if the introitus is narrowed through infibulation (Okonofua et al., 2002). Female genital schistosomiasis, which is common in sub-Saharan Africa, leads to granulomatous inflammation of the cervix and increases the likelihood of other reproductive tract infections (Poggensee et al., 2001; Poggensee & Feldmeier, 2001). Infectious causes appear to be less common in male factor infertility, but parasitic infections (including schistosomiasis, which damages the male genital tract) have been implicated in some countries (Kols & Nguyen, 1997). In developing countries, occupational exposure, for example to heavy metals, biological metabolites, pesticides and heat, may also contribute to infertility (Inhorn & Buss, 1994; Kols & Nguyen, 1997). The assessment of male factors is limited because many men refuse to participate in studies, which may mean that cause is misattributed (Aghanwa et al., 1999).

In groups with limited education, poor access to services or little general knowledge of physiological functioning, superstitious attribution is common. Anthropological investigations of women in Botswana (Upton, 2001), southern Nigeria (Koster-Oyekan, 1999) and Mozambique (Mariano, 2004), using in-depth interviews and field observations, concluded that women are usu-

ally regarded as responsible for infertility. In these investigations, infertility was attributed to: transgression of sexual taboos or rituals relating to burial of a dead child; supernatural factors, including witchcraft or a curse by ancestors or deities; and prior abortions or use of orthodox contraceptives (Koster-Oyekan, 1999; Upton, 2001). Egyptian women of low socioeconomic status living in rural areas, who cannot conceive, are regarded as having been subjected to *kabsa*, or the constraint of reproductive capacity by exposure to contaminated individuals (Inhorn, 1994). Upton (2001) and Mariano (2004) identified a contemporary paradox in some African countries, where men in poor rural communities migrate to urban areas to work and are absent for prolonged periods, but their wives are still expected to have children and are responsible when this does not occur.

People who cannot have children may be stigmatized and socially marginalized in strongly pro-natal settings. Infertility exerts a significant adverse effect on the mental health of couples who want to have children.

Psychological causation of infertility?

There has been a long-standing belief that female infertility, particularly of unknown etiology, is attributable to psychological factors – so-called “psychogenic infertility”. This has commonly been defined as fertility difficulties for which no organic cause can be identified and in which psychological mechanisms are assumed to be operating. Studies have attempted to find personality or psychiatric factors that would explain infertility. Almost all have focused on women, and most have made retrospective attribution of the observed differences between fertile and infertile women (usually those seeking treatment) to pre-existing factors. The issues proposed as etiologically involved have included uncertain gender identity, external locus of control, infertility as a defence against inner conflicts, ambivalence about having children, psychiatric symptoms, in particular, depression and anxiety, marital problems “masquerading as infertility” and sexual dysfunction (Callan & Hennessey, 1988b; Moller & Fallstrom, 1991; Greil, 1997).

There have been no population-based prospective studies that have followed women from adolescence and investigated pre-existing psychological differences between fertile and infertile groups. However, a number of cohort compari-

son studies have used more adequate methodology, including systematic sampling, adequate sample size and standardized measures. These studies have found no significant difference in rates of psychiatric illness, other psychopathology or personality factors between presumed fertile groups and those seeking infertility treatment, or between infertile groups and population norms, or between groups with infertility of different origin and duration (Edelmann et al., 1991; Downey & McKinney, 1992; Visser et al., 1994). It has been argued that women who seek treatment may be psychologically robust and not representative of the population with fertility difficulties, but this assertion has not been tested (Eugster & Vingerhoest, 1999). The observed differences in mood and self-regard between fertile and infertile groups are more accurately regarded as secondary to the infertility, rather than etiologically involved (Edelmann et al., 1991; Downey & McKinney, 1992; Eugster & Vingerhoest, 1999). As understanding of the complex physiology and biology of reproduction has grown over the past three decades, the proportion of infertility attributed to unexplained origins has decreased from about 50% of cases to between 5% and 15% (Moller & Fallstrom, 1991).

One of the criticisms of efforts to ascribe infertility to psychological factors is that they have led to misattribution of responsibility and “blaming” of victims, especially women; little research has investigated this hypothesis in recent years. While agreeing with this view, some authors have argued that certain psychiatric illnesses and behaviours make individuals more vulnerable to infertility and that these should continue to be investigated (Rosenthal & Goldfarb, 1997). In particular, the severe weight loss associated with the eating disorder, anorexia nervosa, can lead to suppression of ovulation; cigarette smoking, and alcohol and drug use, can also lead to decreased fertility. Sexual difficulties, especially erectile dysfunction and vaginismus, can impair the completion of intercourse (Rosenthal & Goldfarb, 1997). The links between behavioural factors and fertility pathology were examined in a substantial epidemiological study, which found that, while there were few differences between fertile and infertile women, tubal obstruction was associated with a higher incidence of previous sexually transmitted disease. Women with this condition had a lower age of sexual debut and more sexual partners, were more likely to have used an intrauterine contraceptive device,

and were less likely to have used condoms than those with other fertility difficulties (Beral et al., 1994). The study also found that obesity was associated with polycystic ovarian disease (Beral et al., 1994). The contribution to fertility difficulties of a delay in the age of marriage and reproduction has been identified as a concern in many industrialized countries, but the complex social and economic factors involved are not well understood (Rosenthal & Goldfarb, 1997).

Psychological impact of infertility

By definition, infertility can be identified only when it has lasted at least a year. The experience and eventual diagnostic confirmation of infertility can have a profound psychological impact (Menning, 1982), which has been conceptualized and assessed in different ways.

Psychiatric illness or normal psychological reaction to an abnormal circumstance?

There is debate about whether the psychological disturbance observable in people with infertility is more accurately conceptualized as a psychiatric illness or as an intense psychological reaction to abnormal personal circumstances. High rates of clinically significant symptoms of depression and anxiety have been reported in surveys of cohorts of women and, to a lesser extent, men seeking fertility treatment (Beaurepaire et al., 1994). More than 20% of women attending an infertility support group reported that they had experienced episodic suicidal ideation (Kerr, Brown & Balen, 1999). However, the labelling of these conditions as psychiatric illness has been criticized, because psychiatric symptom checklists include somatic symptoms (e.g. "Something is wrong with my body...") that are normal among those with infertility. As psychological state is dynamic following diagnosis and during treatment for infertility, it has been argued that a syndrome approach to conceptualization is inaccurate and that a psychological profile, along which individuals are ranged, would be more accurate (Berg & Wilson, 1990). Unlike other adverse life events, which may have a clear resolution, infertility is regarded as uniquely stressful because it can last for many years and for many will not be resolved (Berg & Wilson, 1990). Berg & Wilson (1990) have identified an infertility strain profile, characterized by increased anxiety, irritability, profound sadness, self-blame, lowered energy levels, social isolation and heightened interpersonal sensitivity.

Almost all women presenting for treatment have been found to demonstrate some of these features (Berg & Wilson, 1990).

Two approaches have been taken to describing the psychological sequelae of infertility (Greil, 1997). The first is qualitative investigation and clinical description of the experiential responses to infertility. In this approach, infertility is described as a profound life crisis or existential blow and a number of common themes are identified (Menning, 1982; Mahlstedt, 1985). Guilt is prominent among women, together with fears that earlier sexual experiences, the use of contraceptives, or delaying procreation while pursuing professional goals has compromised fertility (Mahlstedt, 1985). Other less rational beliefs – of being punished for past misdeeds or of intrinsic unworthiness – have also been reported, particularly if infertility is of unexplained origin. The frustration associated with being unable to control conception and physiological functioning commonly leads to feelings of anger (Becker, 1994). This may be directed towards a number of people, including the infertile partner, friends and associates who have been able to conceive easily, and people who offer unsolicited advice (Mahlstedt, 1985).

Reaction to infertility is also conceptualized as grief, including for many intangible or disenfranchised losses (Menning, 1982). The losses include: the experiences of pregnancy, childbirth and breastfeeding; the children and grandchildren who will not exist; a generation and genetic continuity; the state of parenthood and the activities and relationships it entails; and an element of adult and gender identity which will never be realized and is substituted with a flawed infertile identity (Menning, 1982; Olshansky, 1987; Dunnington & Glazer, 1991; Nachtigall, Becker & Wizny, 1992). In addition, individuals may fear losing significant relationships, in particular with the partner, physical attractiveness, or a positive sexual relationship (Mahlstedt, 1985; Nachtigall, Becker & Wizny, 1992). Some may offer to allow their spouse to partner someone else in order to have a child. Fertility difficulties can exert a pervasive negative effect on quality of life, compromising planning and commitment to other life activities. The effect is observable in both men and women, but more so in women (Abbey, Andrews & Halman, 1992).

Quantitative investigations have used psychomet-

ric measures, standardized in general populations, to examine whether the incidence of particular symptoms or syndromes is different in infertile and presumed fertile populations (Greil, 1997). This approach has two potential limitations. First, standardized measures of psychological dysfunction may not be sufficiently sensitive to capture the complexities of the infertility experience (Greil, 1997). Second, the group of women who experience infertility is heterogeneous, in both gynaecological and socioeconomic terms, and it is unlikely that any control or comparison group can be matched in these terms and in length of time to conceive (Hearn et al., 1987). Despite these limitations, there has been substantial research comparing infertile women and couples with presumed fertile controls or already pregnant women. Perhaps because of the limitations, the findings are inconsistent.

Significantly higher levels of depressive symptoms have been found among women seeking treatment for infertility than in presumed fertile controls (Bernstein, Potts & Mattox, 1985; Berg & Wilson, 1990; Domar et al., 1992; Beaurepaire et al., 1994). However, other investigators have reported no significant differences in levels of depression between infertile and comparison groups (Connolly et al., 1992; Downey & McKinney, 1992; Hynes et al., 1992). It has been suggested that there are, nevertheless, differences in distress between the two groups, but that the severity of this distress is not clinically significant (Greil, 1997). This is supported by the findings of significantly more non-specific emotional distress (Moller & Fallstrom, 1991) and less life satisfaction and happiness (Callan & Hennessey, 1988b) in infertile populations. More severe depression is associated with increasing age and being childless (Morrow, Thoreson & Penney, 1995). The findings regarding anxiety are similar, with some studies finding significantly higher levels among infertile groups (Beaurepaire et al., 1994; Visser et al., 1994), and others finding no differences from controls (Connolly et al., 1992). However, Connolly et al. (1992) acknowledge that individuals have differing degrees of dispositional anxiety and that these may lead to varying anxious responses to infertility. Lower levels of self-esteem and self-regard have been reported, although the differences remain within a normal range (Callan & Hennessey, 1988b; Edelmann et al., 1991; Hynes et al., 1992; Nachtigall, Becker & Wizny, 1992; Beaurepaire et al., 1994). Similarly, heightened guilt and self-blame are common, but not

pathological (Bernstein, Potts & Mattox, 1985; Morrow, Thoreson & Penney, 1995).

There have been few systematic studies of the psychological impact of infertility in developing countries, and relatively little is known about the psychological functioning of women with fertility difficulties in these settings. This situation has been described as reflecting the eurocentric focus of most research in this field (Inhorn & Buss, 1994). In a single study, Aghanwa, Dare & Ogunniyi, (1999) reported that 29.7% of infertile patients in Nigeria were depressed or had an anxiety disorder, compared with 2.7% of fertile non-matched hospital staff controls.

It has been suggested that in highly pro-natalist societies, where women may have few occupational choices and motherhood is the only identifier of adult status, infertility is highly stigmatizing (Inhorn, 2003; Koster-Oyekan, 1999; Mariano, 2004; Upton, 2001). The inability to have children damages both cultural and adult identity, and the attribution of responsibility leads to social rejection and marginalization. Infertile women may have their gender identity questioned, experience social exclusion, be suspected of having evil potential and be subject to harassment, especially from their in-laws (Koster-Oyekan, 1999; Upton, 2001). In settings where women are subordinated, they are highly likely to be blamed for infertility (Mariano, 2004). They may be divorced because of their failure to bear children, which itself is highly stigmatizing, or their husband may marry a second wife (Koster-Oyekan, 1999; Mariano, 2004; Upton, 2001). Divorced and childless women are highly vulnerable when old, because adult children are the usual primary supporters of older people. Given the very limited access to assisted reproductive treatments in these settings, infertility has been described as leading to profound human suffering (Inhorn, 2003). Upton (2001) has argued that the presumption that infertility is rare in countries with high fertility rates, and the inaccurate understanding of its determinants, have led to the condition being "invisible" to policy-makers. As a result, there has been insufficient consideration of the psychological and social costs to women of infertility in these contexts.

Gender differences in the psychological sequelae of infertility

Although infertility exerts adverse psychological effects on both men and women, there is evidence that they react differently (Abbey, Andrews

& Halman, 1991; Nachtigall, Becker & Wizny, 1992; Cook, 1993). Women have been found to experience more emotional distress and depressive symptoms associated with infertility than men, except in cases of male factor infertility where the degree of distress is similar (Nachtigall, Becker & Wizny, 1992; Beaurepaire, et al., 1994; Morrow, Thoreson & Penney, 1995). Similarly, there are adverse effects on the gender identity of all women with infertility regardless of the etiological factor; but male gender identity is adversely affected only by male factors (Nachtigall, Becker & Wizny, 1992). Even when male factors are implicated, women experience more guilt and self-blame than their male partners (Abbey, Andrews & Halman, 1991). This may be because, even when male factors are involved, most of the investigation and treatments focus on the female partner. Women's lives are more disrupted by infertility than men's (Abbey, Andrews & Halman, 1991). It also appears that the loss of sex role identity and the experiences of childbirth and parenthood is more profound for women than for men (Abbey, Andrews & Halman, 1991; Nachtigall, Becker & Wizny, 1992; Cook, 1993). Both men and women are more likely to believe that the woman is responsible if unexplained or combined factors are etiologically involved (Abbey, Andrews & Halman, 1991). Men are more likely than women to experience infertility as a sign of compromised potency and sexual adequacy (Nachtigall, Becker & Wizny, 1992).

Individuals respond to disturbing life events in different ways. Women who are able to take an active part in seeking information and making decisions about treatment have lower levels of depression and attract more social support than those who passively submit to medical recommendations (Woods, Olshansky & Draye, 1991). Individuals with high self-esteem and dispositional optimism are better protected against severe depression (Litt et al., 1992). Denial and avoidance are elements of a normal response to adverse experiences, including infertility (Menning, 1982). Some individuals may appear to be more persistently unaffected emotionally by the diagnosis of infertility, but denial is not an effective defence against severe emotional distress. Individuals who use avoidant coping and deny the emotional impact of infertility may seek multiple medical opinions, in order to find an optimistic assessment. They are at higher risk of becoming depressed and may also be vulnerable to exploitation by extravagant claims for treatments, including those for which there is

scant scientific evidence (Woods, Olshansky & Draye, 1991; Litt et al., 1992; Morrow, Thoreson & Penney, 1995).

Impact of infertility and infertility treatment on the marital relationship

Infertility can exert adverse effects on the emotional and sexual relationship between partners (Andrews, Abbey & Halman, 1992; Greil, 1997; Eugster & Vingerhoest, 1999; Hart, 2002). Guilt and inexpressible blame can have insidious effects on intimacy. The infertile partner may fear rejection or may feel obliged to offer the other a divorce so that he or she can achieve genetic parenthood with someone else (Hart, 2002). The expression of anger and frustration about the predicament may be constrained in order to protect the infertile partner (Hart, 2002). Sexual spontaneity can be impaired by the need for sexual intercourse to be carefully timed and by the clinical scrutiny to which the relationship is subjected. Both partners may experience emotional pain seeing other couples with children (Hart, 2002). However, systematic psychometric investigations have revealed few differences in quality of marital relationship between infertile and comparison groups. Rather they suggest that marital intimacy and cohesion can be strengthened and enhanced through confronting the experience of infertility together (Dennerstein & Morse, 1988; Berg & Wilson, 1991; Greil, 1997).

Psychological aspects of treatment of infertility using assisted reproductive technology

Psychological sequelae of diagnosis and treatment

In the past 25 years, technologies to treat both male and female infertility have developed rapidly. In industrialized countries with well developed infertility treatment services, it is estimated that more than 60% of couples with fertility difficulties will seek treatment (Dawson, 1994). Although the need for assisted reproductive technologies in poor countries is high, the public provision of these highly sophisticated services has to be weighed against the competing demands of major infectious and chronic disease burdens, and limited obstetric and perinatal health services (Vayena, Rowe & Griffin, 2002; WHO, 2003). Private infertility treatment services are

being established in many poor countries, but are likely to be accessible and available only to socioeconomically advantaged groups (Vayena, Rowe & Peterson, 2002; WHO, 2003). Teaching hospitals in some developing countries are starting to offer public infertility treatment services (Vayena, Rowe & Griffin, 2002). Overall, the situation in developing countries varies considerably, in terms of availability of appropriately trained health professionals and essential laboratory services, and it is not possible to generalize (Vayena, Rowe & Griffin, 2002).

