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Margie Polden Memorial Lecture: Why women's health needs the WoW factor

F. E. Campbell

Wellbeing of Women, London, UK

Abstract

The health of women in the UK and other 'high income' countries has improved substantially in the past 100 years, as demonstrated by an increase in life expectancy. Has this led to a sense of complacency? Does it mask an underlying stalemate in improvements to health services for women? Have women's attitudes to their health altered with improving life expectancy? It is common to say that the last taboo in women's health is discussion about gynaecological issues. Incontinence is still the topic that is not acceptable on breakfast television. Whilst physically explicit programmes proliferate in the evening, gynaecological topics are rarely mentioned in prime-time media. In the meantime, we are bombarded with 'advice' about good health, diet and exercise. Does this serve to mask an underlying deficiency in the search for real knowledge that can help us to address the most common of women's health conditions? Are we translating the knowledge that we have into clinical practice and properly giving it to the women whose lives could be improved? Wellbeing of Women is a charity that raises money to improve women's health through research, training and education. This paper discusses the current status of women's health and what the role of such a charity should be in the twenty-first century. We can all ask ourselves, 'What is the women's health agenda?'

Keywords: chronic disease, research, risk factors, Wellbeing of Women, women's health.

Introduction

I am honoured to be invited to address you today by giving the 2010 Margie Polden Memorial Lecture (Fig. 1).

My first task in preparing this presentation was to find out something about Margie Polden's life and background. I learned that she was renowned for fierce debate and a drive to disseminate knowledge to as wide an audience as possible. She was a determined individual who was very successful in her attempts to establish the importance of the women's health agenda and improve healthcare for women. Her work had an impact on thousands of women's lives.

The same qualities have been the driving force sustaining Wellbeing of Women (WoW) for the past 5 decades. This morning, I would like to

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Correspondence: Liz Campbell, Director, Wellbeing of
Women, 27 Sussex Place, London NW1 4SP, UK (e-mail:
lcampbell.wellbeingofwomen@rcog.org.uk).



Figure 1. Liz Campbell, Director of Wellbeing of Women.

consider the current status of women's health and the goals that all of us, and particularly a charity such as Wellbeing of Women, might achieve together within the next 20 years.

Background

Wellbeing of Women is a charity that seeks to improve women's health by raising funds for research, training and information. We fund medical research into ways to develop better treatments and training to improve doctors' effectiveness, and we provide education for women so that they can stay well. When the charity was formed as the Childbirth Research Centre in 1964, around 141 babies died every day, either during or shortly after birth; today that number is 17. In 1964, there were 500 maternal deaths each year; today that figure is 100 (DHSS 1972; Lewis 2007). Undeniably, this is a great improvement, but is it good enough? Globally, half a million women die each year from complications related to pregnancy and childbirth, and these problems are the major cause of death for girls between 15 and 19 years of age (WHO 2009a). We will return to the underlying picture later.

The broader picture

In 2009, the World Health Organization (WHO) produced a major report, *Women and Health: Today's Evidence, Tomorrow's Agenda* (WHO 2009a). Dr Margaret Chan, WHO Director General, said at the launch of this publication:

'If women are denied a chance to develop their full human potential, including their potential to lead healthier and at least somewhat happier lives, is society as a whole really healthy? What does this say about the state of social progress in the 21st century?' (WHO 2009b)

I was amazed by some of the conclusions of the report; for example, women provide the bulk of healthcare, which is not a surprise, but rarely receive the care that they need. Heart attacks and stroke, which are often thought to be male problems, are the two leading killers of women. However, I was most surprised by the paucity of reliable data reported by the authors, who state that 'even maternal mortality, one of the most egregious threats to women's health in the developing world, remains poorly measured' (WHO 2009a, p. 87). Of course, we heard again a few weeks ago that the progress of United Nations Millennium Development Goals 4 and 5 is

impossible to verify because the data are so unreliable (WHO 2005; UNICEF 2009; Waage *et al.* 2010).

In preparing for this lecture, my biggest problem was tracking down reliable information about the incidence of a variety of obstetric and gynaecological conditions, and in particular, historical data for an accurate comparison. This seemed to be especially difficult for what we refer to as the 'chronic benign conditions' – those that might not kill you, but which could ruin your life! Most of the general statistics I will quote below come from *Women and Health* (WHO 2009a) and relate to data from 2004.

