‘A FOOT IN TWO WORLDS’: 
YOUNG WOMEN AND IDENTITY 
CONSTRUCTION IN THE CONTEXT 
OF CANCER.

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ABSTRACT
Despite a large number of women being diagnosed with cancer in Australia annually, 
limited research, addresses the issue of young, women and identity construction in the 
context of living with cancer. This research adopted a qualitative research paradigm 
using semi-structured interviews and a multiple case research approach to explore this 
issue. Four young women aged 20-28 years were involved in multiple interviews (two 
participants in three interviews and the remaining two participants in two interviews), 
with each lasting approximately one hour. Interviews were transcribed verbatim and 
data analysis facilitated through the use of constant comparison. Findings suggest that 
the young women in our study had a ‘foot in two worlds’ – a medical world dominated by 
the treatment and management of their illness and a non-medical world where struggles 
to maintain their pre-diagnosis identity and incorporate a post-diagnosis identity were 
played out. Despite the reality of their illness with its physical and emotional 
ramifications, the young women in our study were unwilling to accept an identity 
compromised by cancer.

1 INTRODUCTION
1.1 BACKGROUND AND CONTEXT
Approximately 45,400 females were diagnosed with cancer in Australia during 2006 
(Australian Institute of Health and Welfare, 2006) with the five most common being 
cancers of the breast and lung, colorectal cancer, melanoma and lymphoma. 
Approximately 17,300 females died from their cancer in that year. Incidence figures 
such as these generate a large amount of research activity, however, the bulk of this 
research, tends to focus on its prevention, detection and treatment; biomedical concepts 
such as histology and pathology; risk factors; prognosis, morbidity and mortality; side 
effects of treatments and their management; and the physical and psychosocial concerns 
during and post treatment (Breaden, Rudge & Maddox, 2002). Little research focuses on 
the issues surrounding women, cancer and identity and there is even less specifically on 
young women.

One reason for this lack of focus on young women is that it is difficult to gain agreement 
as to what constitutes a ‘young’ woman. Constructions of ‘young women’ range from 
under 55 (Smeardon, 2001) to under 35 (Kothari & Fentiman, 2002) with a range of 
points in between (Bloom, Stewart, Chang, Banks, 2004; Bloom, Stewart, Johnston, 
& Banks, 1998; Bloom, Stewart, Johnston, Banks, & Fobair, 2001; Friedlander & Thewes, 
2003; ., Breaden et al., 2002; Breaden, 2003; Fitch, Gray, & Franssen, 2000; Mueller, 
Simon, Deapen, Kamineni, Malone, & Daling, 2003; Evans, 2000; Siegel, Gluhoski, 
& Gorey, 1999). In addition, the threshold varies across cancer diagnosis. For example
with breast and ovarian cancers, where there is a greater incidence in older women, the concept of a young women is further blurred and is often defined as under 40 years.

2 DISCUSSION

2.1 CANCER EXPERIENCES OF YOUNG WOMEN
Researchers have argued that young women with cancer experience greater levels of psychological distress than their older counterparts because of age-related concerns such as body image, sexuality, infertility, sexual response, and child rearing (e.g., Evans, 2000; Breaden, 2003; Breaden et al., 2002; Shannon & Smith, 2003; Siegel et al., 1999), which are exacerbated by treatment regimes and their effects (Davis, 2002; Dow & Kuhn, 2004; Evans, 2000; Friedlander & Thewes, 2003). For example, the side effects of premature menopause and its associated fertility concerns are unique to young women with cancer (Friedlander & Thewes, 2003; Fitch et al., 2000). These young women face a life-threatening illness at a time when they are often considering or in the midst of childbearing/caring (Dow, 1994) and this can have profound impact in terms of their identity. Young women often report that bearing a child or children after cancer treatment allows them to gain a sense of normalcy, a way to reconnect with their peers, and a vision for their future (Dow, 1994).