Rates of pregnancy and live births following assisted conception depend on the experience of the treating centre (Eugster & Vingerhoest, 1999). While rates continue to improve, on average only 20% of couples conceive at each embryo transfer cycle (Kovacs, MacLachlan & Brehny, 2001). Using life-table calculations to review 4225 couples who had undergone 8207 cycles over six years, Kovacs, MacLachlan & Brehny (2001) reported that half the women became pregnant within three cycles and two-thirds became pregnant over six cycles. There is a theoretical debate about whether infertility should be considered a disease that requires medical treatment or an unfortunate life circumstance on which public resources should not be spent. Bewley (1995) argues that the physical and mental health risks of treating an individual, in whom the expected successful outcome of a living child is low, may outweigh the benefits. Others have suggested that the availability of assisted reproductive technologies means that both patients and clinicians try to seek a cure for the condition, rather than exploring other means of establishing a fulfilling life (Becker & Nachtigall, 1994). Critics assert that women are coerced into participating in and persisting with treatment, rather than making a free choice (Shattuck & Schwarz, 1991).

There is now substantial evidence that the nature and intensity of emotional distress vary over the course of infertility treatment. At diagnosis, symptoms of acute distress may increase; there then appears to be a decrease in symptoms once treatment starts (Beaurepaire et al., 1994). Severity of depression at this stage has been linked to having a confirmed diagnosis and a history of surgery for investigation or treatment of infertility (Domar et al., 1992). The initiation of treatment arouses optimism that the condition may be alleviated. However, there is evidence

that women hold unrealistically high expectations at this stage of the likely success of treatment (Callan & Hennessey, 1988a; Beaurepaire et al., 1994; Hammarberg, Astbury & Baker, 2001). Injections, scans, blood tests and waiting to know whether eggs have been fertilized are all regarded as more psychologically than physically demanding (Callan & Hennessey, 1988a; Hammarberg, Astbury & Baker, 2001). There is consistent evidence that the moment of embryo transfer arouses optimism, but that the interval between transfer and pregnancy testing to confirm whether implantation and conception have occurred is highly anxiety arousing (Callan & Hennessey, 1988a; Yong, Martin & Thong, 2000; Franco et al., 2002). The onset of menstruation or a negative pregnancy test leads to intense sadness, despair and a sense of lost control (Litt et al., 1992; Franco et al., 2002). Dispositional optimism and active coping are protective against depression following implantation failure; women who use avoidant coping are generally more distressed (Litt et al., 1992).

Repeated unsuccessful treatment cycles can erode the increase in confidence and hope that comes at the start of treatment. It has been shown that, after two years of unsuccessful treatment, distress returns to a higher level than before treatment and can develop into chronic and severe depression (Berg & Wilson, 1990; Domar et al., 1992). Optimism gradually diminishes over repeated cycles and few couples persist for more than six (Callan & Hennessey, 1988a; Kovacs, MacLachlan & Brehny, 2001). Making the decision to stop fertility treatment is not straightforward, as there is no clear terminal point if conception has not yet occurred (Covington, 1995). Among other factors, the decision not to attempt another treatment cycle is strongly influenced by social forces, including the opinions of family members and friends (Callan et al., 1988). One qualitative study suggested that a state of dissociation between the physical treatment and its psychological consequences is necessary in order for couples to persist with repeat cycles (Benjamin & Ha'elyon, 2002). The authors argued that this is a response to the violation of privacy and time that diagnosis and treatment involve, and that once this detachment cannot be sustained, individuals cease treatment.

In many settings, the costs of infertility treatment are not subsidized by the state and fall on the individual. This can add substantially

to the burden of emotional distress, and have a marked effect on decision-making about persistence with treatment; couples have to weigh the financial costs of diagnostic tests and treatment cycles against their yearning for a child (Abbey, Halman & Andrews, 1992; Franco et al., 2002). It has been asserted that couples cannot make a fully informed choice about participation in infertility treatment, because the risks of procedures (including ovarian hyperstimulation and multiple gestations), the economic costs, the limited success rates, and the possible adverse health effects on women and their offspring are generally understated (Pfeffer, 1991; Collins, 1994). Some support for this view has been provided by evidence that, after prolonged infertility, multiple gestations can be idealized and the associated hazards underestimated (Franco et al., 2002). Couples may actively seek a multiple birth in order to create an instant family (Leiblum, Kemmann & Taska, 1990; Gleicher et al., 1995; Goldfarb et al., 1996). Although couples may have significant fears about fetal well-being and doubts about their own capacity to care for more than one infant, they can feel prohibited from expressing this ambivalence because they consented to the transfer of multiple embryos (Leiblum, Kemmann & Taska, 1990; Gleicher et al., 1995; Goldfarb et al., 1996).

Psychological components of treatment

It has been cogently argued that, given the intensity and severity of distress that can be apparent during treatment, infertility clinicians need to have both medical and psychological skills (Covington, 1995). The promotion of optimism and personal control during treatment reduces psychological distress (Abbey, Halman & Andrews, 1992). As irritability, anxiety and depressive symptoms are most intense during the period between embryo transfer and pregnancy-testing, it has been argued that supportive counselling should be available at this time (Yong, Martin & Thong, 2000).

General social support has been found to have a more positive effect on women's distress than on men's (Abbey, Halman & Andrews, 1992). There have been a number of attempts to relieve the psychological distress of infertility and to examine whether this can increase conception rates. Individual, couple and group therapy approaches have been tried (Hart, 2002). A behavioural group treatment approach, including

relaxation training, cognitive therapy, exercise and nutritional counselling, reduced psychological symptoms in women, 34% of whom conceived; however, there was no untreated comparison group (Domar, Seibel & Benson, 1990; Domar, 1994). This psychological improvement was replicated in a subsequent study, (Domar et al., 1992b) but the group did not include women with severe psychological dysfunction. Having a peer counsellor who had experienced infertility, as well as a group leader, was found to be beneficial (Domar, Seibel & Benson, 1990). Fewer men than women want to participate in self-help support groups, although participation has been shown to provide emotional support and practical information and to reduce social isolation. Men who attended such groups to support their wives ultimately found them personally helpful (Lentner & Glazer, 1991).



Termination of infertility treatment

Not all couples with fertility difficulties will conceive following infertility treatment; significant proportions have to adjust to life without a biological offspring. Long-term follow-up studies have examined women's views about, and recollections of, the experience of infertility treatment. Combining a survey of past patients at a hospital in Oslo, Norway with a medical record au-

dit, Sundby, Olsen & Schei (1994) showed that most women had experienced discontinuity of treatment in the public sector, seeing different doctors at each consultation. One-third had stopped treatment without its being formally documented. Those who had a child were satisfied with their treatment, but less than half who did not conceive were satisfied. Independent of whether a child had been born, 70% were dissatisfied with the emotional support that had been provided by health staff (Sundby, Olsen & Schei, 1994). A follow-up study six years after cessation of treatment found that it was recalled as a traumatic life event. Overall, long-term psychological functioning was in the normal range, with greater well-being among those with a child compared with those without a child. Those with a hostile marital relationship, pre-existing psychiatric illness, or low level of education were more vulnerable in the long term. The authors commented that people undergoing infertility treatment should be encouraged, and counselled that psychological stability will eventually be restored and that adoption is often a satisfactory outcome (Sundby, 1992). Similarly, fewer than half the women in a study in Finland were satisfied with their infertility treatment. Dissatisfaction was higher among older women who had not conceived, and the doctor's capacity for empathy and kindness was central to satisfaction (Malin et al., 2001). In an Australian study of 116 women, 2–3 years after ceasing infertility treatment, Hammarberg et al. (2001) found that women who had not conceived were less satisfied with the treatment and clinical care and with their life than those who had a baby.

Psychological aspects of pregnancy, childbirth and the postpartum period after assisted conception

In recent years, the number of children born as a result of assisted reproduction has been increasing. In Australia, for example, 2.5% of live births now follow assisted conception (Waters, Dean & Sullivan, 2006). Pregnancies that have been assisted in this way carry higher risks for both mother and infant. These include increased risk of antepartum haemorrhage, multiple gestation, pregnancy hypertension, caesarean delivery, premature birth, low or very low birth weight, and the infant requiring oxygen at birth (Tallo et al., 1995; Wang et al., 1994; Waters et al., 2006). However, these risks are predominantly those associated with pregnancy at an advanced ma-

ternal age and multiple gestations (Olivennes et al., 1993). Many pregnancies following assisted conception are regarded as high risk (Dulude et al., 2002).

Pregnancy

Multiple gestations are more likely following induction of ovulation, or after the transfer of multiple embryos (McKinney & Leary, 1999). Multiple gestations are usually diagnosed very early after assisted conception, and parents may not think about the possibility of losing one fetus. Grief in those who have a single baby after having lost another fetus during the pregnancy is intense, but can be unrecognized by both health professionals and friends (Kollantai & Fleischer, 2001; Swanson, Pearsall-Jones & Hay, 2002; Fisher & Stocky, 2003). The coincidence of bereavement and pregnancy presents a psychological paradox, which is not easily resolved and may lead to delayed or disturbed grief reactions or disrupt the mother–infant attachment (Bryan & Denton, 2001; Pector & Smith-Levitin, 2002).

Very little is known about the long-term psychological consequences of what is termed planned fetal reduction or selective abortion of one or more fetuses in multiple pregnancy. In a study comparing 42 women who had undergone fetal reduction with women who had conceived a singleton pregnancy after in vitro fertilization (IVF), the rates of depression were equal in those who ultimately had a baby, but was high in those from either group who miscarried the pregnancy. However, many described fetal reduction as extremely stressful, 98% experienced anxiety, 69% sadness and 57% guilt as a result of the procedure. Grief, mourning and underlying feelings of shame were apparent in most (McKinney & Leary, 1999). Perhaps reflecting this, fetal reduction is rarely widely disclosed and may be kept secret. However, it is known that keeping secrets harms family relationships through fear of discovery and mistrust (Covington & Burns, 1999; Bryan, 2002). Qualitative investigations have reported complicated grief reactions in which multiple disenfranchised losses are experienced (Collopy, 2002). The potential impact on the living infant remains unknown, but the possibility of a “survivor syndrome”, characterized by guilt, perplexity and grief for a lost sibling, has been suggested (Bryan & Denton, 2001; Fisher & Stocky, 2003).

Pregnancies in which a heightened risk to maternal or fetal health is identified are more psychologically distressing (Dulude et al., 2002). Women who become pregnant following assisted conception have been described as: having heightened anxiety about pregnancy loss and infant health, less self-confidence, and greater difficulty in acknowledging ambivalence, anxiety or sadness; using avoidant coping; becoming hypervigilant; feeling unable to complain or seek support and denying the pregnant state as self-protection against loss (Dunnington & Glazer, 1991; Bernstein, Lewis & Seibel, 1994; van Balen, Naaktgeboren & Trimbos-Kemper, 1996; Covington & Burns, 1999; Eugster & Vingerhoest, 1999; McMahon, 1999; Hjelmstedt et al., 2003). Concern about fetal development is high even in women whose pregnancies are known to be low-risk (Reading, Chang & Kerin, 1989; Gibson et al., 2000b) and preparation of a home environment for the baby is delayed (Dunnington & Glazer, 1991; Bernstein, Lewis & Seibel, 1994). The universal psychological challenge of pregnancy is to form a maternal identity, and this process appears to be more problematic in women who have a history of infertility. The relinquishing of an infertile identity and the adoption of a fertile and maternal one have to happen rapidly, but may in reality be complicated and prolonged (Covington & Burns, 1999; McMahon, 1999). Motherhood following infertility has usually been idealized and the losses and adverse experiences it inevitably entails may be unexpected (Covington & Burns, 1999; McMahon, 1999). Although women report increased anxiety about intrapartum damage to the baby, they have often underestimated the potential risks of childbirth to themselves (Connolly et al., 1992; McMahon, 1999). In contrast, two studies reported no differences in anxiety or depressive symptoms measured with standardized instruments between women who had conceived spontaneously and those who had conceived after IVF (Stanton & Golombok, 1993; Klock & Greenfield, 2000). None of the studies controlled for the particular effects of multiple gestation, and most studies excluded multiple gestations and women who already had a child.

No differences in the intensity or quality of self-reported maternal–fetal emotional attachment have been reported, although women anticipated that their infants might have more difficulties than those conceived spontaneously. In a single

longitudinal study, anxiety was reported to decrease more as pregnancy progressed in those who had had assisted conception than in those who had conceived spontaneously (Stanton & Golombok, 1993; McMahon, 1999; Klock & Greenfield, 2000). It has been suggested that women may need additional support and sensitized care in pregnancy after assisted conception (McMahon et al. 1995; McMahon, 1999; Hjelmstedt et al., 2003).

Childbirth

Although women are at greatly elevated risk of caesarean birth after assisted conception (Wang et al., 1994), there has been little investigation of the interactions between these two procedures. There is consistent evidence that both instrumental intervention in vaginal birth and caesarean surgery are associated with increased anxiety, disappointment, grief and dissatisfaction (Boyce & Todd, 1992; Fisher, Astbury & Smith, 1997). Although mode of delivery does not appear to make an independent contribution to postpartum depression when other risk factors are taken into account (Johnstone et al., 2001), caesarean surgery can induce post-traumatic stress reactions (Fisher, Astbury & Smith, 1997). After caesarean childbirth, the first encounter between mother and infant and the initiation of breastfeeding are disrupted, with adverse effects on maternal confidence that are still measurable eight months later (Rowe-Murray & Fisher, 2001, 2002). In one study, childbirth was reported as “more exceptional” after assisted conception, but this descriptor was not defined and is difficult to interpret (van Balen, Naaktgeboren & Trimbos-Kemper, 1996).

Operative delivery and premature birth are both more common among women with multiple gestation, which occurs in 20% of pregnancies after assisted conception (Barrett & Ritchie, 2002). Premature birth typically involves separation of the mother from her infants, sometimes for prolonged periods. Intense anxiety about the infants’ health and development and about the separation is universal, and is more severe among those whose infants are seriously unwell; and the anxiety can persist for up to three years (Singer et al., 1999). When babies are kept in neonatal intensive care units, mothers report uncertainty about whether the health professional or the parent has authority over the baby (Bryan & Denton, 2001; Loo et al., 2003). A cooperative approach

to decision-making, respecting parental rights, can be helpful (Carter & Leuthner, 2002). Fear about the infants' health and viability can persist and lead to hypervigilance in relation to infant care, and delayed formation of a secure affectionate emotional attachment (Klock, 2001; Loo et al., 2003). No studies have examined the interacting emotional effects of assisted conception, operative birth, prematurity, neonatal hospitalization and multiple birth. However, the established difficulties are further magnified if the infants are separated, for example by discharge of one infant ahead of another or by care in different hospitals (Bryan & Denton, 2001). Maintaining a supply of breastmilk and establishing breastfeeding are difficult and anxiety-arousing with premature and very low-birthweight infants.

Parenthood after infertility and assisted reproduction

Most of the investigations into the long-term impact of assisted conception have focused on women's capacity to mother, the quality of mother–infant attachment and the developmental outcomes of the children. Few have focused on maternal mental and physical health in itself.

Descriptive and exploratory studies claim that, after assisted conception, mothers are more likely to be overprotective and to recall infertility as an influential negative life event. Burns (1990) concluded that infertility is not transient, continues after conception and may be experienced as long-term adjustment difficulties in the family. Further, parents may be less conscious of the challenges of parenthood and, although the quality of parenting is high, have to make an extraordinary effort to feel effective. Burns (1990) suggested that parents may have formed unrealistic and “utopian fantasies”, which make it difficult for them to adjust to the unique demands and unavoidable ambivalence of parenting. She also suggested that they are particularly likely to have difficulties separating from their infants and with the developmental process of individuation, and may be less able to foster the child's capacity for self-sufficiency (Burns, 1990, 1999). In Australia, there is an excess (6.3–9% compared with 1.2–1.7% of live births) of mothers who have experienced fertility difficulties or assisted conception among those admitted to residential early parenting services because of infant sleep or feeding disorders and mater-

nal exhaustion or mild to moderate depression (Barnett et al., 1993; Fisher et al., 2002; Fisher, Hammarberg & Baker, 2005). A group of mothers who were members of an infertility support group were found to confide less and have fewer acquaintances and friendships than a comparison group who had conceived spontaneously (Munro, Ironside & Smith, 1992). Mothers who had had assistance to conceive anticipated that their infants would have more problems and rated their infants as having more difficult temperaments than a group of controls (McMahon et al., 1997). In contrast, Golombok et al. (1995) found no adverse psychological consequences and “superior parenting” among children conceived with assisted reproductive technologies. Systematic investigations have used the Strange Situations Test, which assesses the quality of mother–child attachment through videotaped observations of the mother and child, while playing together and when separated from each other. These studies have found no differences in mother–child attachment between children conceived spontaneously or with assistance, and that most mothers were sensitive and responsive to their children (Gibson et al., 2000a). None of these studies included infants conceived by use of donor gametes or multiple births (Fisher & Stocky, 2003). In reviewing the early studies, McMahon et al. (1995) concluded that there was little evidence of differences in quality of parenting between families formed with assisted conception and others, but conceded that most of the available studies had methodological limitations.