It is interesting to speculate about the part that increased life expectancy may play in women's health and the extent to which changes in the incidence of some gynaecological health conditions in the UK relate to this longer life span. In the 1950s, the average life expectancy for women in 'higher income' countries was around 65 years and this figure had improved by around 20 years in 2005. It is obvious but undeniable that, as women live longer, the incidence of conditions commonly occurring in older age will have a greater impact. If you die before the menopause or are considered at the limit of normal employable age when this change occurs, the impact that it has on your physical and mental health will be small. However, because increasing numbers of women are economically and socially active in their 60s, the effect will be greater. It is interesting that the percentage increase in sexually transmitted diseases is greatest in those over 50 years (HPA 2009). This makes me wonder if we should be looking at the effectiveness of the human papillomavirus jab for women over 40 and whether it is wise to scale back the screening programme at 50. With the increase in the number of sexual partners of women over 50, will we see cervical cancer become a disease that occurs routinely in women of all ages rather than one that peaks in women aged between 25 and 40?

We have also seen a significant increase in the incidence of uterine (or endometrial) cancer in the past 10 years and little improvement in the survival rates for ovarian cancer, but these two diseases are the most commonly occurring maladies in women over 45 years of age (Cancer Research UK 2005; WoW 2010).

During my research for this presentation, I asked a well-known Professor of Reproductive Medicine how she would describe the state of women's health. After consideration, she said

that the problems are how little we know and that so much research is done in isolated little pockets. At a recent conference attended by leaders in the field of early pregnancy loss (miscarriage), no one was able to give any reliable data about the number of miscarriages per week that occurred in their unit. It would seem that not much information is being collected systematically. Part of the problem is that computer systems at the point of care are not programmed to share information, and therefore, the results of a scan are not automatically transferred to the clinical notes system. In practice, women's health physiotherapists must experience such problems all the time: difficulties for the clinic or doctor trying to transfer information to you in order to enable you to provide the best treatment for the patient, and then equal difficulties for you getting the information back to the referral source. Who collects the data routinely - the clinic, the doctor, the trust? This becomes even more complicated on the macroscale, i.e. at the nation-wide level. I am not sure how you would ever ensure that data is captured adequately from all sources of healthcare, i.e. from both the public and the private sectors. Even where there is a national data collection system, the same one will not necessarily be used by each country in the UK. Indeed, many of the statistics that we rely upon at WoW, and that are in common use, are figures collected by aid organizations such as Cancer Research UK or the good single-issue charities. In the absence of a UK women's health agenda, I suppose that we should not be so surprised. However, how are we going to effectively address problems that we cannot define?

The WHO (2009a) report makes a very good start because it deals with both physical and mental health, and begins to make the links between the two fields. Of course, if you include hormones, a woman's physical health is very much connected with her mental health, and female deaths caused by mental illness or self-inflicted injury are not necessarily unconnected with gynaecological health.

The leading causes of death for women aged between 15 and 44 years in high-income countries are road traffic accidents, suicide/self-inflicted injuries and breast cancer. Together, these account for more than one in every four deaths, and I was astounded by the high percentage of mortality and disease burden that *Women and Health* (WHO 2009a) attributed to mental disorders. In higher-income countries, over 9%

of deaths in this age group are attributed to self-inflicted injury resulting from a mental disorder. Globally, 13% of women are estimated to be affected by post-partum depression within one year of giving birth. It is one of two causes of maternal mortality in the UK against which few improvements have been seen in the past 20 years; in other words, just as many women kill themselves after giving birth as they did 2 decades ago.

Suicide

Higher-income countries have more women than men reporting moderate to severe mental health disorders who receive treatment, but even though more low-income women report mental disorders, a greater percentage of high-income women are treated for their problem. Suicide is the seventh leading cause of death globally for women aged between 20 and 59 years, and the second most reported cause of death in low- and middle-income countries of the Western Pacific Region. One in three female suicides world-wide occurs in women between 25 and 44, and suicide is the fifth most common cause of death globally for women in the 20–44-year-old age group, putting it ahead of road traffic accidents.

More women than men attempt suicide, and suicidal behaviours are a significant public health problem for girls and women world-wide. Factors increasing the risk of suicide in women include exposure to childhood sexual abuse, intimate partner violence and abusive alcohol consumption, which leads, in turn, to depression and opens the way to intentional self-harm.

Another cause of maternal mortality that, like mental illness, has not been much improved is cardiovascular disease.

The six critical risk factors

Much of the burden of disease that adult women face throughout the world could be prevented by addressing critical risk factors and it is important to understand that each risk has specific causes. Six risk factors for chronic disease jointly account for 37% of global deaths in women aged 30 years and over. These problems account for 63% of deaths from cardiovascular disease and diabetes, and over three-quarters of deaths from ischaemic heart disease. They are also responsible for substantial numbers of female deaths from cancer and chronic respiratory disease. While most of the deaths caused by these risk factors occur when women are older, much of

the exposure starts earlier in life, often during adolescence.

