

Illness Identity and the Self-regulatory Model in Recovery from Early Stage Gynaecological Cancer

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Abstract

Women in recovery from early stage gynaecological cancer have extremely good survival and low recurrence rates. Despite this, women continue to feel vulnerable to cancer recurrence for years after treatment. Semi-structured interviews were utilized to explore the factors involved in recovery from gynaecological cancer. This article argues that the illness identity of gynaecological cancer perpetuates a vulnerability to cancer recurrence. The absence of self-diagnosis prior to medical diagnosis is important in the formation of gynaecological cancer illness identity. A lack of self-diagnosis may be due to the 'normalization' of initial symptomatology. It is suggested that illness identity is responsible for maintaining fears of symptom-free cancer recurrence. The self-regulatory model is employed to explore this process, looking in particular at the reinforcement of reassurance needs.

Keywords

gynaecological cancer, illness identity, normalization, reassurance, self-regulatory model

GYNAECOLOGICAL cancer includes ovarian, endometrial, uterine, cervical and vulval cancer. UK estimates suggest that ovarian, cervical and uterine cancers account for 10 percent of new cancer cases in British women (McPherson & Waller, 1997). The prognosis for women with gynaecological cancer is good. The Cancer Research Campaign (1994–5) produced 5-year relative survival percentages for all stages of gynaecological cancer. It is estimated that 28 percent of women with ovarian cancer, 58 percent of women with cervical cancer and 70 percent of women with uterine cancer survive for five years after treatment (Pitts & Phillips, 1998). These survival rates are further increased for women diagnosed with early stage gynaecological cancer. Only one percent of women with stage IB cervical cancer will suffer any recurrent illness (Van Nagell et al., 1979) and 89 percent of women diagnosed with stage I ovarian cancer survive for three years (Woodman, Baghdady, Collins, & Clyma, 1997). Survival rates continue to rise as screening services develop, and national awareness of indicative cancer symptoms improves (Pistrang & Winchurst, 1997). With survival rates improving, there will be increasing numbers of women in recovery from gynaecological cancer. Despite this, gynaecological cancer remains under-researched by health psychologists and there are few studies addressing the issues faced by women who have been disease-free for a period of months to years (Auchinsloss, 1995). A recent survey of literature demonstrates that women with breast cancer are the major focus of much psychological research into cancer (Stanton & Gallant, 1995). Qualitative research, in particular, is rarely employed within cancer survival research studies (see Adewuyi-Dalton, Ziebland, Grunfeld, & Hall, 1998, for a qualitative study of women with breast cancer in remission).

This investigation studied women who have been treated for early stage gynaecological cancer (stages I–II), and have currently no evidence of active disease. The standard procedure for these women is a continuing programme of hospital follow-up at 6-monthly intervals for a period of five years. After a period of 12 months, the follow-up appointment consists of verbal reassurance unless the woman specifically requests physical examination. Pap tests are not carried out as they serve no medical purpose in

the management of endometrial, cervical or ovarian cancer after curative treatment. Some women in recovery from early stage vulval cancer will receive Pap tests. There are no widely accepted standards of practice in the follow-up of cancer survivors. Kerr-Wilson and McCrum conducted an audit in 1995 to investigate the practice of follow-up in the UK for gynaecological cancers. They found that 44 percent of consultants discharged women routinely after five years, 34 percent continued to see women after 10 years and 14 percent saw women for life. However, the clinical value of follow-up for such patients is being questioned. The recurrence rates of these early stage cancer types are strikingly low. Furthermore, the majority of these recurrences are detected symptomatically by women between follow-up appointments (Shumsky et al., 1994). There is no research evidence that shows routine follow-up to increase survival rates among women who had treatment with curative intent (Effective Health Care, 1999). Vaginal vault cytology was not diagnostic in any patient for endometrial cancer recurrence and routine follow-up detected only one recurrence for every 206 routine follow-up visits (Shumsky et al., 1994). Furthermore, there is no difference in survival between cases with symptomatic and asymptomatic recurrences. Medical study of early stage cervical cancer (stage IB) has found that 82 percent of recurrences are symptomatic and reported to a medical professional outside of the routine follow-up appointment (Ansink et al., 1996). It is of note that only one percent of women diagnosed with early stage cervical cancer will suffer a recurrence. As such, medical evidence has declared routine follow-up for early stage gynaecological cancer to be ineffective in detecting recurrent disease.