There is consistent evidence that the emotional health of mothers of multiple infants is poorer than that of mothers of single infants, and that they are at higher risk of becoming depressed, anxious and clinically exhausted after childbirth. Hay et al. (1990) found that 29.7% of mothers of 3-month-old twins reported depression (a rate five times higher than among mothers of single 3-month-old infants); 42% had high anxiety (three times higher than among mothers of single infants). Even higher rates of depression have been reported among mothers of triplets. Robin et al. (1991) found that 40% were depressed 4 months postpartum, while Garel, Salobir & Blondel (1997) found that all reported significant distress and a quarter were being treated for depression one year postpartum. Two studies of the health and social circumstances of women admitted to Australian residential early

parenting services for treatment of unsettled infant behaviour and maternal exhaustion, anxiety and depression found an excess of mothers with multiple infants (3.7–5%, compared with the general population rate of 1.4%) (Barnett et al., 1993; Fisher et al., 2002). In a longitudinal study of more than 13 000 women who gave birth in one month in 1970, Thorpe et al. (1991) found that, five years after the birth, independent of other explanatory factors, mothers of twins were three times more likely to be depressed than those with a single child. In a small comparative study, higher parenting stress was associated with having twins, regardless of mode of conception (Cook, Bradley & Golombok, 1998). This effect may lessen as the children grow older. In examining 158 sets of twins entering preschool, Munro, Ironside & Smith (1990) found less psychiatric disturbance among mothers of twins conceived by IVF than mothers of spontaneously conceived twins.

New technologies and their implications

Donated fresh sperm has been used to treat male factor infertility for 100 years. The use of cryopreservation to store sperm for later donation is a newer technological development. The donation of embryos and oocytes has become possible more recently, and involves the donor undergoing a stimulated cycle and the surgical removal of oocytes for either transfer, cryopreservation or fertilization with donated sperm (Barrero, 2002). The new technologies now available to treat fertility difficulties may themselves carry sequelae for mental health, but very little evidence is so far available (Kirby, 1994).

Issues arising with use of the new technologies include: the ethical, legal and psychological complexities of the use of donated genetic material; payments to donors for their genetic material; debates about the maintenance of secrecy and disclosure, and the impact of legislation regarding children's rights to know their biological heritage versus parents' rights to secrecy. Gestational surrogacy and the use of donor gametes lead to complex considerations of what constitutes a parent–infant relationship (Kirkman, 1996, 1999; Barrero, 2002; Vayena, Rowe & Griffin, 2002). Relatively little is known about the motives and psychological functioning of donors, including those who donate genetic material anonymously

(Rosenthal, 1998). However, it has been established that, over time, donors may change their minds about remaining anonymous or allowing their identity to be disclosed to offspring (Blyth, Crawshaw & Daniels, 2004). In general, people conceived from donated genetic material want to know their genetic heritage and the identity of the donor, and believe that secrecy is harmful to individuals and to families (Blyth, Crawshaw & Daniels, 2004).

A shortage of donated eggs places significant limitations on treatment in most settings. In order to donate ova, women have to undergo ovarian stimulation and surgical aspiration, and the number willing to do so is limited (Cleland, 1994; Murray et al., 1994). Depending on local legislation, eggs may be donated by someone known to the recipient or by an anonymous donor, voluntarily or in exchange for payment. In some European countries, a strategy termed egg sharing is available, in which women undergoing fertility treatment requiring ovarian stimulation and oocyte retrieval can donate half the resulting ova anonymously to another couple in exchange for reduced fees and rapid access to treatment (Ahuja et al., 2003). Investigation of the psychological implications of donating ova to other women has only recently begun. However, in-depth interviews with small samples in the United Kingdom have found that the decision to participate as a donor in egg sharing schemes is influenced by the waiting time for treatment, costs of treatment, individual perceptions of the donated gametes as “tissue” or as a “potential baby”, and a complex existential notion of altruism combined with a desire to achieve a personal life goal (Rapport, 2003; Blyth, 2004). There is ongoing debate about the ethics of this option, in particular since the evidence in its favour has been generated to a large extent by providers. The short- and long-term psychological and emotional sequelae have not been examined systematically by independent investigators (Ahuja et al., 2003; Blyth, Crawshaw & Daniels, 2004).

There is debate about whether tissues with reproductive potential should be treated differently from those donated post mortem. Consideration is being given to whether cadavers, aborted fetuses or live donors may be the best source of eggs (Murray et al., 1994). In order to investigate attitudes to this theoretical possibility, women attending for pregnancy termination, contraception or infertility treatment were surveyed. In

general, there was strong support for methods to increase the supply of donated ova, from all sources, but women having abortions did not in general support post-mortem donation of ova. Neither potential donors nor potential recipients disapproved of the use of fetal ovarian tissue for research (Murray et al., 1994).

There is wide variation internationally regarding record-keeping and access to records following the use of donated genetic material (Kirby, 1994). There is a need for considered public and expert debate regarding a number of issues, e.g. quality control to protect against consanguinity, legal acknowledgment of the social rather than the genetic parent, and the rights of the children and not just the adults exposed to these procedures. The disposal of, and experimentation on, surplus frozen embryos or other genetic material remain controversial (Kirby, 1994). In considering the allocation of health resources, there is debate about whether individuals should bear the cost or whether it is a social cost to be born publicly. The complex economics of the cost-effectiveness of treatment have to be considered (Kirby, 1994; Neumann, Gharib & Weinstein, 1994).

There is also debate about whether treatment should be offered to all who seek it, or whether there should be criteria for inclusion in treatment programmes. The debate regarding the rights of the child is sometimes used to withhold treatment from post-menopausal women, because of the complex ethics relating to being born to parents who may die before the child reached maturity (Hope, Lockwood & Lockwood, 1995). Older women are generally less likely to conceive, and it has been suggested that health professionals who offer fertility treatment to older women are assisting them to act irresponsibly (Jackson, 1995). There is debate about whether these decisions, especially whether women over 50 years of age should be refused treatment, should be made by an ethics committee (who may not know the individual patient) or by a single clinician (Craft, 1995).

The psychological implications of the preservation of tissue to protect fertility in those undergoing chemotherapy are yet to be investigated.

For many women, being a mother is core to the formation of their adult identity, and the availability of technologies means that some will

persevere in their efforts to have a child, even to the extent of putting their own health at risk (Kirkman, 1996). Health professionals face significant difficulties in interpreting social and ethical dilemmas in individual cases. Nurses rated the emotional distress associated with infertility treatment as worse than either patients or physicians did, and patients rated it as worse than physicians did. However, all agreed that infertility treatment was one of the most difficult professional fields in which to practise (Kopitzke et al., 1991). Patients' irritability and frustration may be directed at health professionals, who may be perceived as lacking sensitivity and ability to communicate, or blamed for the limitations of existing knowledge and techniques. Covington (1995) stated that, because of the multiple losses, prolonged treatment, complexities in defining the end of treatment, and high failure rate, all professionals in this field need to integrate psychological with medical care.

The psychosocial sequelae of infertility and the complex psychological responses to technologically assisted conception are central to the health of people facing these life experiences, and should be considered in research and clinical services.

Summary

Future research

1. Causes of infertility differ, and in each country an accurate understanding is needed of the fertility problems of the population.
2. In most countries, the prevalence, etiology and mental health effects of fertility problems have not been established.
3. Research is needed into the demand for, and nature of, infertility treatment services in developing countries.
4. The long-term psychological consequences of infertility, including after the birth of a child, should be investigated.
5. There is a need for data on the short- and long-term psychosocial and medical consequences for both donors and recipients of gametes, including women in egg-sharing programmes.
6. There is a need for long-term comprehensive follow-up of the physical and mental health of offspring of assisted conception, with disaggregation by method of conception.

7. Multiple pregnancies, which are more common after assisted conception, carry greater psychological hazards. The interaction between infertility and multiple gestations in influencing perinatal mental health should be clarified.
8. The short- and long-term psychological effects of fetal reduction in multiple-gestation pregnancy need to be systematically investigated.
9. The potential of psychological treatments to relieve the distress associated with infertility and assisted reproduction should be investigated in randomized controlled trials.

Policy

1. Attention to population control in countries with high fertility rates should not preclude identification and treatment of infertility.
2. The causes of infertility should be accurately ascertained.
3. Specialized diagnostic and treatment services are needed for people with fertility problems.
4. Infertility services need to have clear policies about disclosure of mode of conception, maintenance of donor registries, and protection of the needs of children conceived by assisted reproduction. These policies should be informed by public and professional debate.

Services

1. Infertility treatment services in all settings need to be based on evidence about local causes and best practice in treatment.
2. Infertility treatment services should include mental health care as a component of routine care.
3. Mental health care should be focused on: assisting the person to make a realistic appraisal of the chance of treatment success; providing emotional support in the interval between embryo transfer and pregnancy-testing; and assisting the person to make a clear choice about when to stop treatment.

References

- Abbey A, Andrews F, Halman L (1991) Gender's role in responses to infertility. *Psychology of Women Quarterly*, 15: 295-316.
- Abbey A, Andrews F, Halman L (1992) Infertility and subjective well-being: the mediating roles of self-esteem, internal control, and interpersonal conflict. *Journal of Marriage and the Family*, 54(May): 408-416.
- Abbey A, Halman L, Andrews F (1992) Psychosocial, treatment, and demographic predictors of the stress associated with infertility. *Fertility and Sterility*, 57(1): 122-128.
- Adetoro OO, Ebomoyi EW (1991) The prevalence of infertility in a rural Nigerian community. *African Journal of Medicine and Medical Science* 20: 23-27.
- Aghanwa HS, Dare FO, Ogunniyi SO (1999) Sociodemographic factors in mental disorders associated with infertility in Nigeria. *Journal of Psychosomatic Research*, 46(2): 117-123.
- Ahuja KK et al. (2003) Minimizing risk in anonymous egg donation. *Reproductive Biomedicine Online*, 7: 504-505.
- Andrews FM, Abbey A, Halman L (1992) Is fertility problem stress different? The dynamics of stress in fertile and infertile couples. *Fertility and Sterility*, 46: 1247-1253.
- Australian Bureau of Statistics (2004) *Women in Australia*. Canberra, Commonwealth of Australia.
- Barnett B et al. (1993) Mood disorders among mothers of infants admitted to a mothercraft hospital. *Journal of Paediatrics and Child Health*, 29:270-275.
- Barrero C (2002) Gamete and embryo donation. In: Vayena E, Rowe PJ, Griffin PD, eds., *Current practices and controversies in assisted reproduction. Report of a meeting on medical, ethical and social aspects of assisted reproduction*. Geneva, World Health Organization.
- Barrett JF, Ritchie WK (2002) Twin delivery. *Best Practice and Research in Clinical Obstetrics and Gynaecology*, 16(1): 43-56.
- Beaurepaire J et al. (1994) Psychosocial adjustment to infertility and its treatment: male and female responses at different stages of IVF/ET treatment. *Journal of Psychosomatic Research*, 38(3): 229-240.
- Becker G (1994) Metaphors in disrupted lives: infertility and cultural constructions of continuity. *Medical Anthropology Quarterly*, 8: 383-410.

- Becker G, Nachtigall RD (1994) Born to be a mother: the cultural construction of risk in infertility treatment. *Social Science and Medicine*, 39(4): 507-518.
- Benjamin O, Ha'elyon H (2002) Rewriting fertilization: trust, pain, and exit points. *Women's Studies International Forum*, 25(6): 667-678.
- Beral V et al. (1994) Primary infertility: characteristics of women in North America according to pathological findings. *Journal of Epidemiology and Community Health*, 48: 576-579.
- Berg B, Wilson J (1990) Psychiatric morbidity in the infertile population: a reconceptualization. *Infertility and sterility*, 53(4): 654-661.
- Berg B, Wilson J (1991) Psychological functioning across stages of treatment for fertility. *Journal of Behavioural Medicine*, 14: 11-26.
- Bernstein J, Lewis J, Seibel M (1994) Effect of previous infertility on maternal-fetal attachment, coping styles, and self-concept during pregnancy. *Journal of Women's Health*, 3(2): 125-133.
- Bernstein J, Potts N, Mattox JH (1985) Assessment of psychological dysfunction associated with infertility. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 14: 63-66.
- Bewley S (1995) In vitro fertilisation is rarely successful in older women. *British Medical Journal*, 310: 1457.
- Blyth E (2004) Patient experiences of an "egg sharing" programme. *Human Fertility*, 7: 157-162.
- Blyth E, Crawshaw M, Daniels K (2004) Policy formation in gamete donation and egg sharing in the UK: a critical appraisal. *Social Science and Medicine*, 59: 2617-2626.
- Boyce PM, Todd AL (1992) Increased risk of postnatal depression after emergency caesarean section. *Medical Journal of Australia*, 157(3 August): 172-174.
- Bryan E (2002) Loss in higher multiple pregnancy and multifetal pregnancy reduction. *Twin Research*, 5(3): 169-174.
- Bryan E, Denton J (2001) Education for parents. In: Blickstein I, Keith LG, eds., *Iatrogenic multiple pregnancy: clinical implications*. New York, Parthenon Publishing: 211-222.
- Burns LH (1990) An exploratory study of perceptions of parenting after infertility. *Family Systems Medicine*, 8(2): 177-189.
- Burns LH (1999) Parenting after infertility. In: Burns LH, Covington SN, eds., *Infertility counselling: a comprehensive handbook for clinicians*. London, Parthenon Publishing.
- Callan VJ, Hennessey JF (1988a) Emotional aspects and support in in vitro fertilization and embryo transfer programs. *Journal of In Vitro Fertilization and Embryo Transfer*, 5(5): 290-295.
- Callan VJ, Hennessey JF (1988b) The psychological adjustment of women experiencing infertility. *British Journal of Medical Psychology*, 61: 137-140.
- Callan VJ et al. (1988) Towards understanding women's decisions to continue or stop in vitro fertilization: the role of social, psychological and background factors. *Journal of In Vitro Fertilization and Embryo Transfer*, 5(6): 363-369.
- Carter BS, Leuthner SR (2002) Decision making in the NICU – strategies, statistics, and "satisficing". *Bioethics Forum*, 18(3-4): 7-15.
- Cleland JGF (1994) Ovum donation: move slowly. *Lancet*, 344: 142, 204.
- Collins JA (1994) Reproductive technology: the price of progress. *New England Journal of Medicine*, 331(4): 270-271.
- Collopy KS (2002) We didn't deserve this: bereavement associated with multifetal reduction. *Twin Research*, 5(3): 231-235.
- Connolly K et al. (1992) The impact of infertility on psychological functioning. *Journal of Psychosomatic Research*, 36(5): 459-468.
- Cook R (1993) The relationship between sex role and emotional functioning in patients undergoing assisted conception. *Journal of Psychosomatic Obstetrics and Gynaecology*, 14: 31-40.
- Cook R, Bradley S, Golombok S (1998) A preliminary study of parental stress and child behaviour in families with twins conceived by in-vitro fertilization. *Human Reproduction*, 13(11): 3244-3246.
- Covington SN (1995) The role of the mental health professional in reproductive medicine. *Fertility and Sterility*, 64(5): 895-897.
- Covington SN, Burns LH (1999) Pregnancy after infertility. In: Burns LH, Covington SN, eds., *Infertility counselling: a comprehensive handbook for clinicians*. London, Parthenon Publishing.
- Craft I (1995) The role of ethics committees. *British Medical Journal*, 310: 1457-1458.
- Dawson K (1994) *Reproductive technology, the science, the ethics, the law, and the social issues*. Melbourne, VCTA Publishing.