The risk factors are:

- (1) high blood pressure;
- (2) high blood glucose;
- (3) physical inactivity;
- (4) tobacco use:
- (5) obesity/overweight; and
- (6) high cholesterol.

High blood pressure is the leading risk for adult women everywhere and it is responsible for 18% of deaths in women over 20 years of age. High blood pressure, high blood glucose levels, physical inactivity and high serum cholesterol cause similar proportions of deaths across all income levels.

Overweight and obesity are major risk factors for cardiovascular diseases, diabetes, musculoskeletal disorders and some cancers, and together, these caused an estimated 1.5 million deaths in women aged 30 years and over in 2004. The latest projections by WHO indicate that the number of overweight and obese adult women world-wide will rise to 1.5 billion by 2015.

At a recent WoW event, a leading gynaecological oncologist informed the audience that, in order to improve their chances of avoiding cancer, the most important things that they should do were to avoid obesity, smoking and lack of exercise. Of course, many of these risk factors are linked and one will likely lead to another, with physical inactivity being a precursor for most of the others. I do wonder how many women begin the drift into inactivity, obesity and so on because of continence problems after pregnancy or during menopause? And does the depression come before, after or during these times?

Women's health

The more that I thought about the information contained in *Women and Health* (WHO 2009a), the more questions came to mind that were not answered by the report. Do we have any idea at all about what is going on in women's health? Have we reached a point in the UK and other high-income countries where, having reduced maternal and child death by such an extent in 50 years, current death rates are felt to be 'acceptable' or 'inevitable'? Do we have some peculiar guilt complex about not 'complaining' further about our situation when things are so much worse in many other parts of the world?

This is a ridiculous idea, and if we give up on the search for answers in countries with great histories of research and improvements in treatment, places where we are perhaps close to getting answers, then what hope is there for solving the problems of the lessdeveloped world? Just because we have a solution, this does not mean that it is the best one. For example, a significant number of deaths during childbirth involve prolonged labour as a contributing factor, and therefore, detecting that a prolonged labour is developing is very important and will save lives. In 1954, the partograph was developed to detect prolonged labour, but there have been no further innovations in this field since then. Similarly, there is only one drug to treat prolonged labour, oxytocin, which was developed in 1954, and there has been no new drug therapy introduced since then. By comparison, 1954 was the year that the first drug was produced to treat heart failure and there are now a 56 drugs that a doctor can administer for this condition. The question that we should be asking ourselves is: how will we reduce maternal and child deaths if we do not look for answers (Quenby 2009)?

Many prolonged labours result in a Caesarean section and approximately 50 000 are performed each year in the UK alone. Around 10% of first-time pregnancies result in a CS and each operation costs the National Health Service (NHS) £1000 more than delivering a baby naturally. This amounts to millions of pounds each year, but the annual investment in women's health research in the UK, including cancer, is only around £20 million in total. Of the 17 neonatal deaths each day in the UK, around 50% cannot be explained (Sands 2010; Lewis 2007). Are we comfortable with that?

Interestingly, because deaths from communicable diseases are reducing globally, this trend is exposing the actual level of death from other causes, such as maternal mortality. Since maternal and neonatal mortality rates are also improving, this is, I am told, uncovering the incidence of congenital birth defects – many preventable – but challenging all healthcare systems to look at the most cost-effective methods of preventing many of these occurrences. This will only be achieved by pooling information and research, and testing different approaches.

Research in women's gynaecological and reproductive health

I decided to take a look at the quantity of research being carried out in the broad area of women's gynaecological and reproductive health. I began by using the Google search engine and the keywords 'women's health stats'. Second or perhaps third in the results list was a US website selling outfits for the mother of the bride – I am still trying to figure out where that came into things!

A session on the National Institute for Health Research website (www.nihr.ac.uk) led me to the Portfolio Database, where I found a total of 161 projects connected with reproductive medicine and 930 for cancer. Perhaps because of my ineptitude, I found the database incredibly difficult to use, and in general, my Google search found little evidence of major research or clinical trials in areas such as chronic pelvic pain, incontinence, prolapse or endometriosis, especially in comparison with the quantity of work in fields such as cancer, breast cancer and heart disease.