Despite the absence of medical benefit, some women are reluctant to be discharged from the follow-up service, even with a discharge contract guaranteeing speedy re-entry (Glynne-Jones, Thomas, Chait, & Marks, 1997). Indeed, up to 20 percent of cancer survivors attend follow-up for longer than 10 years. This implicates the role of psychological factors in maintaining follow-up needs for early stage gynaecological cancers. Despite the lack of survival benefit from follow-up, many would advocate that these visits provide psychological support (Morris, Corder,

& Taylor, 1992). Thirty percent of long-term cancer survivors have possible 'case' levels of anxiety (Cull, Stewart, & Altman, 1995; Glynne-Jones et al., 1997), but while this illustrates the high anxiety levels of cancer survivors, it is unclear whether anxiety is a cause (Hadjistavropoulos, Craig, & Hadjistavropoulos, 1998) or a consequence of follow-up appointments (Auchinsloss, 1995).

Research undertaken by our group (Bradley et al., 2000) has investigated whether there are any psychological, clinical or demographic differences between those women with a preference for continued follow-up and those with a preference for discharge from follow-up. Although there was evidence of elevated anxiety in the follow-up group (as measured by the Spielberger scale), this was not replicated by other anxiety measures (such as the HADS). No other significant differences were found between the two groups of women. This is not particularly surprising as individuals are subject to considerable health information from a multiplicity of sources, leaving the researcher to deal with a large number of potential factors that may influence health-related evaluations and decisions (Diefenbach & Leventhal, 1996).

Robust significant trait differences between women with different follow-up preferences have not been demonstrated. An alternative approach to understanding follow-up preference is to examine how women think and feel about cancer. This article addresses the possibility that it is the representations of gynaecological cancer held by women that prolong cancer worry for a period unsupported by medical evidence. In particular, it is suggested that it is the illness identity of gynaecological cancer from which coping strategies are derived. Cognitive representations of illness are thought to guide the selection and execution of coping strategies (Cameron, Leventhal, & Leventhal, 1993) and, as such, attendance at follow-up is influenced by illness representations.

Illness is the social expression of disease (Diefenbach & Leventhal, 1996). Individuals construct common-sense models to define and understand their illness experience. It is these common-sense models of illness that guide health behaviour. Self-regulatory theory describes the process by which people form these common-sense models, and provides a

contextual approach for understanding the cognitive, emotional and somatic factors influencing health behaviour decisions (Cameron & Leventhal, 1995). For the purpose of this article, decision to attend routine follow-up appointments within a hospital clinic constitutes a health behaviour decision.

Three central tenets underlie the Self Regulatory Model (SRM). First, the individual is an active problem-solver, seeking information and testing hypotheses about the meaning of somatic sensations. Second, the central cognitive construct of the SRM is the formation of an illness representation which guides coping and appraisal of health action (Schiaffino, Shawaryn, & Blum, 1998). Finally, illness representations are highly individual and are not necessarily formed in accordance with medical facts (Diefenbach & Leventhal, 1996).

Efforts within health psychology have sought to understand 'lay' symptom interpretation (Andersen, Cacioppo, & Roberts, 1995). When people experience an illness threat, they employ implicit or lay theories for purposes of interpretation (Buick, 1997). There are five dimensions according to which illness experiences are organized cognitively, and lay theories developed. These five dimensions are beliefs about identity, causes, consequences, cures and illness time scale which, when integrated, form an illness representation. Illness representations are seen as deriving from past experiences of illness, and information from a wide range of sources (Schiaffino et al., 1998). They are thus specific to each individual's knowledge and experience.

One important area of health research is the investigation of medically inappropriate patient behaviour in the face of health threat. It is thought that illness representations help with the interpretation of different health behaviours in the presence of similar health threats (Leventhal et al., 1997). Illness representations are thought to be associated with the seeking and utilization of medical services (Heijmans, 1999). Attendance at routine follow-up appointments can be described within this study as a specific coping strategy for the reassurance of continuing cancer fears. This premise is supported by research conducted on disease detection behaviour proposing that in the performance of such behaviours, the purpose is to preclude the

possibility of disease and to be reassured (van Zuuren & Dooper, 1999).

According to the SRM, symptoms are key factors in the cognitive representation of health threats (Cameron et al., 1993). Central to the SRM is the development of an illness identity. Illness identity has been described as the 'label placed on the symptoms being experienced and their association with the possibility of illness diagnosis' (Petrie & Weinman, 1997). The identity includes a disease label and ideas about the somatic manifestation of that disease (Diefenbach & Leventhal, 1996). The illness identity yields a self-diagnosis prior to medical confirmation of disease. Symptom amelioration is critical for the appraisal of progress in mitigating health threat (Cameron et al., 1993). Illness identity is one of the five elements central to the construction of illness representations (Diefenbach & Leventhal, 1996) which in turn form part of the SRM. The SRM was developed to investigate perceptions of health threats and describes the cognitive and emotional activity involved in the construction of illness (Scharloo & Kaptein, 1997). The main assumptions of the model are that people generate both a representation of illness and an emotional reaction to that representation (Petrie & Weinman, 1997).