- Dennerstein L, Morse C (1988) A review of psychological and social aspects of *in vitro* fertilization. *Journal of Psychosomatic Obstetrics and Gynaecology*, 9: 159-170.
- Domar AD (1994) A behavioral approach to infertility treatment. *Clinical Consultations in Obstetrics and Gynecology*, 6(2): 116-121.
- Domar AD, Seibel MM, Benson H (1990) The mind/body program for infertility: a new behavioral treatment approach for women with infertility. *Fertility and Sterility*, 53(2): 246-249.
- Domar A et al. (1992a) The prevalence and predictability of depression in infertile women. *Fertility and Sterility*, 58(6): 1158-1163.
- Domar AD et al. (1992b) Psychological improvement in infertile women after behavioral treatment: a replication. *Fertility and Sterility*, 58(1): 144-147.
- Downey J, McKinney M (1992) The psychiatric status of women presenting for infertility evaluation. *American Journal of Orthopsychiatry*, 62(2): 196-205.
- Dulude D et al. (2002) High-risk pregnancies, psychological distress, and dyadic adjustment. *Journal of Reproductive and Infant Psychology*, 20(2): 101-123.
- Dunnington RM, Glazer G (1991) Maternal identity and early mothering behaviour in previously infertile and never infertile women. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 20(4): 309-333.
- Edelmann RJ et al. (1991) Psychogenic infertility: some findings. *Journal of Psychosomatic Obstetrics and Gynaecology*, 12: 163-168.
- Eugster A, Vingerhoest AJJM (1999) Psychological aspects of *in vitro* fertilization: a review. *Social Science and Medicine*, 48: 575-589.
- Fathalla MF (1992) Reproductive health – a global overview. *Early Human Development*, 29(1-3): 35-42.
- Fisher JRW, Stocky AJ (2003) Maternal perinatal mental health and multiple birth: implications for practice. *Twin Research*, 6: 506-513.
- Fisher J, Astbury J, Smith A (1997) Adverse psychological impact of operative obstetric interventions: a prospective study. *Australian and New Zealand Journal of Psychiatry*, 31: 728-738.
- Fisher JRW, Hammarberg K, Baker HWG (2005) Assisted conception is a risk factor for perinatal mood disturbance and early parenting difficulties *Fertility and Sterility*, 84: 426-430.
- Fisher JRW et al. (2002) Health and social circumstances of women admitted to a private mother baby unit. A descriptive cohort study. *Australian Family Physician*, 31(10): 966-969.
- Franco JG et al. (2002) Psychological evaluation test after use of assisted reproduction technologies. *Journal of Assisted Reproduction and Genetics*, 19(6): 274-278.
- Garel M, Salobir C, Blondel B (1997) Psychological consequences of having triplets: a 4-year follow-up study. *Fertility and Sterility*, 67(6): 1162-1165.
- Gibson FL et al. (2000a) The mother-child relationship following *in vitro* fertilisation (IVF): infant attachment, responsivity, and maternal sensitivity. *Journal of Child Psychology and Psychiatry*, 41(8): 1015-1023.
- Gibson FL et al. (2000b) Parental adjustment and attitudes to parenting after *in vitro* fertilization. *Fertility and Sterility*, 73(3): 565-574.
- Gleicher N et al. (1995) The desire for multiple births in couples with infertility problems contradicts present practice patterns. *Human Reproduction*, 10(5): 1079-1084.
- Goldfarb JD et al. (1996) Attitudes of *in vitro* fertilization and intrauterine insemination couples toward multiple gestation pregnancy and multifetal pregnancy reduction. *Fertility and Sterility*, 65(4): 815-820.
- Golombok S et al. (1995) Families created by the new reproductive technologies: quality of parenting and social and emotional development of the children. *Child Development*, 66: 285-298.
- Greil A (1997) Infertility and psychological distress: a critical review of the literature. *Social Science and Medicine*, 45(11): 1679-1704.
- Hammarberg K, Astbury J, Baker HWG (2001) Women's experience of IVF: a follow-up study. *Human Reproduction*, 16(2): 374-383.
- Hart VA (2002) Infertility and the role of psychotherapy. *Issues in Mental Health Nursing*, 23(1): 31-41.
- Hay DA et al. (1990) What information should the multiple birth family receive before, during and after the birth? *Acta Geneticae Medicae et Gemellologiae*, 39: 259-269.
- Hearn MT et al. (1987) Psychological characteristics of *in vitro* fertilization participants. *American Journal of Obstetrics and Gynecology*, 156(2): 269-274.

- Hjelmstedt A et al. (2003) Personality factors and emotional responses to pregnancy among IVF couples in early pregnancy: a comparative study. *Acta Obstetrica et Gynecologica Scandinavica*, 82: 152-161.
- Hope T, Lockwood G, Lockwood M (1995) Should older women be offered in vitro fertilization? The interests of the potential child. *British Medical Journal*, 310: 1455-1456.
- Hurst T, Lancaster P (2001) *Assisted conception Australia and New Zealand 1999 and 2000*. Sydney, Australian Institute of Health and Welfare.
- Hynes GJ et al. (1992) The psychological wellbeing of infertile women after a failed IVF attempt: the effects of coping. *British Journal of Medical Psychology*, 65: 269-278.
- Inhorn MC (1994) Kabsa (a.k.a. Mushara) and threatened fertility in Egypt. *Social Science and Medicine*, 39(4): 487-505.
- Inhorn MC (2003) Global infertility and the globalization of new reproductive technologies: illustrations from Egypt. *Social Science and Medicine*, 56(9): 1837-1851.
- Inhorn M, Buss K (1994) Ethnography, epidemiology and infertility in Egypt. *Social Science and Medicine*, 39(5): 671-686.
- Jackson J (1995) Can older women cope with motherhood? *British Medical Journal*, 310: 1456-1457.
- Johnson MH, Everitt BJ (2000) *Essential reproduction*. Oxford, Blackwell Science.
- Johnstone S et al. (2001) Obstetric risk factors for postnatal depression in urban and rural community samples. *Australian & New Zealand Journal of Psychiatry*, 35(1): 69-74.
- Kerr J, Brown C, Balen AH (1999) The experience of couples who have had infertility treatment in the United Kingdom: results of a survey performed in 1997. *Human Reproduction*, 14: 934-938.
- Kirby MD (1994) Reproductive technology and law reform. *Medical Journal of Australia*, 161: 580-581.
- Kirkman L (1999) Still not maternal: giving birth to my niece (10 years on). In: *Fertility and Genetics Beyond 1999. The Plenary Proceedings of the 11th World Congress on In Vitro Fertilization and Human Reproductive Genetics*. Sydney, Parthenon Publishing.
- Kirkman M (1996) "Life doesn't go according to plan." Narratives of infertility. *Sixth International Interdisciplinary Congress on Women*, Adelaide.
- Klock SC (2001) The transition to parenthood. In: Blickstein I, Keith LG, eds., *Iatrogenic multiple pregnancy: clinical implications*. New York, Parthenon Publishing: 225-234.
- Klock SC, Greenfield DA (2000) Psychological status of in vitro fertilization patients during pregnancy: a longitudinal study. *Fertility and Sterility*, 73(6): 1159-1164.
- Kollantai J, Fleischer LM (2001) Insert 16.3. Realities: coping with the impact of death in a multiple pregnancy. In: Blickstein I, Keith LG, eds., *Iatrogenic multiple pregnancy: clinical implications*. New York, Parthenon Publishing: 216-217.
- Kols A, Nguyen T (1997) Infertility in developing countries. *Reproductive Health Outlook*, 15(3): 1-14.
- Kopitzke EJ et al. (1991) Physical and emotional stress associated with components of the infertility investigation: perspectives of professionals and patients. *Fertility and Sterility*, 55(6): 1137-1143.
- Koster-Oyekan W (1999) Infertility among Yoruba women: perceptions, causes, treatments and consequences. *African Journal of Reproductive Health*, 3: 13-26.
- Kovacs G, MacLachlan V, Brehny S (2001) What is the probability of conception for couples entering an IVF program? *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 41: 208-209.
- Larsen U (2000) Primary and secondary infertility in sub-Saharan Africa. *International Journal of Epidemiology*, 29: 285-291.
- Leiblum SR, Kemmann E, Taska L (1990) Attitudes toward multiple births and pregnancy concerns in infertile and non-infertile women. *Journal of Psychosomatic Obstetrics and Gynaecology*, 11: 197-210.
- Lentner E, Glazer G (1991) Infertile couples' perceptions of infertility support-group participation. *Health Care for Women International*, 12: 317-330.
- Litt MD et al. (1992) Coping and cognitive factors in adaptation to in vitro fertilization failure. *Journal of Behavioural Medicine*, 15(2): 171-187.
- Loo KK et al. (2003) Using knowledge to cope with stress in the NICU: how parents integrate learning to read the physiologic and behavioral cues of the infant. *Neonatal Networks*, 22(1): 31-37.
- Mahlstedt PP (1985) The psychological component of infertility. *Fertility and Sterility*, 43(3): 335-346.

- Malin M et al. (2001) What do women want? Women's experiences of infertility treatment. *Social Science and Medicine*, 53(1): 123-133.
- Marchbanks PA et al. (1989) Research on infertility: definition makes a difference. *American Journal of Epidemiology*, 130(2): 259-267.
- McKinney M, Leary K (1999) Integrating quantitative and qualitative methods to study multifetal pregnancy reduction. *Journal of Women's Health*, 8(2): 259-269.
- McMahon CA (1999) Does assisted reproduction make an impact on the identity and self-esteem of infertile women during the transition to parenthood? *Journal of Assisted Reproduction and Genetics*, 16(2): 59-62.
- McMahon CA et al. (1995) Psychosocial outcomes for parents and children after in vitro fertilization: a review. *Journal of Reproductive and Infant Psychology*, 13: 1-16.
- McMahon CA et al. (1997) Anxiety during pregnancy and fetal attachment after in-vitro fertilization conception. *Human Reproduction*, 12(1): 176-182.
- Menning BE (1982) The psychosocial impact of infertility. *Symposium in Women's Health Issues*, 17(1): 155-163.
- Moller A, Fallstrom K (1991) Psychological factors in the etiology of infertility: a longitudinal study. *Journal Psychosomatic Obstetrics and Gynaecology*, 12: 13-26.
- Morrow KA, Thoreson RW, Penney LL (1995) Predictors of psychological distress among infertility clinic patients. *Journal of Consulting and Clinical Psychology*, 63(1): 163-167.
- Munro JM, Ironside W, Smith G (1990) Psychiatric morbidity in parents of twins born after in vitro fertilization (IVF) techniques. *Journal of In Vitro Fertilization and Embryo Transfer*, 7(6): 332-336.
- Munro JM, Ironside W, Smith G (1992) Successful parents of an in vitro fertilization (IVF): the social repercussions. *Journal of Assisted Reproduction and Genetics*, 9(2): 170-176.
- Murray E et al. (1994) Donated ovarian tissue: the public's view. *Lancet*, 344: 204.
- Nachtigall HD, Becker G, Wizny D (1992) The effects of gender-specific diagnosis on men's and women's response to infertility. *Fertility and Sterility*, 57(1): 113-121.
- Neumann PJ, Gharib S, Weinstein MC (1994) The cost of a successful delivery with in vitro fertilization. *New England Journal of Medicine*, 331(4): 239-243.
- Ng F (2000) Female genital mutilation; its implications for reproductive health. An overview. *British Journal of Family Planning*, 26(1): 47-51.
- Okonofua FE et al. (1997) Serological and clinical correlates of gonorrhea and syphilis in fertile and infertile Nigerian women. *Genitourinary Medicine*, 73: 194-197.
- Okonofua FE et al. (2002) The association between female genital cutting and correlates of sexual and gynaecological morbidity in Edo State, Nigeria. *BJOG: an International Journal of Obstetrics and Gynaecology*, 109: 1089-1096.
- Olivennes F et al. (1993) The increased risk of complications observed in singleton pregnancies resulting from IVF does not seem to be related to the IVF method itself. *Human Reproduction*, 8: 1297-1300.
- Olshansky EF (1987) Identity of self as infertile: an example of theory generating research. *Advances in Nursing Science*, 9(2): 54-63.
- Pector EA, Smith-Levitin M (2002) Mourning and psychological issues in multiple birth loss. *Seminars in Neonatology*, 7(3): 247-256.
- Pfeffer N (1991) The uninformed conception. *New Scientist*, (July 20th): 32-33.
- Poggensee G, Feldmeier H (2001) Female genital schistosomiasis: facts and hypotheses. *Acta Tropica*, 79(3): 193-210.
- Poggensee G et al. (2001) Diagnosis of genital cervical schistosomiasis: comparison of cytological, histopathological and parasitological examinations. *American Journal of Tropical Medicine and Hygiene*, 65(3): 233-236.
- Rapport F (2003) Exploring the beliefs and experiences of potential egg share donors. *Journal of Advanced Nursing*, 43: 28-42.
- Reading AE, Chang LC, Kerin JF (1989) Attitudes and anxiety levels in women conceiving through in vitro fertilization and gamete intrafallopian transfer. *Fertility and Sterility*, 52(1): 95-98.
- Robin M et al. (1991) Maternal reactions to the birth of triplets. *Acta Geneticae Medicae et Gemellologiae*. 40: 41-51.
- Rosenthal M (1998) Further needs in clinical assessment: women and infertility. *Psychopharmacology Bulletin*, 34(3): 307-309.
- Rosenthal MB, Goldfarb J (1997) Infertility and assisted reproductive technology: an update for mental health professionals. *Harvard Review of Psychiatry*, 5(3): 169-172.

- Rowe-Murray HJ, Fisher J (2001) Operative intervention in delivery is associated with disruptions to early mother-infant contact. *BJOG: an international journal of obstetrics and gynaecology*, 108: 1068-1075.
- Rowe-Murray H, Fisher J (2002) Baby friendly hospital practices: cesarean section is a persistent barrier to early initiation of breastfeeding. *Birth*, 29(2): 124-130.
- Schmidt L, Munster K (1995) Infertility, involuntary infecundity, and the seeking of medical advice in industrialized countries 1970-1992: a review of concepts, measurements and results. *Human Reproduction*, 10(6): 1407-1418.
- Shattuck J, Schwarz K (1991) Walking the line between feminism and infertility: implications for nursing, medicine, and patient care. *Health Care for Women International*, 12(3): 331-339.
- Singer LT et al. (1999) Maternal psychological distress and parenting stress after the birth of a very low-birth-weight infant. *Journal of the American Medical Association*, 281(9): 799-805.
- Stanton F, Golombok S (1993) Maternal-fetal attachment during pregnancy following *in vitro* fertilization. *Journal of Psychosomatic Obstetrics and Gynaecology*, 14: 153-158.
- Sundby J (1992) Long-term psychological consequences of infertility: a follow-up study of former patients. *Journal of Women's Health*, 1(3): 209-217.
- Sundby J, Mboge R, Sonko S (1998) Infertility in the Gambia: frequency and health care seeking. *Social Science and Medicine*, 46(7): 891-899.
- Sundby J, Olsen A, Schei B (1994) Quality of care for infertility patients. An evaluation of a plan for a hospital investigation. *Scandinavian Journal of Social Medicine*, 22(2): 139-144.
- Swanson PB, Pearsall-Jones JG, Hay DA (2002) How mothers cope with the death of a twin or higher multiple. *Twin Research*, 5(3): 156-164.
- Tallo CP et al. (1995) Maternal and neonatal morbidity associated with *in vitro* fertilization. *Journal of Pediatrics*, 127(5): 794-800.
- Thorpe K et al. (1991) Comparison of prevalence of depression in mothers of twins and mothers of singletons. *British Medical Journal*, 302: 875-878.
- Thwaites T (2002) Infertility treatment in Vietnam. *Orgyn, Organon's Magazine on Women and Health*, (4): 2-6.
- Upton RL (2001) "Infertility makes you invisible": gender, health and the negotiation of fertility in northern Botswana. *Journal of Southern African Studies*, 27: 349-362.
- van Balen F, Naaktgeboren N, Trimbos-Kemper TCM (1996) In-vitro fertilization: the experience of treatment, pregnancy and delivery. *Human Reproduction*, 11(1): 95-98.
- Vayena E, Rowe PJ, Peterson HB (2002) Assisted reproductive technology in developing countries: why should we care? *Fertility and Sterility*, 78: 13-15.
- Vayena E, Rowe PJ, Griffin PD, eds (2002) *Current practices and controversies in assisted reproduction. Report of a meeting on medical, ethical and social aspects of assisted reproduction*. Geneva, World Health Organization.
- Visser AP et al. (1994) Psychosocial aspects of *in vitro* fertilization. *Journal of Psychosomatic Obstetrics and Gynaecology*, 15: 35-43.
- Wang J et al. (1994) The obstetric outcome of singleton pregnancies following fertilization/gameter intra-Fallopian transfer. *Human Reproduction*, 9(1): 141-146.
- Waters A-M, Dean JH, Sullivan EA (2006) *Assisted reproduction technology in Australia and New Zealand 2003*. Sydney, AIHW National Perinatal Statistics Unit.
- WHO (2003) Assisted reproduction in developing countries: facing up to the issues. *Progress in Reproductive Health Research*, 63.
- Woods NF, Olshansky EF, Draye MA (1991) Infertility: women's experiences. *Health Care for Women International*, 12(1991): 179-190.
- Yong P, Martin C, Thong J (2000) A comparison of psychological functioning in women at different stages of *in vitro* fertilization treatment using the Mean Affect Adjective Check List. *Journal of Assisted Reproduction and Genetics*, 17(10): 553-556.