A further detrimental feature of young women’s experiences with cancer is the effect of the illness on their sexuality (Dow & Lafftery, 2000), body image and self esteem. Breaden et al. (2002) reported findings from interviews with 12 young women with advanced breast cancer and reported that most were significantly distressed about their changed appearances. Treatments such as chemotherapy and steroidal and hormonal medications can lead to physical changes which are usually more drastic in young women than in their older counterparts (Breaden et al., 2002) and when combined with dominant discourses concerning youthfulness and good looks, result in younger women with cancer becoming extremely distressed by the changes to their physical appearance (Breaden et al., 2002; Dunn & Steginga, 2000).

Other physical side effects also, impact on body image and sexuality including hair loss (Friedlander & Thewes, 2003; Golat, 2002) and rashes (Fitch et al., 2000), resulting in young women with cancer feeling less attractive and less feminine (Dunn & Stenginga, 2000). Young women diagnosed with breast cancer are more likely to be affected by the removal of one or both of their breasts than much older women. Although young women are more likely to request breast-conserving treatments, mastectomy is often preferred by medical professionals given the aggressive nature of cancer for this age group (Kothari & Fentiman, 2002).

In looking at resources and supports to buffer the impacts of challenges faced by young women with cancer, recent research suggests that larger and more integrated social networks are related to emotional and instrumental support (Bloom et al., 2001). This being said, however, Dunn & Steginga (2000) and Evans (2000) report that young women with cancer often experience loneliness because other women their age are not dealing with life-threatening illnesses. As a result, they often find it difficult to normalise their cancer experience through being able to locate others similarly situated within a discourse of ‘cancer’ (Wray, Markovic & Manderson, 2007) as older women are able to do and are, thus, less likely to experience supportive networks. Additionally, cancer support groups for women often serve to emphasise difference, rather than precipitating connections between young and older women consequently adding to the isolation of young women and the impact on identity.

2.2 CONCEPTUALISING CANCER AND IDENTITY
The previously reported literature highlights the challenges that young women with cancer face as they attempt to reconcile their more recent ‘cancer’ identity with how they
perceived and understood themselves pre cancer and with the identities of other young women, who are not facing the challenges that cancer brings. Williams (1996) articulates a framework for understanding these experiences. He argues that chronic illness sharpens awareness of what constitutes a ‘normal state’ of embodiment. Those living with a chronic illness such as cancer engage in a struggle between states of ‘dys-embodiment’ (embodiment within a damaged or traumatised body) and efforts of re-embodiment. This struggle fundamentally transforms previous concepts of the body, the self and society. For Williams the extent to which individuals either identify with or react against the state of dys-embodiment depends, in part, on their identification or otherwise with the sick role. The sick role essentially constitutes a binary vision of embodiment, one in which the sick and the healthy body dwell in an often uncomfortable and paradoxical relation to each other (Gwyn, 2002).

Other authors have utilised these concepts too. French (1998) encapsulates Williams’ notion of ‘dys-embodiment’ by referring to her cancer experience as not being “inside myself” (1998, p. 71). Sontag makes a similar point, but uses the analogy of ‘citizenship’ to illustrate the way in which she sees individuals with cancer at once being members of the ‘kingdom of the well’ and the ‘kingdom of the sick’ (1991, p.3) and Campbell, (1993) speaks of being a ‘master of two worlds’ (p. 326). In a similar manner Diamond (1998), a cancer sufferer himself, presents dys-embodiment and re-embodiment as a continuing dialogue between his dual identities as a newspaper columnist and cancer patient, and his readership. Diamond continually returns to the question of his identity as a person with cancer, and how that identity is reconstituted through illness – an identity thrust upon him, often by powerful others (Lupton, 1997) and one that he resents.