Method

Permission to contact patients was obtained from the local research ethics committee. Women attending routine follow-up at the hospital clinic after treatment for early stage gynaecological cancer were sent an interview consent form. This form explained that the interview

study was being conducted to gather women's opinions on the process of follow-up and made it clear that no future care would be affected if the woman chose not to participate. Twelve women who agreed to be interviewed were contacted and interviewed individually by one of the authors (EJB). All the women were regularly attending routine follow-up appointments at the hospital and had no evidence of active disease. Active treatment had ceased a minimum of six months previously, with a range up to 72 months. The ages of the women, the type of disease suffered and the length of follow-up attendance were varied (see Table 1).

In accordance with national cancer guidelines (NHS Executive, 1999), predicted 5-year survival rates for the sample are 80 percent for ovarian and cervical cancer (73 percent for cervical IIb), 70 percent for endometrial cancer and 51 percent for vulval cancer.

The innovative nature of this study recommends qualitative research. Qualitative research has long been recognized as a rich source of descriptive and explanatory inquiry (Gascoigne, Mason, & Roberts, 1999), and qualitative methods play a primary role in hypothesis generation (Burt & Oaksford, 1999). Semi-structured interviews that allowed for the 'interviewees own frame of reference to emerge' were conducted with women in their homes (Gascoigne et al., 1999). A theme list was used including the following topics: preference for follow-up/discharge; feelings prior to clinic visit; information needs; coping with cancer recovery; sexual recovery; and future health needs. The women guided the interviews. All interviews were tape recorded and transcribed. Grounded

Table 1. Participant characteristics

<i>Age (years)</i>	<i>Type/stage disease</i>	<i>Attendance at follow-up appointments</i>
66	IIa endometrial cancer	3 years
75	Ic ovarian cancer	4 years
36	Ib cervical cancer	6 years
49	Ib cervical cancer	12 months
71	Ia ovarian cancer	12 months
59	IIa endometrial cancer	18 months
52	IIa endometrial cancer	18 months
41	IIb cervical cancer	4 years
44	IIa vulval cancer	4 years
69	Ia endometrial cancer	12 months
28	Ib cervical cancer	6 months
51	Ib cervical cancer	18 months

theory principles were utilized for the analysis of the interview material (Glaser & Strauss, 1967). Grounded theory was selected as a means of generating theory from the interview data. For the purpose of analysis the data were coded (by labelling concepts within the text); this stage of analysis took place throughout the interview period. Constant comparison (the continual sifting and comparing of concepts) was implemented for the exploration of similarities and differences within the coded concepts (Richardson, 1996). This process allowed sampling to proceed from open sampling to theoretical sampling (Strauss & Corbin, 1990). Theoretical sampling describes the selection of participants on the basis that they may provide variation to theoretically relevant concepts, challenging hypotheses. At a later stage of analysis, sets of related concepts were sorted and grouped so that emerging categories of concepts could be integrated. Interviews ceased when the data failed to contribute any further insights to the process of categorization (Glaser & Strauss, 1967).

Results/discussion

Self-diagnosis and 'normalization'

I mean if you're sort of working to that end and you think there is a chance you've got cancer [pause] it didn't occur to me at all. Now, if it had of done, if it had of done I might of found the initial shock not quite as bad.

No, I felt fine, it was a big shock, I went on my own because, to get my results, because I thought 'oh it's nothing' and when he told me I just thought, you know, it was the biggest shock of my life . . . Yeah, that, and I was having problems, you know, after having the baby, they just picked it up from that.

So when they call you back early it's there again, so you know, you sort of half expect it when you go in, you don't think it must be but you deny it. And yes it's a shock, and it's a shock because you just don't know how far it's gone, you know, or you don't know what the prognosis is and not knowing how major it is . . .

I had such a funny feeling, no pain just a funny

feeling and I thought gosh if [my husband] had of been alive and I was a bit younger, I'd swear blind I was pregnant, because it was like the movement of a baby.

I mean beforehand some of the signs were there but er, I didn't really recognize them at the time. I was only like 31 when I was first diagnosed but even at that age I just put it down to my age thinking maybe I was going on the change earlier or something. You just sort of find an excuse for it . . .

it was basically something like, um, like an ulcer . . .