Chapter

Female genital mutilation

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Female genital mutilation (FGM) or female genital cutting – sometimes termed female circumcision – is a common practice in some parts of the world (Ladjali, Rattray & Walder, 1993; Okonofua et al., 2002; UNICEF, 2005). Approximately 130 million women alive today have experienced some form of this procedure, and at least three million girls are at risk or are subjected to it each year (WHO, 1998, 2000a; UNICEF, 2005). The practice is most common in the countries of sub-Saharan Africa, parts of the Eastern Mediterranean, including Egypt, Oman, Sudan and Yemen, and Indonesia and Malaysia. It is also seen in other countries, including industrialized countries, among immigrants and refugees (Black & DeBelle, 1995; UNICEF, 2005). Estimates of prevalence in different population groups range from 5% to 99%; in Egypt, Eritrea, Ethiopia, Somalia and Sudan, 70–98% of women have undergone the procedure (Dorkenoo, 1994; Toubia, 1994; Leonard, 1996; Sayed, Abd El-Aty & Fadel, 1996; Chelala, 1998; Eke, 2000; WHO, 2000a; Al-Hussaini, 2003; UNICEF, 2005). The rate of female genital mutilation is higher in settings where there are low levels of adult literacy and high rates of poverty. In general, prevalence is lower among better-educated women (Sayed, Abd El-Aty & Fatel, 1996; UNICEF, 2005).

Female genital mutilation is defined as any procedure that involves irremediable partial or total removal of, or injury to, external female genital organs for non-therapeutic reasons. WHO classifies this mutilation into a number of types, according to the severity of structural damage. Type I, or Sunna, is excision of the prepuce and part or all of the clitoris. Type II is removal of the clitoris and part or complete removal of the

labia minora; this is anatomically equivalent to amputation of the penis (Toubia, 1994). Type III, or Pharaonic, also known as infibulation, is the excision of all external female genital organs and the use of stitches or other techniques to close the wound, leaving a narrow opening for the flow of urine and menstrual blood. Forms that do not fit the criteria for these three typologies are classified as Type IV. These include: pricking, piercing, cutting or distending the clitoris or labia; burning the external genital organs; cutting or scraping the vagina or placing herbs or corrosive agents into the vagina to cause bleeding or tissue damage and lead to tightening of the vaginal opening (Ng, 2000; Weir, 2000; WHO, 2000a). The most extreme forms of genital cutting are the least prevalent (Slinger, Snow & Okonofua, 2002).

As a result of migration and humanitarian programmes of relocation for refugees, Australia, Canada, some European countries and some states in the USA have now developed legislation, policies and clinical practice guidelines related to female genital mutilation (Allotey, Manderson & Grover, 2001). Accurate estimates of prevalence among immigrants in such countries are not available (Webb, 1995), but large numbers of people have migrated from the sub-Saharan African communities in which FGM is practised.

The age at which FGM is carried out varies, according to region, type of procedure and the existence of prohibiting legislation. It may be done a few days after birth, at the age of 8–10 years, prior to marriage, or after the birth of a first child (Dorkenoo & Elworthy, 1992; Toubia,

1994; Young, 2002). It is usually performed by untrained people, often traditional birth attendants or village barbers. They are likely to use unsterilized instruments, including razor blades, knives, broken glass, scissors or sharpened stones, without anaesthetic in unhygienic settings (Little, 2003; Odoi, Brody & Elkins, 1997). Recently, there has been a trend for FGM to be undertaken by medical personnel in medical settings (Toubia, 1994; UNICEF, 2005). This development has been strongly condemned by the World Health Organization and various professional bodies, which recommend that female genital mutilation should stop, and that it should never be performed by doctors or nurses (Wright, 1996; American Academy of Pediatrics Committee on Bioethics, 1998; WHO, 2000a).

Female genital mutilation is widely regarded as an ancient practice, which preceded the founding of both Christianity and Islam. However, there is evidence that FGM is not always a deeply embedded practice and that, in some settings, it has been practised for less than a century (Leonard, 1996). It is not consistently more common in one religious group than another (Little, 2003; UNICEF, 2005). It is deemed a tradition that is culturally and ethnically determined and is not mandated by religious doctrine (al-Sabbagh, 1996; Dorkenoo, 1994; Leonard, 1996; Cook, Dickens & Fathalla, 2002; UNICEF, 2005). The custom is rationalized and maintained by cultural beliefs. These include culturally defined rituals of initiation into adulthood; replication of the experience of previous generations; promotion of hygiene; maintenance of chastity through the construction of a physical barrier to sexual intercourse and reduction of potential sexual pleasure; and as an identifier of chaste status and thereby a prerequisite to marriage (Al-Hussaini, 2003; Dorkenoo, 1994; Ng, 2000; Sayed, Abd El-Aty & Fatel, 1996; Wright, 1996; Cook, Dickens & Fathalla, 2002; UNICEF, 2005). Other rationales for FGM are that it is performed for aesthetic reasons because the female genitals are regarded as intrinsically unattractive or may grow to an excessive length if left in a natural state (Dorkenoo, 1994; Ng, 2000; UNICEF, 2005). In some African groups there is a belief that removal of the clitoris clearly demarcates femininity, because its presence may lead to sexual confusion (Dorkenoo, 1994).

Marriageability is essential for economic security and social inclusion in settings where wom-

en have few occupational choices. Families are unlikely to break with tradition if it places their daughters at risk of remaining unmarried (Cook, Dickens & Fathalla, 2002; Lightfoot-Klein & Shaw, 1990; Missailidis & Gebre-Mehdin, 2000; Toubia, 1994). Ogunlola, Orji & Owalabi (2003) found that the father of a female child in Nigeria has the greatest power in making the decision to circumcise her, and that the decision is made before birth.



Health effects of female genital mutilation

The health effects of female genital mutilation, where the practice is widespread, are just starting to be documented. WHO (2000a) commissioned a systematic review of the health consequences of female genital mutilation, which retrieved 504 relevant articles published between 1925 and 1998. The review identified methodological limitations in many of the studies. Most of the publications were case reports or case series, while only a few studies compared women who had and had not had FGM. In some articles, the type of FGM was not defined, while in others type I and type II were combined. Often, results were given for all types of FGM combined. In addition, the age or developmental stage at which the procedure was performed was often not reported (WHO, 2000a). Many of the investigations did not include clinical examination of the perineum, and classification of FGM status may not be reliable under these circumstances (Odujinrin, Akitoye & Oyediran, 1989).

Most of the studies examining the complications of female genital mutilation have been done in Africa, but some evidence has been gathered in industrialized countries among immigrant populations. The adverse physical sequelae of female genital mutilation have been much more com-

prehensively investigated and described than the psychological effects.

Immediate and short-term health effects

The most common immediate adverse effects of the procedure are intense pain and haemorrhage, which can lead to hypovolaemic shock and death (Toubia, 1994; Johansen, 2002). Mortality rates are likely to be obscured by under-reporting, and qualitative investigations suggest that they are high (Lightfoot-Klein, 1991; Ng, 2000). Abscesses, wound contamination and local infections are common because of “gross disregard for asepsis” (Eke, 2000), the unhygienic circumstances in which the procedure is conducted, and the use of substances such as ash or crushed herbs to cover the wound (Toubia, 1994; Moller & Hansen, 2003; Rushwan, 2000). Adjacent anatomical structures, including the urethra, bladder, vagina and rectum, may be damaged because of poor technique or if the girl or woman struggles (Fox, de Ruiter & Bingham, 1997a; Ng, 2000). Systemic septicaemia, gangrene and tetanus infection can occur, and healing of the wound is often slow (Ng, 2000; Toubia, 1994).

In the short term, prolonged bleeding can cause anaemia, which has adverse effects on growth and development, especially in the presence of under-nutrition (Toubia, 1994). Slow-healing vulval abscesses may form (Rushwan, 2000) and dermoid cysts or keloids may grow on the clitoral stump or infibulation scar (Thabet & Thabet, 2003). Enlarged cysts and scar tissue can become grossly disfiguring (Toubia, 1994).

There are substantial long-term risks associated with female genital mutilation, especially following infibulation. The drainage of urine, vaginal secretions and menstrual blood is commonly obstructed, which can lead to chronic pelvic infections, menstrual dysfunction and menstrual pain (Fox, de Ruiter & Bingham, 1997b; Ng, 2000; Johansen, 2002). Urinary retention leads to chronic urinary tract infection and renal damage (Ng, 2000; Toubia, 1994). The procedure renders women vulnerable to chronic reproductive tract and pelvic infections, with associated abdominal pain and offensive vaginal discharge (Okonofua et al., 2002). Anecdotal reports describe young women developing abdominal swelling because menstrual blood is unable to flow out of the vagina. The lack of menstrual flow, coupled with abdominal distension, has

been misinterpreted as pregnancy, with anecdotal reports that it has led to unmarried women being killed in order to preserve the family's reputation (Dorkenoo, 1994). More recently, it has been suggested that genital cutting of women increases the risk of transmission of HIV, both through the use of unsterilized instruments and because cuts and tears are more likely to occur during intercourse (Rushwan, 2000).

The most obvious long-term adverse effects of FGM are on gynaecological health, especially sexual and obstetric functioning.

Effects on sexual and psychosexual functioning

Women who have been infibulated may have difficulty having sexual intercourse, as a result of a narrow introitus (Johansen, 2002; Okonofua et al., 2002). Absolute failure of penetration because of FGM, especially type III, has been reported (WHO, 2000a). Defibulation, by tearing or cutting, may be necessary before sexual penetration is possible (Lightfoot-Klein, 1991; Little, 2003; Wright, 1996). Studies of clinic populations have found that up to 25% of infibulated women require surgery before vaginal intercourse is possible (Fox, de Ruiter & Bingham, 1997b; Knight et al., 1999). However, it is difficult for women to seek health care for these problems. Mawad & Hassanein (1994) reviewed 934 patients attending Khartoum North Hospital between 1987 and 1989 with complications of genital mutilation. They found that women tended to seek health care only when they experienced severe pain, and that they were generally inhibited in discussing sexual matters. They concluded that fear of, and dissatisfaction with, sex were common, especially among those who had undergone type III FGM.

Sexual desire and frequency of intercourse may also be adversely affected. Although there have been few comprehensive studies, sexual problems, including persistent painful intercourse (13%), prolonged postcoital bleeding (5%) and anorgasmia (12%), were reported in a consecutive cohort study of women attending hospital clinics in northern Ghana (Odoi et al., 1997). The authors compared 76 women who had undergone FGM with 119 who had not. FGM was associated with a threefold increase in postcoital bleeding and a twelvefold increase in anorgasmia. In a systematic comparison of women

who had experienced varying degrees of genital cutting with an unaffected comparison group in a Cairo University hospital, it was found that sexual desire and capacity for sexual arousal and orgasm were significantly adversely affected in those who had undergone type II mutilation, or who had developed clitoral cysts after any type of mutilation (Thabet & Thabet, 2003). El-Defrawi et al. (2001) selected 250 women at random among those attending maternal and child health centres in Ismailia, Egypt. Participants were given a gynaecological examination and interviewed; 80% had undergone FGM. These women were significantly more likely than those who had not undergone FGM to report one or more adverse psychosexual effects. These included painful menstruation (81%), low sexual desire (45%), sexual dissatisfaction (49%) and anorgasmia (61%). In contrast, Stewart, Morison & White (2002) undertook secondary analysis of data generated through a household survey in the Central African Republic, in which experience of female genital mutilation and frequency of sexual intercourse were ascertained through self-report. In total, data were available for 2188 married women. When other determinants, including length of marital relationship, level of education, being one of a number of wives, and desire to conceive, were taken into account, frequency of intercourse was not found to be associated with FGM. Similarly, Okonofua et al. (2002) compared 827 women who had experienced genital cutting and were attending family planning and antenatal clinics in Edo State, Nigeria, with 1009 women patients who had not been cut. Data were collected through gynaecological examination and self-report questionnaires. No differences were found between the two groups in terms of sexual arousal, frequency of intercourse and capacity for orgasm, although women who had experienced genital cutting were less likely to report high clitoral sensitivity than those who had not. However, women who had been cut were more likely to have had reproductive tract infections and premature births. These apparently conflicting findings may be related in part to the method of investigation, and be governed by women's capacity to report sexual impairment and to discuss sexual experiences freely (Morrison & Sherf, 2003). Lightfoot-Klein (1989) interviewed 300 Sudanese women who had experienced "extreme sexual mutilation", and found that most experienced sexual desire, arousal and orgasm. It has been suggested that the degree of cutting, consequent anatomic in-

jury, and women's capacity to derive sexual pleasure from non-genital stimulation or sexual fantasy interact to govern the degree of sexual impairment (Toubia, 1994).

Knight et al. (1999) found high rates of reported painful intercourse (76.5%) in a hospital cohort of women who had migrated to Australia after having experienced genital cutting, usually type III. Frequency of sexual intercourse and capacity for orgasm were reduced as a result of the pain. In a medical record audit of a small sample of 22 women who had experienced genital mutilation in their country of origin before migrating to the United Kingdom, 60% of those who had undergone infibulation had health problems, including perineal scarring, pain on intercourse and pelvic infections (Fox, de Ruiter & Bingham, 1997b).

Effects on fertility

Fertility may be diminished following genital mutilation, as a result of chronic pelvic infections leading to obstruction of the fallopian tubes. Narrowing of the introitus may lead to the anus or urethra being used for intercourse (Ng, 2000). Hormonal changes during pregnancy lead to increased vulnerability to genital and urinary tract infections, and risk is further increased in those who have undergone genital cutting (Rushwan, 2000). Vaginal examination is more difficult, which may mean that infections are difficult to diagnose (Rushwan, 2000). Cysts may develop or swell because of increased vulval vascularity (Rushwan, 2000). Almroth et al. (2005) conducted a meticulous case-control gynaecological, laparoscopic and laboratory test comparison of 99 women presenting for investigation of primary infertility in Khartoum, Sudan with 180 primigravid women. Women who had undergone extensive FGM, involving the labia majora, were more likely to be infertile than those who had not, probably as a result of recurrent tubal infections.

Obstetric effects

Significant obstetric difficulties are associated with genital cutting. In WHO's systematic review (WHO, 2000a), 67 of the 504 retrieved articles had primary data on obstetric sequelae. The authors concluded that the most significant adverse obstetric effects of FGM are usually scarring and vaginal obstruction. Jones et al. (1999) investigated self-reported obstetric complica-

tion rates in more than 3000 women attending for routine antenatal or gynaecological care in Burkina Faso (where 93% had experienced FGM) and Mali (where 94% had undergone FGM). Women who had experienced FGM were at significantly higher risk of obstetric complications. Larsen & Okonofua (2002) assessed 1851 women attending family planning and antenatal clinics in Nigerian hospitals, of whom 45% had undergone FGM. From interviews and physical examinations, they found that the prevalence of birth complications was higher among those who had had FGM. Slinger, Snow & Okonofua (2002) compared obstetric outcomes of first births among 1107 women in Nigeria, 56% of whom had experienced FGM. They found that adverse obstetric outcomes were no more common in the cut group, when socioeconomic status and place of birth were taken into account. Obstetric outcomes were worse in very poor women who gave birth without medical assistance regardless of whether they had had FGM. The authors concluded that the type of genital cutting has to be defined and coincidental social circumstances assessed in examining associations with obstetric outcome.