Writers such as Diamond, Sontag, Williams and Gwyn then, note how ‘otherness’ takes place within the self. It could be assumed, therefore, that if the ‘person’ is not found within the body (French, 1998), then s/he is consigned to an anonymous otherness (Gwyn, 2002) or the person inside the body is no longer the one it once was (Diamond, 1998). Cancer sufferers report they are often unfamiliar with the person they have become (Dow, 1994) with this unfamiliarity resulting both from the effects of physical treatments and the concomitant re-figuration of themselves that they construe from it (Gwyn, 2002).

2.3 THE CURRENT STUDY
This study is a component of a larger study the aims of which were to explore the experiences of young adults living with a terminal illness. This component specifically explores the manner in which the young women construct identity in the context of living with cancer.

2.4 PARTICIPANTS
Participants in this study were four young women, aged 20-28 years with cancer diagnoses of leukaemia, breast cancer, stoma and ovarian cancer. Participants were recruited from Royal Perth Hospital palliative care and haematology units and the community-based Silver Chain nursing support service. Ethical approval to undertake the study was obtained from Edith Cowan University Human Research Ethics Committee, Royal Perth Hospital Ethics Committee and Silver Chain Human Research Ethics Committee.

2.5 METHODOLOGY
This study adopted a qualitative research paradigm using semi-structured interviews. A multiple case research approach (Burgess-Limerick & Burgess-Limerick, 1998) was utilised which permits the construction of theory at an individual level, while embracing the connections between individuals. By returning to each participant and raising new issues or issues that emerged from other participants, individual cases are brought into
conversation with one another in order to construct shared realities out of individuals’ perspectives. Two of the participants were involved in three interviews each and two participants undertook two interviews, with each interview lasting approximately one hour. An advantage of the multiple case method is that it seeks both an understanding of the individual, as an individual and an understanding of the theoretical constructs that are relevant between individuals (Burgess-Limerick & Burgess-Limerick, 1998).

2.6 DATA ANALYSIS
Interviews with the respondents were transcribed verbatim and imported into the QSR N6 computer-based qualitative data management programme. Analysis of the data was facilitated through the use of the method of constant comparison described by Glaser and Strauss (1967) and Glaser (1978), and operationally refined by Lincoln and Guba (1985). Scientific rigour for the data analysis was ensured using the criteria recommended by Beanland, Schneider, LoBiondo-Wood, & Haber, 1999).

2.7 FINDINGS AND DISCUSSION
Findings of this research suggest that the young women in our study ‘had a foot in two worlds’: a medical world dominated by diagnosis, drugs, treatment and treatment options, and discussions around death; and a non-medical world of friends, family, and attempts to maintain normalcy. It was in this non-medical world that struggles to maintain their pre-diagnosis identity and simultaneously, construct a post-diagnosis identity that incorporated the former, were played out. Four broad themes emerged from the data which provide a framework in which to understand and interpret the ways in which the women attempted to reconcile two disparate identities – a pre diagnosis identity with hope and plans for the future, and a post diagnosis identity that was bound up in illness and illness routines. These four themes – (i) Cancer diagnosis – a shattered sense of self, (ii) dys-embodiment – a young adult in a cancerous body, (iii) Close friends and their impact on identity and (iv) A façade of wellness, were intertwined in dynamic and complex ways. Understanding and unpacking the impact of these three dimensions on identity is important to better understand an important, but often neglected, issue in cancer research.

2.8 CANCER DIAGNOSIS – A SHATTERED SENSE OF SELF
The diagnosis of cancer had a profound impact on the lives of the young women in our study. In the early stages of their cancer trajectory the young women felt their sense of self completely shattered as they ruminated on their illness and their own mortality. To the outside world, however, their identity remained unaltered until they either showed external signs of deterioration:

Before I got sick I had long blond hair. I was the kind of person who got attention wherever I wanted, not overly, but enough. But people see you differently when you’re ‘dog ugly’. Seriously, men in particular, women just looked down their nose at me, younger women and young men just wouldn’t even look me in the eye. I just became a nobody I suppose (Alyce).

When I looked in a mirror I’d want to know “who is that? That is not me”. Yet I still felt like myself [inside] (Sarah).

or gave off other cues either intentionally or unintentionally.

