

PSYCHOSOCIAL DISTRESS AND CERVICAL CANCER

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Abstract

This overview of the psychosocial distress experienced by women diagnosed with cervical cancer addresses the important tasks of individually assessing and managing the impact of the diagnosis and treatment for all women and their caregivers. Distress in the context of a cancer diagnosis is a normal, anticipated response. While the experience of distress is universal, the intensity and duration of distress varies according to prognosis, social circumstances of the patient and the morbidity associated with treatment. Symptoms of elevated distress may persist long after treatment ceases, even for patients who have a favourable prognosis. For cervical cancer patients, there are unique factors associated with their experience of distress. In this article the factors associated with distress are discussed. The socio-demographic characteristics of 90 women treated at a large gynaecological cancer treatment centre in metropolitan Sydney are reviewed. Differences between women who present with early versus late-stage disease are examined. Regardless of disease stage or prognosis, there are long-term consequences of cervical cancer treatment and these are highlighted. The major side-effects of cervical cancer treatments impact on bladder, bowel and sexual function, as well as overall quality of life. Three case studies of women with cervical cancer are presented to illustrate the importance of high quality, individualised psychosocial care as an integral component of the comprehensive cancer care of women with cervical cancer.

The diagnosis of cancer in any site has the potential to be a catastrophic, life-altering event. Immediate responses usually focus on existential issues of survival and impact on family and caregivers. In the longer term the focus shifts to management of treatment side-effects, which may impose a considerable physical and emotional burden.¹ Beyond the impact of the treatment and questions concerning prognosis, the legacy of being a cancer patient is pervasive. Even for long-term survivors, significant numbers report considerable distress associated with the fear of recurrence and adjustment to a new self-concept.^{2,4}

In the case of cervical cancer, women may experience a unique emotional and psychological burden for three main reasons: cervical cancer is largely a preventable cancer; there is an effective screening test, readily available to most in the Australian population; and it is associated with a sexually transmitted virus, raising the spectre of guilt and blame, at least in the minds of many women and families if not in the minds of health care providers.⁵

Anecdotally, and at the risk of over-generalising, women with cervical cancer fall into two main groups. The first group are those with (usually) early stage disease for whom the cancer has manifested within the screening interval. Women in this category are often young and usually have an adequate Pap test screening history. A small number of these women are found, on review of pathology, to have had a false negative result on a previous Pap test. Not infrequently, the diagnosis is made in the context of child-bearing; either on routine ante-natal screening, or at post-natal follow-up.

No matter what the circumstances in which women in this group find themselves with an un-anticipated diagnosis of cervical cancer, the dominant issue is profound distress that their best endeavours at

attending to their own health have let them down. Often there is anger and a sense of injustice directed at health care practitioners whom women may perceive as having failed to protect them. In these cases, the distress at the diagnosis of cancer and the immediate questions concerning threat to survival may be compounded by worries about future reproductive ability, sexual function and body image,⁶ as well as a generalised distrust of health care providers.

The second main group of women are those who have advanced disease at presentation, usually because they have not been adequately screened and in some cases, not screened at all. There are a variety of factors which mitigate against women accessing Pap test screening. These factors include, usually in combination: socioeconomic disadvantage; physical, intellectual or psychiatric disability; history of sexual abuse; family dysfunction; or simply being born in a country where there is no routine screening.⁷ For many of these women, the diagnosis of advanced cervical cancer is yet another disaster in a lifetime characterised by catastrophe, impoverishment, neglect and disadvantage; the sense of injustice here relates not so much to individuals as to endemic social injustice.

Impact of treatment

Regardless of the stage of cancer or the circumstances of the woman and her family, beyond the primary concern for survival is the challenge of managing the real impact of the disease, the quality of survival in the context of side-effects and consequences of treatment.

For women diagnosed with early stage disease, treated with surgery alone, the prospects for cure are high,⁸ but so too are the prospects for long-term morbidity. While these women can expect to survive their cancer, cure

may come at the cost of infertility, sexual dysfunction, bladder dysfunction, changes to body image and/or lower limb lymphoedema. Ongoing problems with anxiety, depression and relationship difficulties are often reported, as are persistent difficulties with sexual function.^{9,10-15} Additionally, there is frequently generalised anxiety and worry associated with fear of recurrence, or development of a new cancer.