Antenatal and intrapartum vaginal examinations are more difficult in women who have had FGM, leading to difficulties in assessing pregnancy state and progress during labour (WHO, 2000a). De Silva (1989) compared obstetric outcomes in 167 Sudanese women who had undergone FGM (20 with type I, 76 with type II and 71 with type III) with those in 1990 Saudi women with no FGM. Duration of the second stage of labour was found to be significantly prolonged in the mutilated group. Rates of urinary retention during labour were also higher in women who had undergone FGM (WHO, 2000a),

Women who have been infibulated cannot give birth unassisted, since the scar has to be cut, in a procedure known as defibulation, in order to allow the fetus to pass (Rushwan, 2000). Episiotomy has been recommended as part of routine care for women whose genitals have been cut, but these women still have higher rates of perineal tears (WHO, 2000a; Al-Hussaini, 2003). Vaginal and perineal tears are common, and are associated with postpartum haemorrhage and high rates of postpartum perineal infection (WHO, 2000a; Rushwan, 2000). Together, these factors contribute to higher maternal mortal-

ity among women who have undergone FGM (WHO, 2000a). Obstructed or prolonged unassisted labour can lead to the formation of vesicovaginal or rectovaginal fistulae (Fox, de Ruiter & Bingham, 1997a; WHO, 2000a; Ng, 2000). These lead to urinary and faecal incontinence; it is common for incontinent women to be rejected by their partner and family (Rushwan, 2000). In countries with limited experience of managing childbirth in women who have been infibulated, caesarean sections are frequently performed (Fox, de Ruiter & Bingham, 1997a).

The newborn infants of women who have had FGM may also be adversely affected. WHO (2000a) reported higher rates of fetal distress during childbirth among women who had experienced FGM. Increased rates of stillbirth and neonatal death have been attributed to genital cutting, in particular infibulation, in some settings (Mella, 2003), but comparable, comprehensive international data are unavailable. Essen et al. (2002) reviewed perinatal deaths in Sweden between 1990 and 1996, including among women from Eritrea, Ethiopia and Somalia who had undergone genital cutting. They concluded that perinatal death was not associated with FGM per se, but with the women's refusal to accept caesarean delivery and difficulties in communicating with them, because of a lack of interpreters. Knight et al. (1999) also found that women who had experienced infibulation and who gave birth in a tertiary hospital in Melbourne, Australia, where caesarean section was readily available, had similar obstetric outcomes to the general population. Studies in industrialized countries with highly sophisticated medical care and where almost all women give birth in hospital cannot be generalized to settings with few trained medical personnel, in which many women give birth at home and maternal mortality rates are high. Following childbirth, many women who have been infibulated request re-infibulation, which can present ethical dilemmas for health professionals, especially in countries where it is illegal (Rushwan, 2000). Clinical practice guidelines usually discourage re-infibulation, but the physical and psychological health effects of not re-stitching the vulva are not known (Allotey, Manderson & Grover, 2001). It has been suggested that refusing to re-infibulate may cause women to avoid using the hospital for subsequent deliveries, to perceive institutional racism, or to resort to non-medical personnel to perform the procedure without an-

aesthetic in unhygienic settings (Gibeau, 1998; Rushwan, 2000; Allotey, Manderson & Grover, 2001). However, perhaps because of a desire for acculturation, neither infibulated women nor their partners requested re-infibulation after childbirth in one clinical practice in Canada (Lalonde, 1995). Almroth-Berggren et al. (2001) interviewed 60 women living in a rural setting in Sudan; many of the women reported that the decision to re-infibulate them after childbirth was made by senior female family members or by the birth attendant, because of a strong social belief that men preferred it. However, a small group of women had elected not to be re-infibulated, and were supported in this decision by their husbands.

Effects on mental health

There is an almost complete lack of systematic evidence about the psychological sequelae, including mental health effects, of female genital cutting. WHO's systematic review (WHO, 2000a) found that only 15% of the studies of the health effects of FGM considered mental health; most of these were case reports. It has been suggested that this situation has led to speculation about the psychological impact of FGM in the absence of scientific evidence. Toubia (1994) described the conflict faced by young women, who want to conform to parental and societal expectations by complying with FGM, but who are thereby exposed to fear, pain, complicated recovery and possible long-term health problems. She reported clinical observations of chronic depression and anxiety, associated with genital disfigurement and gynaecological dysfunction, as well as with specific fears that cysts or scars were cancer or that the genitals were re-growing (Toubia, 1994). Lightfoot-Klein & Shaw (1990) interviewed 300 women and health care providers, and found that anxiety was associated with obstructed menstrual flow and both anticipation of and actual experience of painful intercourse; some women reported intensely traumatic memories of their wedding night. Menage (1993, 1995) suggested that women might be traumatized by the procedure, on the basis of such responses having been observed in women who had undergone mutilating gynaecological procedures for clinical reasons. However, Black & DeBelle (1996) have challenged the validity of this assertion for different cultural settings, considering that it cannot be inferred in the absence of supporting evidence.

Incontinence resulting from FGM may lead to ostracization and impede full social participation. Difficult vaginal penetration may be used as grounds for divorce (Rushwan, 2000). Women are reported to believe that their husband's sexual pleasure will be enhanced if they have been infibulated and re-infibulated. They fear being abandoned by their partner if they do not comply (Lightfoot-Klein, 1991). Depression following re-infibulation (in type III FGM) after childbirth has also been described (Lightfoot-Klein, 1983).



The most comprehensive study of the mental health effects of FGM reported the findings of structured interviews with 432 Somali women living in Canada, who had previously experienced genital cutting. The investigation focused on their experiences of childbirth, but also ascertained their recollections of the experience of genital cutting. Participants recalled intense fear, severe pain, and being seriously ill at the time of mutilation, but also recounted a sense of pride, happiness and enhanced purity and beauty (Chalmers & Hashi, 2000). It has been reported that, in countries where genital cutting is not commonly practised or is illegal, women who have had FGM fear that the quality of obstetric care provided by health professionals may be compromised by their lack of experience (Lightfoot-Klein & Shaw, 1990; Vangen et al., 2004). Pelvic examinations may be experienced as humiliating or offensive especially if conducted by male practitioners. These examinations need to be done with great sensitivity for women whose safety is predicated on modesty (Lightfoot-Klein & Shaw, 1990). Intense fear of caesarean surgery was universal in an interview study of 23 Somali women receiving antenatal

care in Norway, who had been infibulated prior to migration (Vangen et al., 2004)

In 1959 the United Nations adopted the Convention on the Rights of the Child, which states that “all effective and appropriate measures to abolish traditional practices prejudicial to the health of children” should be taken (Black & DeBelle, 1995). In 1979, the World Health Organization convened a round-table discussion on *Traditional practices affecting the health of women and children*, which concluded that female genital mutilation constituted a grave hazard to health and that the practice should end (Wright, 1996). Further, in 1997, WHO convened a technical consultation focusing on obstetric and postnatal health care “in the presence of FGM”, which concluded that FGM carries grave consequences for the health and well-being of women and girl children, and reaffirming support for the United Nations Convention on the Rights of the Child. WHO, UNICEF and UNFPA issued a joint statement in 1997 outlining the need for cultures to adapt to knowledge about harmful practices, by relinquishing them.

There is debate about whether female genital mutilation constitutes a human rights violation or is an established cultural ritual that identifies social membership and should not be challenged (Aikman, 2001; Cook, Dickens & Fathalla, 2002).

Aikman (2001) and UNICEF (2005) concluded that the practice violates human rights to bodily integrity and freedom from torture, but that its elimination requires understanding of the cultural traditions that maintain it.

It has also been suggested that, by endangering the life and physical and mental health of children, genital cutting is a form of child abuse (Schroeder, 1994). An alternative view is that parents subject their daughters to this procedure to protect them and to ensure their social inclusion (Black & DeBelle, 1995, 1996). In practice, it is difficult to prove child abuse under established legislation, because risk does not continue after

the mutilation has taken place (Webb, 1995). In Canada, specific sections of child protection acts identify FGM as assault causing actual bodily harm (Weir, 2000). It has been strongly argued that, in balancing these ethical dilemmas, health concerns should have absolute primacy (Wright, 1996).

The controversy about whether FGM constitutes a human rights violation or a tradition continues, and United Nations human rights procedures have had limited success in reducing the practice (Wright, 1996). Pilot programmes to reduce and ultimately eliminate female genital cutting have been implemented over the past 20 years, and have led to some reduction in incidence. The practice is now prohibited in some countries where it was previously common, but the initiative has had limited efficacy in reducing rates (Chelala, 1998; El Hadi, 1997). Walder (1995) argued that criminalizing the practice has driven it to become a clandestine activity in the United Kingdom. Health professionals in Egypt have objected to its prohibition, arguing that outlawing the procedure in health care settings increases the likelihood that it will be done without anaesthesia or hygiene precautions (American Academy of Pediatrics Committee on Bioethics, 1998; El Hadi, 1997). It has also been argued that, although women arrange the procedure for their daughters, it has little intrinsic value for them and is maintained because it is expected by men (El Hadi, 1997). It has been proposed that educational programmes for community members and health professionals are essential to promote change. Approaches that substitute alternative ceremonies or rituals combined with specific education to mark the transition to adulthood are beginning to have some success in replacing genital mutilation (Chelala, 1998; Shaaban & Harbison, 2005).

Gynaecological surgery, fertility difficulties, incontinence, operative interventions in childbirth, and chronic reproductive tract infections can each have adverse effects on women's mental health. It is likely, therefore, that the physical consequences of female genital mutilation will be psychologically problematic, although systematic investigations are needed to confirm this and to characterize the effects. The severe and lasting pain, coupled with the human rights transgression of performing a harmful procedure to which young girls cannot give voluntary and informed consent, is highly likely

to have lasting adverse psychological sequelae (Johansen, 2002). Acceptance of social expectations and adherence to cultural norms may inhibit complaints or protests, and can lead to denial of associated difficulties (Toubia, 1994). Psychological reactions may be different in migrant or refugee populations, as they attempt to conform to different social norms (Toubia, 1994). Clinicians have recommended that sensitive health promotion and health education should be routinely done with women who have experienced genital cutting (Lalonde, 1995; Fox, de Ruiter & Bingham, 1997b; American Academy of Pediatrics Committee on Bioethics, 1998; Bayly, 1998; Knight et al., 1999). More specifically, Eke (2000) recommended psychological counselling for them. Overall, given the severity of physical damage and long-term adverse health effects, it is highly likely that genital cutting exerts an adverse effect on women's mental health. As long as the practice continues, systematic and comprehensive examination of these effects is urgently needed.

Summary

Future research

1. Research is urgently needed to determine:
 - the global extent and rates of the different forms of female genital mutilation;
 - the immediate, medium- and long-term consequences for mental health of female genital mutilation;
 - the complex interactions between the social position of women and the pressure to maintain tradition and to adhere to family expectations, and their effects on the psychological response to genital mutilation; and
 - the psychological effects of failing to comply with genital mutilation in settings where it is an established traditional practice.
2. There is a need to generate comprehensive international evidence regarding the psychological, psychosexual, psychosocial and cultural sequelae of female genital mutilation.

Implications for policy

1. Genital mutilation constitutes a risk to the health of women and girls, and a violation of their human rights.
2. Health professionals are in a unique position to advocate for the human rights of women in relation to female genital mutilation, and need to feel able to do so without fear of being criticised for challenging an established practice.
3. Female genital mutilation should not be undertaken by health personnel.

Services

1. Health professionals, in countries where female genital mutilation is practised or to which women who have experienced genital mutilation migrate, need to have specific knowledge and skills about the procedure in order to provide appropriate health care.
2. Obstetric health professionals should be trained to provide antenatal, intrapartum and postpartum health care for women who have undergone FGM, especially type III.
3. Health care for women who have experienced genital mutilation needs to be informed by cultural sensitivity, provision of choice, and an appreciation of human rights.
4. Women who have experienced genital mutilation should be counselled on its adverse health effects, encouraged to discuss the implications for their daughters, and helped to make intergenerational changes related to this practice.

References

- Aikman P (2001) Female genital mutilation: human rights abuse or protected cultural practice. *Health Science Journal* (www.docs/vol1-1/fgm.html 1-6).
- Al-Hussaini TK (2003) Female genital cutting: types, motives and perineal damage in labouring Egyptian women. *Medical Principles and Practice*, 12(2): 123-128.
- Allotey P, Manderson L, Grover S (2001) The politics of female genital surgery in displaced communities. *Critical Public Health*, 11(3): 189-201.
- Almroth L et al. (2005) Primary infertility after genital mutilation in girlhood in Sudan: a case-control study. *Lancet*, 366: 385-391.
- Almroth-Berggren V et al. (2001) Reinfibulation among women in a rural area in central Sudan. *Health Care for Women International*, 22: 711-721.
- al-Sabbagh ML (1996) Islamic ruling on female and male circumcision. Alexandria, WHO Regional Office for the Eastern Mediterranean.
- American Academy of Pediatrics Committee on Bioethics (1998) Female genital mutilation. *Pediatrics*, 102(1): 153-156.
- Bayly CM (1998) Female genital mutilation: responding to health needs. *Medical Journal of Australia*, 169: 455-456.
- Black JA, Debelle GD (1995) Female genital mutilation in Britain. *British Medical Journal*, 310(6994): 1590-1592.
- Black JA, Debelle GD (1996) Female genital mutilation. *British Medical Journal*, 312 (7027): 377-378.
- Chalmers B, Hashi KO (2000) 432 Somali women's birth experiences after earlier female genital mutilation. *Birth*, 27: 227-234.
- Chelala C (1998) An alternative way to stop female genital mutilation. *Lancet*, 352 (9122): 126.
- Cook RJ, Dickens BM, Fathalla M (2002) Female genital cutting (mutilation / circumcision): ethical and legal dimensions. *International Journal of Gynaecology and Obstetrics*, 79: 281-287.
- De Silva S (1989) Obstetric sequelae of female circumcision. *European Journal of Obstetrics, Gynaecology and Reproductive Biology*, 32: 233-240.
- Dorkenoo E (1994) *Cutting the rose. Female genital mutilation: the practice and its prevention*. London, Minority Rights Publications.
- Dorkenoo E, Elworthy S (1992) *Female genital mutilation: proposals for change*. London, Minority Rights Group.
- Eke N (2000) Female genital mutilation: what can be done? *Lancet*, 356(suppl.): s57.
- El-Defrawi MH et al. (2001) Female genital mutilation and its psychosexual impact. *Journal of Sex and Marital Therapy*, 27: 465-473.
- El Hadi A (1997) A step forward for opponents of female genital mutilation in Egypt. *Lancet*, 349(9045): 129-130.
- Essen B et al. (2002) Is there an association between female circumcision and perinatal death? *Bulletin of the World Health Organization*, 80(8): 629-632.
- Fox E, de Ruiter A, Bingham J (1997a) Female genital mutilation. *International Journal of STD and AIDS*, 8(10): 599-601.
- Fox E, de Ruiter A, Bingham J (1997b) Female genital mutilation in a genitourinary medicine clinic: a case note review. *International Journal of STD and AIDS*, 8(10): 659-660.
- Gallard C (1995) Female genital mutilation in Britain: female genital mutilation in France. *British Medical Journal*, 310(6994): 1592-1593.
- Gibeau AM (1998) Female genital mutilation: when a cultural practice generates clinical and ethical dilemmas. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 27(1): 85-91.
- Johansen REB (2002) Pain as a counterpoint to culture: toward an analysis of pain associated with infibulations among Somali immigrants in Norway. *Medical Anthropology Quarterly*, 16(3): 312-340.
- Jones H et al. (1999) Female genital cutting practices in Burkina Faso and Mali and their negative health outcomes. *Studies in Family Planning*, 30: 219-230.
- Knight R et al. (1999) Female genital mutilation - experience of The Royal Women's Hospital, Melbourne. Australian and New Zealand *Journal of Obstetrics and Gynaecology*, 39(1): 50-54.
- Ladjali M, Rattray TW, Walder RJW (1993) Female genital mutilation. *British Medical Journal*, 307(6902): 460.
- Lalonde A (1995) Clinical management of female genital mutilation must be handled with understanding, compassion. *Canadian Medical Association Journal*, 152(6): 949-950.