I’ve always been kind of a strong person....to be in tears and so weak is just not me (Rebecca).

These outward signs and cues signalled the need for a revision of identity (Kelly & Field, 1996) for the young women in our study.
2.9 DYS-EMBODIMENT – A YOUNG ADULT IN A CANCEROUS BODY

The sentiments described above appear to support the literature on chronic illness and identity which suggest the person post-diagnosis is foreign – and so the task of identity construction that incorporates both the pre and post-diagnoses selves is fraught. Indeed, the young women in our study attempted to cling to their pre-diagnosis identity when they were outside medical institutions and their engagement with health professions. As such they had a ‘foot in two worlds’, an analogy not dissimilar to Sontag’s (1991) ‘citizenship’ of the ‘kingdoms of the well and sick’.

As noted above, often the impetus to re-construct identity is brought about by changes in the physical body. For the young women in our study, attempts to maintain a pre-diagnosis identity, one that was not dominated by illness were often hampered by their visual appearance.

People who didn’t know me were treating me differently based on my appearance. Or treating me differently to the way they had before, the young blond curly haired girl to the bloated faced girl. (Alyce)

The young women contrasted their current appearance to that of pre diagnosis, and concluded that their current appearance ensured that they were seen, first and foremost, in terms of their illness. That is, their current visual appearance was inscribed with discourses of cancer and illness. With such an inscription came the connotations and meanings attached to living with cancer. This they considered belied the person underneath – the person they felt they were.

When I first got cancer and I lost all my hair, I was wearing a wig and my face, from the drugs I was taking ballooned out a bit. I was very self conscious. I used to be a confident person and I felt that I couldn’t look people in the eye. I didn’t want to meet new people. I didn’t want them to think this was me, cos for me it wasn’t me. (Rebecca)

Attempting to maintain a pre-diagnosis identity for the young women in our study was made difficult by those people they had just met. It was those people who, first and foremost, saw the young women as a ‘person with cancer’.

It’s kinda different when you do meet new people, because they usually know that I am a leukaemia person before they meet me, because they’re friends of other friends and then they want to know my whole life story. I don’t mind sharing, but sometimes I think that people must think that this is all that I can talk about. (Alyce).

According to Goffman (1968) when individuals have a visible stigma, such as those produced by the side effects of many cancer treatments, they are exposed to invasions of privacy including being bothered by those with a morbid curiosity regarding their conditions, as described by Alyce above. The young women, however, had strategies to counter this. They attempt to show another side of themselves, one where cancer is absent and one that represents the ‘person they think they are’, ostensibly their pre-diagnosis identity.

I make a conscious effort to steer it [conversation] away [from talk about my illness] and talk about things on common ground rather than just my illness...I don’t want to appear to have nothing else to me except the disease (Alyce).
2.10 CLOSE FRIENDS AND THEIR IMPACT ON IDENTITY

Despite attempting to keep a distance between their medical world and their non-medical world, from our data it appears that the young women allowed friends into this medical world when they were struggling with emotional issues.

Dave…..[is] a very wonderful friend. He’s been my friend since school days and… I can talk to him about lots of things as well. When I had been going through this down time, he rang me and we had a chat. He came over that day with his things and sort of sat and said you have to be sad to be happy. These are things you can do to get out of that sad spot (Rebecca).

If I need them [friends] they’ll be over. It doesn’t matter how much I cry or whatever, they can handle it. They’ve pulled me through in every way. They’ve been there, especially one friend Tracey, she’s my best friend, she’s had problems of her own which was really difficult (Sarah).

Entry of friends into this world became problematic, however, when the young women were struggling with issues surrounding their physical body.

I rang some friends and told them that I’m in there [hospital] and “shall we come and see you”? “No, I don’t want you to see me like this, you know. (Alyce).