Women whose treatment for stage II cervical cancer is primary chemo-radiation and those who have combined surgery and chemo-radiation, have a relatively good chance of cure. However, the morbidity from treatment is usually more significant than for those who have surgery alone. Along with loss of fertility, sexual dysfunction¹⁶ and lower limb lymphoedema, these women may have to contend with the additional burdens of menopausal symptoms (premature for many) and vaginal stenosis, both of which may make more difficult their sexual rehabilitation and resumption of a normal lifestyle. In a small number of cases, even though treatment confers long-term survival or cure, severe bladder and bowel complications may result in the development of fistulae, requiring surgical intervention and the formation of ostomies. Not surprisingly, patients report significant distress associated with persistent bladder or bowel problems.¹⁷ Paradoxically, the cancer may be in abeyance, but the associated existential angst may persist, as does the fear of recurrence.¹⁸

Treatment for very advanced cervical cancer offers a small chance of cure, but incurs a high rate of severe treatment related complications for many women. Nevertheless, it is offered to and accepted by most women, because it carries the hope of extended survival and is effective in palliating symptoms of pain and vaginal bleeding. Whilst morbidity following treatment is significant, quality of life may be enhanced by the opportunity to have treatment and to optimistically anticipate improved functioning and survival.^{19,20}

Cervical cancer in context

Moving on from an abstract discourse about the impact of cervical cancer in a theoretical sense, what is the 'lived experience' of the women themselves? What are the characteristics of women who have recently been treated for the disease in the gynaecological cancer service of a major, capital city teaching hospital?

In the period from January 2005 to July 2007, 90 women with a new diagnosis of cervical cancer presented to Sydney's Westmead Centre for Gynaecological Cancer. So, who are they?

Snapshot summary

Table 1: *Country of birth, n=90*

Australia	59
United Kingdom	10
New Zealand/Oceania	7
Asia	6
Europe	4
Middle East	3
South America	1

Table 2: *Place of residence, n=90.*

Sydney West Area Health Service	70
Rural/regional areas	17
Other metropolitan health services	3

Patients treated in this unit were predominantly English-speaking (78%), with three-quarters of them living in the local area health service. On the face of it, arranging and completing treatment would appear to be relatively uncomplicated for most of these women; they are not impeded by communication barriers and they live within a reasonable distance of the treatment facility. However, for many, their lack of adequate social supports, lack of reliable private transport options, socioeconomic impoverishment, poor performance status at diagnosis and the morbidity associated with several weeks of chemo-radiation, combined to make the treatment course a difficult process.

Table 3: *Clinical stage, n=90.*

Stage 1A	15
Stage 1B	25
Stage 2A	11
Stage 2B	20
Stage 3	12
Stage 4	7

Table 4: *Age at Diagnosis, n=90.*

Less than 30 years	5
30-39 years	22
40-49 years	19
50-59 years	13
60-69 years	16
70-79 years	8
80+ years	7

Encouragingly, almost half the women had stage I disease at presentation, with excellent prospects for long-term survival or cure. However, 20% had very advanced cancers (stages III and IV). This has obvious implications for the increased need of ongoing hospital and community-based health care services, including palliative care services, for both optimal management of difficult symptoms and end of life care.

There was a wide distribution of ages, reinforcing the fact that cervical cancer can occur across the life cycle. Thirty per cent of women were aged less than 40 years at the time of diagnosis, which has potential implications for fertility issues, as well as for coping with the long-term consequences of treatment. At the other end of the spectrum, 16% of women were aged more than 70 years when diagnosed. This has implications for the capacity of these women to maintain an independent living status and flags the potential for them to require increased utilisation of domiciliary aged-care services in their communities. For all age groups,

the support and assistance of partners and family caregivers, if available and competent, is crucial to the ability of these women to manage arduous treatment regimens and long-term follow up.

Psychosocial care

Every woman diagnosed with cervical cancer has a separate and unique story. Recounting the real life stories of three women will demonstrate their complexity and the need for sensitive assessment and service provision on many levels.

Ms M.C. Age: 42

This woman, with a stage III cancer at presentation, lived alone in a remote location. Her dwelling was primitive, with no running water, no land line phone service, inconsistent mobile phone coverage and an unreliable electricity generator. She had a long standing history of mental illness, substance abuse, an addiction to prescription analgesics and several previous suicide attempts. She was scornful and dismissive of the community-based mental health services which had tried on many occasions to engage and assist her. All of her childhood and adult relationships had been characterised by violence and abuse. She had few friends (and those she had were similarly troubled with mental health concerns) and was estranged from her family. She trusted no-one.