- Larsen U, Okonofua FE (2002) Female circumcision and obstetric complications. *International Journal of Gynaecology and Obstetrics*, 77: 255-265.
- Leonard L (1996) Female circumcision in southern Chad: origins, meaning and cultural practice. *Social Science and Medicine*, 43(2): 255-263.
- Lightfoot-Klein H (1983) Pharaonic circumcision of females in the Sudan. *Medicine and Law*, 2: 353-360.
- Lightfoot-Klein H (1989) The sexual experience and marital adjustment of genitally circumcised and infibulated females in Sudan. *Journal of Sex Research*, 26(3): 375-392.
- Lightfoot-Klein H (1991) *Prisoners of ritual: some contemporary developments in the history of female genital mutilation*. Second International Symposium on Circumcision, San Francisco.
- Lightfoot-Klein H, Shaw E (1990) Special needs of ritually circumcised women patients. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 20(2): 102-107.
- Little C (2003) Female genital circumcision: medical and cultural considerations. *Journal of Cultural Diversity*, 10(1): 30-34.
- Mawad NM, Hassanein OM (1994) Female circumcision: three years experience of common complaints in patients treated in Khartoum teaching hospitals. *Journal of Obstetrics and Gynaecology*, 14: 40-43.
- Mella PP (2003) Major factors that impact on women's health in Tanzania: the way forward. *Health Care for Women International*, 24: 712-722.
- Menage J (1993) Post-traumatic stress disorder in women who have undergone obstetric and/or gynaecological procedures. *Journal of Reproductive and Infant Psychology*, 11: 221-228.
- Menage J (1995) Female genital mutilation: professionals should not collude with abusive systems. *British Medical Journal*, 311 (7012): 1088-1089.
- Missailidis K, Gebre-Mehdin M (2000) Female genital mutilation in eastern Ethiopia. *Lancet*, 356 (9224): 137-138.
- Moller BR, Hansen UD (2003) Foreign bodies as a complication of female genital mutilation. *Journal of Obstetrics and Gynaecology* 23: 449-450
- Morrison L, Scherf C (2003) The association between female genital cutting and correlates of sexual and gynaecological morbidity in Edo State, Nigeria. *BJOG: an International Journal of Obstetrics and Gynaecology*, 110: 1137-1140.
- Ng F (2000) Female genital mutilation; its implications for reproductive health. An overview. *British Journal of Family Planning*, 26(1): 47-51.
- Odoi A, Brody SP, Elkins TE (1997) Female genital mutilation in rural Ghana, West Africa. *International Journal of Gynecology and Obstetrics*, 56: 179-180.
- Odujinrin OM, Akitoye CO, Oyediran MA (1989) A study on female circumcision in Nigeria. *West African Journal of Medicine*, 8: 183-192.
- Ogunlola O, Orji EO, Owolabi AT (2003) Female genital mutilation and the unborn female child in southwest Nigeria. *Journal of Obstetrics and Gynaecology*, 23: 143-145.
- Okonofua FE et al. (2002) The association between female genital cutting and correlates of sexual and gynaecological morbidity in Edo State, Nigeria. *BJOG: an International Journal of Obstetrics and Gynaecology*, 109: 1089-1096.
- Rushwan H (2000) Female genital mutilation (FGM) management during pregnancy, childbirth and the postpartum period. *International Journal of Gynecology and Obstetrics*, 70: 99-104.
- Sayed GH, Abd El-Aty MA, Fadel KA (1996) The practice of female genital mutilation in Upper Egypt. *International Journal of Gynecology and Obstetrics*, 55: 285-291.
- Schroeder P (1994) Female genital mutilation: a form of child abuse. *New England Journal of Medicine*, 33(11): 739-740.
- Shaaban LM, Harbison S (2005) Reaching the tipping point against female genital mutilation. *Lancet*, 366: 347-349.
- Slanger TE, Snow RC, Okonofua FE (2002) The impact of female genital cutting on first delivery in southwest Nigeria. *Studies in Family Planning*, 33(2): 173-180.
- Stewart H, Morison L, White R (2002) Determinants of coital frequency among married women in Central African Republic: the role of female genital cutting. *Journal of Biosocial Science*, 34: 525-539.
- Thabet SM, Thabet AS (2003) Defective sexuality and female circumcision: the cause and possible management. *Journal of Obstetric and Gynaecological Research*, 29(1): 12-19.
- Toubia N (1994) Female circumcision as a public health issue. *New England Journal of Medicine*, 33(11): 712-716.
- UNICEF (2005) *Female genital mutilation/cutting: a statistical exploration*. New York, United Nations Children's Fund.

- Vangen S et al. (2004) Qualitative study of perinatal care experiences among Somali women and local health care professionals in Norway. *European Journal of Obstetrics and Gynaecology and Reproductive Biology*, 112: 29-35.
- Walder RJW (1995) Female genital mutilation in Britain: why the problem continues in Britain. *British Medical Journal*, 310(6994): 1593-1594.
- Webb E (1995) Female genital mutilation: cultural knowledge is the key to understanding. *British Medical Journal*, 311(7012): 1088.
- Weir E (2000) Female genital mutilation. *Canadian Medical Association Journal*, 162(9): 1344.
- WHO (1997) *Management of pregnancy, childbirth and the postpartum period in the presence of female genital mutilation. Report of a WHO Technical Consultation*. Geneva, World Health Organization.
- WHO (1998) *Female genital mutilation – an overview*. Geneva, World Health Organization.
- WHO (2000a) *A systematic review of the health complications of female genital mutilation including sequelae in childbirth*. Geneva, World Health Organization.
- WHO (2000b) *Female genital mutilation. Fact Sheet 241*. Geneva, World Health Organization.
- WHO, UNICEF, UNFPA (1997) *Female genital mutilation: a joint WHO/UNICEF/UNFPA statement*. Geneva, World Health Organization.
- Wright J (1996) Female genital mutilation: an overview. *Journal of Advanced Nursing*, 24(2): 251-259.
- Young JS (2002) Editor's note: Female genital mutilation. *Journal of the American Medical Association*, 288(9): 1130.

Chapter 10

Conclusions

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It is becoming increasingly clear that mental and physical health are closely linked, influencing each other in powerful and complex ways. This understanding is helping to break down some long-standing barriers to good health and is beginning to offer new hope of care and cure. This review has sought to increase understanding of the interaction of reproductive health with mental health, especially in relation to women's lives and well-being.

According to WHO (WHO, 2001), depression is the single largest contributor to years lived with disability in adults. Symptoms of depression and anxiety, as well as unspecified psychiatric disorder and psychological distress, are 2–3 times more prevalent among women than among men. There is considerable evidence that stressful life events and reproductive health problems are closely associated with depression and anxiety disorders. Such events and problems are more common in the lives of women; in particular, gender inequality leads to considerable stress for women. Nowhere is this more evident than in situations where girls and women are subject to violence, particularly from an intimate partner. The violence can include physical, sexual and emotional abuse, and is common throughout the world. Available data suggest that, in some countries, nearly one woman in four experiences sexual violence from an intimate partner. Large numbers of women experience violence during pregnancy, with adverse consequences both for them and for their baby, such as miscarriage, premature labour and low birth weight.

Reproductive and sexual ill-health is estimated to account for 20% of the global burden of ill-

health for women, and 14% for men. These figures, however, do not capture the full burden of ill-health. Reproductive problems may be linked to antenatal care, delivery, postpartum care, family planning; infertility, unsafe abortion, sexually transmitted infections, including HIV, reproductive tract infections, cervical cancer and other gynaecological problems. These can have major social, emotional and physical consequences, which are severely underestimated in global burden of disease estimates. WHO considers unsafe sex to be one of the most important risk factors for health in the world, particularly for girls and women, whose low social status in many parts of the world means they have little control over their sexual and reproductive lives.

Although mental health is widely recognized as closely linked to reproductive health, in many countries it remains, at best, a marginal concern. Nevertheless, the areas of interaction of reproductive and mental health are considerable, and include, for example, psychological issues related to sexuality, childbirth, sexual violence, adverse maternal outcomes (such as stillbirths and abortions), sexually transmitted infections, including HIV/AIDS, family planning, reproductive tract surgery, sterilization, premarital pregnancy, menopause and infertility. These issues relate to both men's and women's reproductive health, as well as their relationships.

It has not been possible to consider all these issues in this review, because the evidence base for many is simply non-existent at present. Nevertheless, the available evidence on a number of key issues has been consolidated and analysed to present as complete a picture as possible

of the current situation. A considerable amount of research on reproductive and mental health has been reported in recent years, but most of this research has focused on a relatively small number of sexual and reproductive health conditions. More importantly, much of the research has been done in developed countries, with very little coming from developing countries. As an example, an electronic search revealed that, between 1992 and 2006, some 1500 research papers were published on postnatal depression, but none on depression following vaginal fistula. There is a complete lack of information on the mental health aspects of chronic health problems, such as vesicovaginal fistula, perineal tears and uterovaginal prolapse, which are much more common among women living in resource-poor and research-poor settings. This can lead to the erroneous conclusion that there are no mental health consequences of these conditions. Moreover, even in middle- and high-income countries, where many more data are available on the interaction between reproductive and mental health, the available evidence primarily concerns married women of childbearing age. The reproductive and mental health of men and of young, single women remains largely unexplored. Also seriously underinvestigated are the important inter-relationships between women's and men's reproductive health.

The developing countries have benefited from considerable research efforts on certain reproductive health issues, such as family planning, pregnancy, childbirth and lactation. Unfortunately, very few, if any, of these efforts have considered the mental health implications of these conditions to any significant extent. The gaps in the evidence have been highlighted throughout the present review.

From the available evidence, however, it is already clear that mental health needs to be an integral part of any programme that aims to address the major reproductive health priorities in developing countries. There is a high prevalence of depression and anxiety disorders in women attending gynaecological clinics in developing countries. Qualitative studies have demonstrated a strong relationship between psychological distress, depression and anxiety disorders, and aspects of reproductive health, such as sexually transmitted infections, HIV, childbirth and the postpartum period, pregnancy termination, spontaneous pregnancy loss, menopause, infer-

tility, and a number of gynaecological injuries and conditions. Mental health problems are also more frequent in women who are disproportionately exposed to risk factors and adverse life experiences that also affect their reproductive health.

The framework for analysis used in this review was informed by two interconnected concepts – namely, gender and human rights, especially reproductive rights – in identifying the risk factors and vulnerability of women to emotional distress associated with reproductive health conditions. The review draws attention to the critical importance of the dynamic interplay between women's reproductive and mental functioning. Even though the evidence presented is, of necessity, uneven, it is hoped that it will stimulate much-needed additional research, especially in developing countries, and that it will encourage policy-makers and reproductive health managers to expand the scope of existing services to embrace a holistic perspective. Policy-makers and service providers need to begin to address the mental health dimensions of many reproductive health conditions, and to look at how reproductive health services, and their treatment of women, can have profound effects on mental as well as physical health.

The burden of both reproductive and mental ill-health is greatest in the poorest countries, where health services tend to be dispersed or physically inaccessible, poorly staffed, resourced and equipped, and beyond the reach of many poor people. Increasing access to reproductive health services, and **mainstreaming mental health concerns** within them, are essential. The mental health of women is also closely linked to their capacity to give essential responsive care to their infants, children and other family members, and any initiative to improve family health must also seek to improve women's mental health. Mental health can no longer be considered an unaffordable “luxury” for women in resource-poor settings.

An obvious implication of these conclusions is that a two-pronged approach needs to be pursued: first, to give more attention to research on reproductive mental health in developing countries and to build the capacity of researchers in this neglected area; and second, to incorporate mental health considerations into reproductive

health programmes and into the training of providers of reproductive health care at all levels.

Overview of key areas discussed

Some of the key findings from earlier chapters are presented below. The major gaps and needs for further research and action are highlighted.

Pregnancy, childbirth and the postpartum period

Research has shown that, although mental health is inextricably linked to maternal and child mortality and morbidity, it has so far been neglected in initiatives to improve maternal and child health. In high-income countries, 10–15% of women who have recently given birth suffer from depression. In addition to the distress caused to the woman herself, postnatal depression can interfere with interpersonal relationships and have a negative effect on the cognitive and emotional development of the child. In developing countries, attention has tended to focus on physical health problems, such as infectious diseases, which may appear to be more urgent, and postnatal depression has received little attention. Yet recent studies have shown that as many as 25–30% of new mothers in these countries suffer from postnatal depression – a prevalence double that in the developed world.

The underlying determinants of postnatal depression are complex, and include the low status of women relative to men in many countries, their lack of autonomy, the birth of a girl in regions where there is a strong preference for male children, poor housing, marital and family discord, including violence, poor health, lack of emotional and practical support, isolation and poverty. There is increasing evidence related to the predictors, prevalence and correlates of poor mental health postpartum in developing regions, but investigations are yet to be conducted in some of the poorest countries.

It is not just the woman who is at risk: postnatal depression in low-income countries also affects the infant's cognitive and emotional development, and appears to play a crucial – and previously unrecognized – role in physical growth and survival. As a consequence of the more difficult environmental conditions in developing countries, depression may have a greater effect on the mother and her capacity to give respon-

sive care to her baby. Investigations of infant development following maternal depression should ascertain and control for the contribution of social adversity.

While effective treatments for postnatal depression, such as psychotherapy and antidepressant medications, are available in the developed world, interventions have so far focused almost exclusively on individual women. Evidence is emerging to suggest that strategies involving the partner may be more effective, but such strategies need to be designed and appropriately evaluated. It may not be possible to transfer existing approaches directly to developing countries, which have very different health care systems and cultural beliefs. Randomized controlled trials are needed to develop treatments for depression during pregnancy and after childbirth that are suitable for use in primary health care in resource-poor settings.

High rates of maternal depression constitute a major public health problem. It might appear anomalous to give attention to perinatal depression in developing countries, where other health problems seem so compelling, but it is likely that these are precisely the places where mental health is worst and contributes most significantly to the severity of other health problems. Programmes aimed at improving child health depend on the effective participation of mothers, but women who are depressed are less able to understand and respond to health-promoting interventions and education.

More generally, research attention has focused on mental health after childbirth rather than mental health during pregnancy, which warrants more comprehensive investigation.

Psychosocial aspects of family planning

Central to the discussion of the mental health implications of contraceptive use is the issue of women's agency, and how a gender-based lack of power and control affects women's ability to make contraceptive choices and undermines their mental health and emotional well-being. Women's ability to make decisions, including on participation in family planning programmes and use of contraception, is closely linked to their emotional well-being and their status in the family. Women who receive support from health professionals for autonomous decision-making

have fewer psychosomatic complaints and depressive symptoms.

The relationship between broad situational and interpersonal determinants of contraceptive use, decision-making, and the development of emotional distress, depression and other psychological disorders that primarily affect women has not been adequately investigated. Extensive research on the characteristics of situations that trigger clinical depression has revealed many areas of overlap with situations of intimate partner violence. Family planning programmes need to extend their explanatory models for unmet need and non-use or inconsistent use of contraceptives to include the possibility that intimate partner violence and lack of autonomy may be major causes of low rates of contraceptive use and poor reproductive health outcomes. Programmes to increase contraceptive use need to be based on an accurate understanding of the multiple determinants of contraceptive use.

Much of the research on the psychological effects of different methods of contraception, including female sterilization and the intrauterine device, has found that negative effects on mood are usually attributable to a lack of confidence in the effectiveness of the method, coincidental adverse life events, relationship problems or a family history of psychiatric illness, rather than the method itself. Negative psychological effects have been found among women who were coerced into being sterilized, those who did not understand the consequences of sterilization or experienced complications after the procedure, those who disagreed with their partner about the sterilization, and those whose marriage was unstable before sterilization. Adverse psychological effects are more likely to be a consequence of violations of reproductive rights, including the rights to accurate health information and to give free and informed consent to medical intervention, than to the procedure itself.

More recent research has confirmed the importance to psychological well-being of women being given adequate information before sterilization, and feeling that they have been able to make their own decision without pressure from either the partner or health care providers. The timing of the sterilization procedure is also relevant; women who are sterilized immediately after delivery, abortion or Caesarean section have

an increased incidence of psychosomatic complaints and depressive symptoms.

Women who are mentally ill or who abuse alcohol or drugs may be unable to give meaningful consent to sexual activity, and are less likely to use contraception effectively; they are at high risk of sexual exploitation. Some hormonal contraceptives should not be prescribed to women who are currently depressed, because they might contribute to further worsening mood. However, health professionals are less likely to discuss contraception with women who have serious psychiatric illness, and provision of contraception is problematic for groups who do not attend routine medical or reproductive health services.

Further participatory research is required to establish accurately needs for contraception, and to examine the disparity between contraceptive intentions and contraceptive use, looking beyond women's "failure" to adhere to their intentions. Investigations are needed of the coercion and pressure women experience from family planning programmes regarding child-spacing and uptake of contraceptive methods, including sterilization.

The mental health aspects of elective abortion are linked to the particular context of reproductive health and rights, attitudes to sexuality, and specific attitudes and laws relating to abortion and to women. Specific issues include women's access to safe, timely and affordable abortion, and the degree to which they receive interpersonal and societal support. Psychiatric sequelae of elective, safe abortion are rare. Typically, women experience heightened distress before abortion, and show significantly improved mental health indices afterwards. Following abortion, approximately 10% of women report regret, guilt, or other symptoms of psychological intrusion or avoidance. Over a longer time span, up to 20% of women may report some abortion-related regret or distress. The mental health consequences of unsafe abortion are not known. Qualitative data suggest that unsafe abortion can be traumatic, and is likely to cause more psychological harm to considerably more women than safe abortion.

There is a need for systematic methodologically rigorous investigations into the psychological aspects of abortion, including decision-making, the procedure itself, post-abortion adjustment, and need for counselling and follow-up medical

care. Comprehensive qualitative and quantitative investigations are needed in both developing and industrialized countries. The interactions between risk and protective factors in determining mental health in relation to abortion need to be clarified. Finally, the psychosocial aspects of sex-selective abortion are at present unknown and need to be systematically investigated.