Menopause was an interesting topic because the only trials I could find were connected with hormone replacement therapy (HRT) and breast cancer. Actually, if we can believe the figures (Menon et al. 2007), only 20% of perimenopausal women in the UK use HRT. In fact, as far as I am aware, WoW is funding the only scientific/clinical work investigating the mechanism of hot flushes in order to develop a nonhormonal solution (WoW 2009a). Nevertheless, this is something that will affect almost every woman and it is becoming an increasing problem as life expectancy increases. What exactly are the issues for the post-menopausal woman, given that she will most probably be post-menopausal for longer than she was reproductive?

I would argue that I found more questions than answers in the innumerable cases within reproductive medicine in which having one answer seemed to be enough, even though it was not a complete solution. This is like using a sledgehammer to crack a nut.

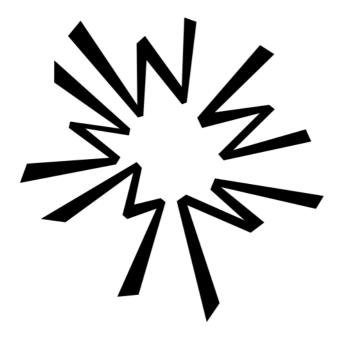
In the late 1950s early 1960s, only one drug was used to treat cancer – all cancers – and therefore, whatever type of cancer you had, you were treated chemotherapeutically with the same medication. Of course, this situation has changed dramatically in cancer therapy, as it has in most areas of medicine, with the exception of women's health. As I have already mentioned, there is still only one drug to treat prolonged labour. There is no cure for endometriosis, even

though 2 million women in the UK suffer from it (Pearson & Pickersgill 2004, 2009b). There is no cure for polycystic ovary syndrome (PCOS), but it is the most googled topic in reproductive health (as demonstrated by tracking Google AdWord searches for the keyword 'PCOS' against six to 10 other obstetrics and gynaecology keywords on Google Analytics over period of 6 months from March to September 2010). There is limited understanding about why some women miscarry and the number of premature births is increasing, but no one knows why. The cause of many of miscarriages is unknown in the first place. These are just some examples from a longer list. Of course, there are interventions that can be used; for example, women with endometriosis are offered hormone therapy, often the Mirena coil, which has proved very successful for many. Numerous research projects have advanced our knowledge about what to do in the event of premature labour, but there are no predictors, and the situation is similar with regard to miscarriage.

Why is there an apparent lack of interest? It is nothing to do with the clinicians who work in the field of reproductive medicine because they are a most enthusiastic group of people who are desperate to advance knowledge in their field. Currently, many are fighting to save their university departments since a considerable number are under threat of being merged with another speciality such as cancer.

Royal College of Obstetricians and Gynaecologists

Interestingly, this turns the origin of the Royal College of Obstetricians and Gynaecologists (RCOG) on its head. In the 1920s, obstetricians were members of the Royal Society of Physicians of London and gynaecologists were members of the Royal College of Surgeons of England. There was much debate amongst those doctors who practised in the field of women's health as to how satisfactory this was. Remember, in the late nineteenth century, most women died from CS, which was largely performed to save the baby, so I presume that obstetricians were not thought to be surgeons! Conversely, the solution to most gynaecological problems in the early twentieth century was to remove the bits causing the problem! It is interesting to speculate where women's health would be now if the structure of obstetrics and gynaecology had remained thus divided. In fact, the foresight and imagination of



WELLBEING OF WOMEN

Figure 2. Wellbeing of Women logo.

a small group led by William Blair-Bell and Sir William Fletcher Shaw led the doctors to found their own Society, then College and ultimately Royal College (Peel 1986). It was the first college/medical society to emerge from the larger groupings of physicians and surgeons.

Is it that people are not interested in women's health? That cannot be the case because women are the most avid consumers of health information and access health services far more frequently than men. I have been informed that 70% of visits by women to in-company medical services are for gynaecological problems.

Wellbeing of Women

Wellbeing of Women (Fig. 2), the partner charity of RCOG, runs a programme of in-company health awareness for a range of businesses. Under the title 'Gynaecology Is Fun!', some of the best speakers among the fellows of RCOG are sent to talk about reproductive health to male and female employees. At the end of every seminar, we ask the audience to tell us if they knew all of the information that the speaker covered. So far, nobody has answered 'Yes!' to this question.

Indeed, most attendees say that they were horrified by how little they knew.

Occasional surveys that we have carried out also suggest that gynaecological topics are not discussed much, even on a woman-to-woman basis. I believe that this is changing, but there are still plenty of us around who were brought up only to whisper about anything gynaecological and check that no one was listening if we were imparting obstetric information. You will be aware that this is one of the main reasons that so many women do not seek help for incontinence.