Support from friends, however, was not always positive. At times, the presence of friends acted as a stark reminder to the young women of all the things they had lost in life, or as Williams would argue, an enhanced awareness of what constitutes a ‘normal state’ of embodiment (Williams, 1996). The young women in our study discussed the loss of similar things that are reported elsewhere in the literature: their chance to be a mother, loss of intimate relationships, career; and most notably, their future (see for example Shannon & Smith, 2003; Breaden, 2000; Breaden et al., 2002Dow & Kuhn, 2004; Dow, 1994).

I burst into tears and it was just draining and I couldn’t control that. Friends would ring up and I couldn’t talk to them on the phone cos I didn’t want to be reminded about and upset again [about the things I’ve lost] (Rebecca).

The presence of young healthy friends then, often made it more difficult for the young women in our study to maintain a pre-diagnosis identity.

In addition to the reminder of loss, the young women reported that their friends often became over protective of them:

“Oh my gosh. You shouldn’t be going out or you shouldn’t be doing this or you shouldn’t you know, you shouldn’t. It’s like everything is ‘you shouldn’t, you shouldn’t’” (Vicki).

They [friends] try to baby me too much sometimes. Like, I’d drink a juice, like a veggie juice and things like that. And “make sure you do this and make sure you take your tablets and make sure you do that”. It’s like – “I’m not a child. Don’t tell me what to do!” (Sarah)

Despite the good intentions of their friends, being over protective acted to reinforce a sick identity and disempowered the young women. If the young women are constructed as ‘sick’ then it follows that they have a diminished capacity to be in control of her lives and make decisions for themselves. This compromises their identity as capable and independent young adults.
2.11 FAÇADE OF WELLNESS

In a further attempt to maintain a pre-diagnosis identity, the young women in our study often displayed a ‘façade of wellness’ to the outside world. Portraying themselves to the outside world in an inauthentic manner such as this, minimised the cues upon which others could use to bestow a ‘sick identity’ (Kelly & Field, 1996).

I have a long standing friend who for possibly 7 years has wanted a relationship with me. Even though I am no longer healthy he’s still there. He’s still waiting in the wings and he tells me all the time. He only sees me when I’m out. So he sees me when I’m at my best. I mean, he’s not the type of person that come in and visits when I’m sick and in hospital. So he thinks that when he see me out that’s what I’m like all the time and he’s happy to accept that. But he just doesn’t see me at my worst so there will be no relationship, no. That’s a conscious decision on my part (Alyce).

As part of this façade, the young women would only go out when they felt and looked ‘well’

They [friends and acquaintances] go to work every day and don’t see the daily grind or the chemo whatever and I don’t go out much at all when I am really sick. I stay home (Rebecca).

This façade of wellness, however, may be a double edged sword for the young women, with some acquaintances not believing the extent of their illness and labelling them as ‘frauds’.

I feel like you know, “oh, she’s just putting an act on” or you know things like that. (Vicki).

I’m constantly fatigued... and my endurance is pretty low. But I don’t...look sick. My eyes aren’t weeping, I’m not coughing. There’s no visual symptoms for people to identify ...People often say "you’re all right, what are you complaining about?” You know, that sort of thing. They just don’t realise. (Alyce)

Labelling feeds back directly to self conception as the young women construct and reconstruct the meaning of their bodily mal-functioning and the responses of others to this (Kelly & Field, 1996).

3 CONCLUSIONS

The young women in our study had a ‘foot in a two worlds’. They attempted to hold on to their identity built around hope for the future and the vitality of young adulthood. The visual representation of their physical bodies and discourses of illness that became inscribed on them, were pivotal challenges that the women had to reconcile in an attempt to maintain their pre-diagnosis identities. Friends, while offering support to the young women, were also constant reminders of the loss the young women had felt upon diagnosis. Additionally, friends often inadvertently re-constructed the young women as ‘sick’ and thus invoked an identity that was bound up in their cancer diagnosis. The young women in our study understood the reality of their illness and despite their physical appearance and discourses of illness, they were unwilling to accept this compromised identity.
4 REFERENCES