Spontaneous pregnancy loss

There is an abundance of evidence documenting the wide range of psychological reactions to the experience of miscarriage. These reactions are mediated by differences in sociocultural as well as personal and health service factors. There is general agreement in the literature that many women experience miscarriage as highly distressing, and that subsequent rates of psychopathology, including depression and anxiety, are higher than in the general population. The particular factors that predispose some women to more intense psychological reactions have not yet been clearly identified, but vulnerability as a result of earlier adverse events appears salient and warrants additional investigation.

Although psychological reactions to miscarriage resolve spontaneously in most women, there appears to be a role for psychological intervention, immediately after treatment or in the long term. It is not clear whether some or all women would benefit from this type of intervention, or what form it should take, and there has been no evaluation of existing services. Medical services are routinely involved in preventing the potential complications of miscarriage, but are not generally perceived as providing psychological support at the time of treatment or at follow-up. In fact, the psychological component of medical care for miscarriage is largely neglected, and there is little agreement in the literature about the form that psychological intervention should take, or from which women would benefit most. It is, nevertheless, acknowledged that women who use health services after losing a pregnancy may benefit from a more psychologically informed model of care than currently exists in most settings. In practice, it is unlikely that a single approach to the psychological care of women after spontaneous pregnancy loss will be effective in all settings and for all cultural groups.

Menopause

It is necessary to look beyond menopausal status, hormone levels and menopausal symptoms to explain depression in women in midlife. A life course approach, rather than a cross-sectional one, is necessary to understand emotional distress in midlife. The "classical" social determinants of depression, as well as the presence of distressing somatic symptoms and reduced sexual functioning and pleasure, are likely to contribute to dysphoria and depression. A history of depression and high levels of psychosocial adversity may be more important than menopausal status in explaining emotional distress. It is important to evaluate the sources and impact of stress, and of social support, on women's emotional well-being. Family and friends may function as conduits of stress, as well as sources of support.

While there is considerable anthropological literature on the cultural construction of menopause in low- and middle-income countries, and on women's expectations and experiences of it, data on the links between mental health and menopause are more limited. Research on this relationship is needed to provide culturally specific data for decision-making at programme, policy and service-provision level. In particular, data are needed on whether the factors identified in high-income countries as critical to women's mental life in midlife are also relevant for women in low- and middle-income countries. Other relevant socioeconomic, cultural and interpersonal factors also need to be identified, and assessments made of the effectiveness of assistance given to women in low- and middle-income countries for health problems and physically or psychologically distressing symptoms related to menopause.

Gynaecological conditions

Gynaecological injuries and diseases are common, and yet women who develop these problems often feel isolated and distressed as a result of inadequate general understanding of their injury or disease, and inaccurate beliefs about the causes. If surgery is required, it may be deeply traumatic, adversely affecting the woman's body image, self-esteem, social confidence and sexual life, and having short- and long-term effects on mood and personal relationships. These potential effects have not yet been systematically

investigated. Relatively little research has been conducted outside the United States on the mental health aspects of gynaecological injuries and diseases, and knowledge of the wider psychological and social factors associated with them is limited. Overall, many problems result in significant psychological stress and psychosexual morbidity, with a marked negative impact on quality of life. Distress is greater in those who are young and poor or socially disadvantaged, and who have a history of undergoing violence. The diagnosis of an STI or cancer is often associated with a range of psychological responses, including anguish, anger, lowered self-esteem, hostility, shame, depression, and anxiety.

There has been virtually no consideration of the mental health factors associated with the diagnosis or outcome of any of these conditions in developing countries, even though they have direct and significant effects on mental health and psychological functioning.

The psychosocial consequences of obstetric injury, reproductive tract morbidity and cancers in women should be included in all research into these conditions. The specific needs of women in culturally diverse settings for advice, support and counselling during treatment and rehabilitation for gynaecological conditions should be systematically ascertained.

Programmes for primary prevention of gynaecological morbidity need to be designed and evaluated. Where women's access to health services is constrained by social and cultural factors, strategies to reduce obstetric injury and gynaecological morbidity should be accompanied by efforts to improve women's social position. Obstetric injury and consequent gynaecological morbidity can also be reduced by: encouraging social changes that promote the value of girls and delay marriage and first birth; ensuring rapid access to trained personnel during labour and childbirth; and ensuring that women do not return to hard manual labour shortly after childbirth.

Gynaecological and obstetric health services need to be accessible, affordable and appropriate to women's needs. The staff of such services should be trained to manage sensitively gynaecological morbidity and obstetric injury; they should try to change cultural practices that reduce women's self-determination and to identify psychological distress and anxiety. Health serv-

ice staff should offer non-judgemental, empathic care, which encourages women to talk about their reproductive health concerns. They should also be capable of providing support to minimize the mental health impact associated with treatment and care. Gynaecological and cancer screening services should recognize that women may be embarrassed or ashamed of tests, treatment and possible disease, and should ensure that they understand the nature of screening.

Mental health in the context of HIV/AIDS

The psychological morbidity experienced by women who have HIV infection is considerable and has multiple causes. There is an intricate relationship between mental health, disease progression, quality of life and disease outcome. Qualitative differences have been found between women and men in the emotional impact of HIV infection, in terms of grief, shame, and depression.

Regardless of ethnicity, women who are seropositive are more likely to report being victims of sexual and physical violence. They often have inadequate social support and express concerns about stigma, discrimination and hopelessness. They are more likely to report psychological distress, symptoms of depression, and distress related to physical symptoms. In addition, women experience gender-specific social stigma, a greater sense of isolation, and oppression related to gender, stigma, ethnicity, poverty, and route of infection. In stigmatized groups, disclosure of HIV infection is predictive of poorer mental health status. Conversely, poorer mental health might also predict lower levels of disclosure. Women experiencing both sexual and physical abuse are more likely to have a history of multiple sexually transmitted infections, be worried about the fact that they are infected with HIV, use marijuana and alcohol to cope, attempt suicide, feel as though they have no control in their relationships, and experience more episodes of physical abuse. Such traumatic life experiences are often associated with high rates of psychiatric co-morbidity, clinical depression or anxiety, substance abuse, and possible non-compliance with recommended health care and treatment.

In addition to the physical effects of HIV infection, women often lose their jobs and the support of their husband, and may be forced to turn to prostitution to feed, clothe, and educate their

children. The multiple problems, loss of physical and financial independence, discrimination, and other HIV-related difficulties can often lead to significant distress and a risk of suicide. Conversely, having a wide social network can be associated with better mental health and overall quality of life.

An emerging trend is the increase in HIV infection among people aged over 50 years, especially women, reaching approximately 2.8 million cases in 2005. Older people with HIV require special attention because they are likely to have a variety of other health, social, and emotional concerns. The mental health aspects of older women, in relation to sexual health, tend to be ignored except in terms of menopause. These women are often denied appropriate sexual health information, for instance regarding risk and vulnerability to reproductive tract and sexually transmitted infections, including HIV.

Depression is common among those who are HIV-infected, and is associated with a variety of other problems, including lowered immune response, shorter survival time, increased disability, and a lower quality of life. With the progression of the disease, there is the added risk of AIDS dementia complex.

Considerable attention, in terms of research, and policy and programme development, has been given to reducing mother-to-child transmission of HIV/AIDS. However, there have been few reports on the psychological well-being of new mothers with HIV, or on the mental health impact on young girls and boys of the death of their mother from AIDS in both developed and developing countries. This is an important area for research.

One of the most worrying and complex aspects of the spread of HIV/AIDS is its link to the widespread sexual exploitation of children, who are most vulnerable to contracting HIV/AIDS. Young girls whose parents have died of AIDS are often targeted by older men for sex. Another under-researched aspect is the mental health impact of the fact that the burden of care for people with HIV/AIDS falls primarily on women.

Rights violations, economic dependence, lack of decision-making power, conflicting gender roles, disproportionate domestic responsibilities, and gender-based violence contribute to

reproductive and mental health problems for women. There is a marked lack of evidence on women's mental health and how it interacts with vulnerability, risk of HIV infection, response to diagnosis, and subsequent health care. Most research on AIDS and its effects on mental health has been conducted in the United States; there is some from other rich countries, but very little from developing countries. This should be corrected.

Infertility and assisted reproduction

Infertility is experienced by many women as a profound life crisis or existential blow, which is uniquely stressful because it can last for many years and for many will not be resolved. The experience and eventual diagnostic confirmation of infertility can have a profound psychological impact, which has been conceptualized and assessed in different ways.

Women have been found to experience more emotional distress and depressive symptoms associated with infertility than men, and their lives are more disrupted by infertility than men's. Almost all women presenting for treatment for infertility have been found to demonstrate some of the following characteristics: increased anxiety, irritability, anger, profound sadness, self-blame, lowered energy levels, social isolation and heightened interpersonal sensitivity. Many women fear that earlier sexual experiences, the use of contraceptives or delaying procreation while pursuing professional goals may have compromised their fertility. Other less rational beliefs – of being punished for past misdeeds or of intrinsic unworthiness – have also been reported, particularly when infertility is of unexplained origin. Reaction to infertility is also conceptualized as grief, including for many intangible or disenfranchised losses, such as: the experiences of pregnancy, childbirth and breastfeeding; the children and grandchildren who will not exist; a generation and genetic continuity; the state of parenthood and the activities and relationships it entails; and an element of adult and gender identity which will never be realized and is substituted with a flawed infertile identity. In addition, individuals may fear losing significant relationships, in particular with the partner, physical attractiveness, or a positive sexual relationship. Fertility difficulties can exert a pervasive negative effect on quality of life, compromising planning and commitment to

other life activities. The effect is observable in both men and women, but more so in women.

The inability to bear children is highly stigmatized in strongly pro-natalist settings, and people who cannot have children may be socially marginalized. In poor countries, women with fertility problems may have their gender identity questioned, experience social exclusion or divorce, be suspected of having evil potential and be subject to harassment, especially from their in-laws. In settings where women are subordinated, they are highly likely to be blamed for infertility. Given the very limited access to assisted reproductive treatments in these settings, infertility leads to profound human suffering.



The diagnosis and psychosocial sequelae of infertility and the complex psychological responses to technologically assisted conception are central to the health of people facing these life experiences, and should be considered in research and clinical services. Causes of infertility differ, and in each country an accurate understanding is needed of the fertility problems of the population. In most countries, the prevalence, etiology and mental health effects of fertility problems have not been established, and relatively little is known about the psychological functioning of affected people, especially in developing countries.

There is a need for information on the nature of infertility treatment services in developing countries, and the long-term psychological consequences of infertility, including after the birth of a child. Data are needed on the short- and long-term psychosocial and medical consequences for both donors and recipients of gametes, including women in egg-sharing programmes. There is also a need for long-term comprehensive follow-up of the physical and mental health of offspring of assisted conception, with disaggregation by method of conception. Multiple pregnancies, which are more common after assisted conception, carry greater psychological hazards. The interaction between infertility and multiple gestations in influencing perinatal mental health should be clarified. The short- and long-term psychological effects of fetal reduction in multiple-gestation pregnancy need to be systematically investigated. The potential of psychological treatments to relieve the distress associated with infertility and assisted reproduction should be investigated in randomized controlled trials.

Infertility treatment services in all settings need to be based on evidence about local causes and best practice in treatment, and should include mental health care as a component of routine care. Mental health care should be focused on assisting the person to make a realistic appraisal of the chance of treatment success; providing emotional support in the interval between embryo transfer and pregnancy testing; and assisting the person to make a clear choice about when to stop treatment.

Female genital mutilation

The health effects of female genital mutilation, in areas where the practice is widespread, are just starting to be documented, and many of the existing data come from studies with methodological limitations. Most of the publications are case reports or case series, while only a few studies have compared women who have and have not had FGM. In some articles, the type of FGM is not defined, while in others all types are combined. In addition, the age or developmental stage at which the procedure was performed is often not reported. Many of the investigations have not included clinical examination of the perineum, and classification of FGM status may not be reliable in these circumstances.

Most of the studies examining the complications of female genital mutilation have been done in Africa, but some evidence has been gathered in industrialized countries, among immigrant populations. The adverse physical sequelae of female genital mutilation have been more comprehensively investigated and described than the psychological effects. The most obvious long-term adverse effects of FGM are on gynaecological health, especially sexual and obstetric functioning.

There is an almost complete lack of systematic evidence on the psychological sequelae, including mental health effects, of female genital cutting. It has been suggested that this situation has led to unfounded speculation about the psychological impact of FGM. Some reports have described the conflict faced by young women who want to conform to parental and societal expectations by complying with FGM, but who are thereby exposed to fear, pain, complicated recovery and possible long-term health problems. Chronic depression and anxiety have been observed among women who have had FGM, associated with genital disfigurement, gynaecological dysfunction and specific fears that cysts or scars are cancer or that the genitals are re-growing. Anxiety is also associated with obstructed menstrual flow and both anticipation of, and actual experience of, painful intercourse. It has been suggested that women might be traumatized by the procedure, on the basis of such responses having been observed in women who have undergone mutilating gynaecological procedures for clinical reasons.

Overall, given the severity of physical damage and long-term adverse health effects, it is highly likely that genital cutting has an adverse effect on women's mental health. As long as the practice continues, systematic and comprehensive examination of these effects is urgently needed. Information is also needed on the complex interactions between the social position of women and the pressure to maintain tradition and to adhere to family expectations, and their effects on the psychological response to genital mutilation. The psychological effects of failing to comply with genital mutilation in settings where it is an established traditional practice need to be assessed.

Health professionals in countries where female genital mutilation is practised, or to which women who have experienced genital mutilation migrate, need to have specific knowledge and skills in order to provide appropriate health care. Obstetric health professionals should be trained to provide antenatal, intrapartum and postpartum health care for women who have undergone FGM, especially type III. The care provided needs to be informed by cultural sensitivity, provision of choice, and an appreciation of human rights. Research exploring the possibilities and implications of changing this practice in communities where it is common is urgently needed.

Reference

WHO (2001) *The World Health Report 2001. Mental health: new understanding, new hope*. Geneva, World Health Organization.

Annex

WHO SURVEY QUESTIONNAIRE ON THE MENTAL HEALTH ASPECTS OF REPRODUCTIVE HEALTH

WHO is currently carrying out a global review of women's mental health as it intersects with their reproductive health with emphasis on STDs/HIV/AIDS, pregnancy and postpartum, miscarriage, unwanted pregnancy/abortion, infertility, peri and post menopause, and domestic and sexual violence.

This involves reviewing the published and unpublished literature on the subject of the last 10 years from developing and developed countries with special emphasis on developing countries, including all epidemiological, clinical and operational research; programme/interventions evaluations, ongoing or completed country project work on the subject, pilot projects etc. On the basis of an analysis and synthesis of such literature, the review document entitled "Implications of Reproductive Health on Women's Mental Health" would provide:

- the most updated information/ knowledge on the epidemiology and ways in which Reproductive health events impact on women's mental health;
- the biopsychosocial factors that create vulnerability to mental problems and those that may be protective; and
- the types of programmes that could mitigate the adverse effects and promote positive mental health; and
- indications of the most feasible ways in which health authorities could advance policies, formulate programs and reorient services to meet the mental health needs of women during their reproductive lives.

In order to assist us in compiling this much-needed review, we would be grateful if you could take some time to answer the following:

Have you carried out research dealing with the epidemiology, determinants and/or outcomes of different reproductive health events during women's lifecycle?

1. **Yes**
2. **No**

If yes, could you please list the topics covered and supply us with copies of any relevant reports/publications.

Are you currently or have you in the past conducted any research on the determinants and outcomes of women's mental health?

1. **Yes**
2. **No**

If yes, could you please list the topics covered and supply us with copies of the relevant reports/publications.

Does your research incorporate any focus on the impact of various reproductive health events during the lifecycle on women's mental health?

1. **Yes**
2. **No**

If yes, could you identify the specific areas of reproductive health involved and the aspects of mental health you address? Please supply us with copies of the relevant reports/publications.

Have you been involved in policy development/programmes/services addressing women's mental health? reproductive health? or both?

1. **Yes**
2. **No**

If yes, could you please explain and list the issues covered and supply us with copies of any relevant reports/publications.

What aspects of reproductive/mental health do you believe require increased attention?

Please list topics and explain why you believe further knowledge is necessary?

Please indicate contact details of other sources of information on this subject.

Other comments/suggestions.

We thank you in advance for your collaboration in this important but too often neglected area. All information provided will be carefully reviewed and duly acknowledged if used.

Sincerely

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