Do we really think that this is not a topic for polite conversation? Do we really think that gynaecological problems are things that we should just suffer in silence?

I think that this taboo is changing. There have been a number of very explicit factual programmes on television about gynaecological matters, and as we all know, it is what is on screen that is significant, i.e. if it is not on the box, it is not important! I was even surprised by how difficult it was to get Ulrika Jonsson on television when we ran our incontinence awareness campaign with Always Envive in 2009.

Among younger women, there is greater openness, and as employers come to realize the importance of women to the economic success of their organizations, they are becoming more interested in women's health. However, it is interesting that, despite the atmosphere of political correctness and equality, an enduring topic of workplace 'humour' are remarks about how 'it must be her time of the month'. We were helping a Professor of Occupational Health Psychology to gather data for a piece of research about the impact of the menopause on women working in offices. This followed some work that she was commissioned to do about the menopause and shift work. Interestingly, she found that the ability to personally control the temperature of the working environment was one of the most important factors for women during the menopause. Anyway, we struggled to find organizations that were willing to engage with her survey because they worried about their female employees feeling that it was discriminatory in some way!

Conclusion

What have I learned while preparing for this lecture? My conclusions are:

• There is a terrifying lack of comparative data being routinely collected and routinely made available in the field of women's health.

 There is a reluctance to discuss and/or debate women's health issues in case of some perverse lapse into inequality.

Conversely, by highlighting the different issues and/or needs affecting women's health, we are disadvantaging women in the workplace:

- Money for research into women's health is contracting.
- The status of women's health is under threat.
- Philanthropy is obsessed with health issues in the developing world.

Wellbeing of Women receives three times as many top-quality research applications as it can fund and we need to raise more money to enable additional work to be done. However, even more important is the need to ensure that money is spent as effectively as possible since we could spend an extra £20 million each year on medical research and clinical trials to improve women's health.

There is currently a shortage of 600 doctors in Obstetrics and Gynaecology. Research demonstrates that there is insufficient communication between midwives and doctors, which has been proven to cause medical problems during pregnancy and lead to postnatal depression. Other work has proved that multidisciplinary teams achieve the best obstetric and gynaecological outcomes, and further investigation suggests that many gynaecological issues are diagnosed only on the sixth visit to a primary care clinician.

There is a need for more research, training and education, but how do we achieve this and what do we prioritize?

Wellbeing of Women intends to raise the profile of women's health and make access to the necessary clinical information even easier. We need to communicate more effectively: we need to tell people what the big questions are and offer them the solutions that they need.

The breast cancer charities have been very successful with their simple message: give us money and we will stop breast cancer. Cancer Research UK uses 'Together we will beat cancer' as its slogan. 'Together we can rule out incontinence' will never have the same appeal, I am afraid, and anything to do with 'women's bits' tends to produce an horrified reaction from women as well as men.

However, we can remind people of the fundamental role that women play in society. The lynchpin of many homes and families is female, whether as mother, grandmother, sister, daughter or partner. Increasingly, women are lynch-

pins in commerce and much of the public sector would collapse without us. I do not mean only those women in senior roles or that women should run everything, but day by day, week by week, a large proportion of our life is held together by women. If those women are held back by illness or by a chronic debilitating symptom, perhaps every month, perhaps even daily, they fail to reach their full potential and so does society.

Let us return to WHO Director General Dr Margaret Chan:

'If women are denied a chance to develop their full human potential including their potential to lead healthier and at least somewhat happier lives, is society as a whole really healthy? Imagine needing a report to say that healthcare shouldn't have a gender bias.' (WHO 2009b)

Wellbeing of Women is the only charity that encompasses the whole range of women's health and it has a very practical agenda for improvement. We will be raising the profile of the big women's health issues and encouraging others to join us so that we can find solutions together. I hope that you will join us on our journey to save women and save the world.

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Liz Campbell has been the Director of WoW since 2006.

Wellbeing of Women is a charity that works to improve women's health through research, training and education: it funds medical research to develop better treatments; it supports specialist training to improve doctors' effectiveness; and it provides education for women so that they can stay well.

Wellbeing of Women was formed in 1964, but traces its origins back to the National Birthday Trust Fund, which was established in 1928.

Prior to joining WoW, Liz was an independent member, Vice-chairman and then Chairman of the Surrey Police Authority, National Lead for Professional Standards and Probationer Training, and a member of the Police Negotiating Board. Previously, Liz was a non-executive director of two NHS trusts, owned and ran an industrial employment agency, served as trustee and fundraiser for a number of charities, and was a human resources professional in the construction industry.