It is eight years since her diagnosis and she remains cancer free, discharged from clinical follow-up. However, she has suffered severe radiation enteritis, requiring a bowel resection. She continues to live an isolated existence, with rigid dietary and lifestyle restrictions, along with poorly controlled chronic pain and an ongoing battle with substance addiction.

Mrs A.N. Age: 31

In the early 1960s a six year-old girl, along with her two older siblings, was abandoned by her parents in rural NSW. For the next 10 years she lived in a children's home (otherwise known as orphanage). At age 16 she elected to be placed with a foster family who had visited her regularly and taken her on holidays and to their family home throughout her period in the orphanage. They had wanted to permanently foster her from a younger age, but did not have parental consent. Her education in the children's home had been patchy, but after moving to live with the foster family, she attended TAFE, completed a diploma with distinction and commenced work with a passion to succeed.

At 29, married with two children, she was managing a small business and was well regarded in her local community. She was an active participant in school and sporting committees. She was diagnosed with a stage II cervical cancer, which initially responded well to chemo-radiation. However, her cancer recurred after a brief disease-free interval. She investigated and tried every available option to treat her recurrent disease, displaying the same tenacity and resilience which had seen her survive a disastrous early childhood.

She died, aged 31, leaving a devastated husband, two children and a devoted foster family.

Mrs G.K. Age: 72

This woman, with a long history of paranoid schizophrenia and multiple presentations to her local community health service, was brought by ambulance to the emergency department of a regional hospital after setting fire to her nightdress on a radiator in the dilapidated caravan where she had lived for many years. She was estranged from her family and no longer knew where any of them resided. The community nurse who had been visiting to dress her varicose ulcers was aware of her squalid living conditions and of her chronic health problems, but was unsuccessful in persuading her to attend a medical practice, due to her pervasive suspicion and paranoia.

On arrival at hospital, in addition to her burns, she was found to be in renal failure. Further investigations revealed advanced cervical cancer. A guardianship order was obtained to administer palliative radiotherapy and to prescribe medication to treat her florid psychosis. The radiotherapy was effective in reducing her pain and stopping her vaginal bleeding; medication relieved her psychotic symptoms. Treatment of her burns continued beyond the short course of radiotherapy and at the completion of this she was transferred to a nursing home where she was permitted to take her small dog. She died 18 months later. Efforts to find her family resulted in a son being contacted in another country, but he declined to visit or to correspond with her.

The psychosocial issues which accompany a diagnosis of cervical cancer are frequently long-standing and entrenched. Social workers, clinical psychologists and care coordinators need to be well acquainted with the range of community support services which can be engaged in parallel with the cancer care team, to assist women and their families as they confront the problems associated with the diagnosis and treatment of cervical cancer. There is a diverse range of services and there is variability across regions. Services which can be utilised to assist in the care of these women may include a combination of community nursing, mental health teams, domestic assistance and personal care agencies, meals on wheels, family support, community legal services, women's health centres, disability advocacy services, charitable and church-based organisations, community transport, palliative care teams, support groups and the various programs offered by state and territory Cancer Councils.

All women need individualised, tailored psychosocial care plans, in just the same way as their oncological care plans are individualised and tailored according to disease stage, co-morbidities and histopathology. For many women, the psychosocial distress evident at the time of the cancer diagnosis, relates to more than just the cancer itself. For women who are battling family dysfunction, mental illness, disability, remoteness from home or poverty, the additional challenges posed by an intensive course of treatment are simply overwhelming. High quality, targeted psychosocial care assists in optimising adjustment, coping and compliance even for the most complex cases.²¹⁻²²

Cervical cancer in the future

In spite of successful screening programs and population immunisation programs, cervical cancer will continue to exist, although the number of new cases of cervical cancer is likely to be dramatically reduced as the benefits of immunisation are realised. So, who will develop cervical cancer in future generations? Answer: the most marginal and dispossessed within our society.

Cervical cancer will largely (but not exclusively) be confined to women who have not been immunised, or for whom immunisation comes well after exposure to the human papilloma virus. While cervical cancer in developed countries may eventually be classified as a rare cancer, the special management and care needs of the disadvantaged women who have it will continue to present challenges to the next generation of health care practitioners.

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