The medical diagnosis of gynaecological cancer is recalled as a time of great distress. This is not surprising in itself, but there is a great deal of commonality within the recollections. There is a notable absence of gynaecological symptomatology described prior to medical recognition of disease. Those women with some recollection of symptoms prior to diagnosis remembered symptoms as non-threatening, and indicative of 'normal' bodily changes. The interpretation of symptoms within a model of 'healthiness' permits symmetry allowing the woman to remain within a societal role. However, this also precludes a period of self-diagnosis whereby women can orientate themselves to the possibility of disease. Identifying bodily changes as 'normal' that later prove to be symptomatic can be termed 'normalization'. The purpose of normalization is to maintain an identity of the healthy self, thus not categorizing bodily changes as indicative of potential illness but of 'normal' changes. Childhood experiences teach us that being sick means not feeling well (Diefenbach & Leventhal, 1996). These experiences are usually reinforced by the medical interaction with doctors probing for symptoms to aid diagnosis. We seek to achieve congruity between experience/sensation and categorization. We search for a label when we experience bodily changes, and conversely expect to suffer symptoms when we feel ill. This has been termed the 'symmetry rule' by Diefenbach and Leventhal (1996). If changes, later defined as symptoms, are experienced, individuals are motivated to maintain an explicable world (Andersen et al., 1995).

When illness is suggested by a somatic change,

the illness representation generated will depend on its similarity either to a prior illness episode, or an imagined disease (Diefenbach & Leventhal, 1996). Somatic changes are compared with memories of prior symptom episodes to generate a cognitive representation of the health threat (Cameron et al., 1993). When 'normalizing' somatic variation, gynaecological changes are compared with past 'normal' episodes and symptoms indicative of cancer are viewed as benign. However, this process of 'normalization' may not be entirely responsible for the absence of period of self-diagnosis. Cancer as a specific disease may affect willingness to self-diagnose:

My husband was devastated, you think it is the end of the earth what's coming to you, it's just the word [cancer] isn't it.

It's been cancer and they don't know anything about cancer. It's the most frightening disease there is . . .

. . . and he said this isn't a, this isn't a prolapse this is a tumour and then and there took a biopsy immediately so it was only then and I came out and the word cancer was not discussed at home at all.

Cancer is an illness associated with stigma and grim prognosis (Barraclough, 1994). A diagnosis of cancer invokes fear and distress, worldwide surveys indicate that cancer is the most feared of all diseases (Steptoe, Horti, & Stanton, 1986). Cancer is a life-threatening and a low-probability disease; both these conditions foster distress and appraisal delay (Andersen et al., 1995). The development of malignancy is often protracted with complex and changing symptoms being typical. Cancer symptomatology varies with both site and extent. Cancer of the ovary has a particularly varied presentation: pelvic cramping, low back pain, pain or bleeding with intercourse, irregularities in urinary frequency, constipation. As cancer progresses, symptoms change from specific or localized complaints (e.g. vaginal discharge/bleeding) to diffuse ones, such as 'flu' symptoms (Andersen et al., 1995). It may be that the women within this study did not recognize their 'vague' symptoms as indicative of cancer. Cancer is a serious illness and as such women may expect dramatic rather than diffuse symptoms. However, Green (1976) observed that 'knowledge in the form of correctly

attributing cancer symptoms does not guarantee early case finding' (Gascoigne et al., 1999).

The serious nature and relative infrequency of cancer encourages optimistic bias where changes are interpreted as symptoms. In experiencing symptomatology indicative of cancer, individuals may privately adopt innocuous rather than threatening outcome hypotheses. For example, a 45-year-old woman may hypothesize 'menopause' for her irregular bleeding symptoms rather than cervical cancer (Andersen et al., 1995). Thus, the process of 'normalization' permits symmetry via optimistic bias.

A period of self-diagnosis is crucial in the formation of illness identity. The interdependent nature of self-diagnosis and illness identity is illustrated by the definition of illness identity as the 'label placed on the symptoms being experienced and their association with the possibility of illness diagnosis' (Petrie & Weinman, 1997). The self-diagnostic period affects the disease experience far beyond initial medical recognition of disease. Women are not necessarily aware of the somatic changes that can be symptomatic of the onset of gynaecological cancer. Indeed, somatic changes are typically interpreted as normal variation, therefore the question of self-diagnosis does not arise:

I felt so well after the smear I thought there can't possibly be anything wrong and I, I became very complacent. And I went back to the hospital, and suddenly they told me that I'd got cancer, and I feel that to ever get totally complacent is wrong, so I always keep it there at the back of my mind.

You're walking round like we all do thinking everything's fine. And then you get something like that [cancer] it sort of knocks you back . . .

This creates a sense of vulnerability and builds reliance on medical professionals to identify recurrence symptoms via examination and investigation:

I would prefer to see the specialist and him having seen the scan and said 'yes everything's fine' you would, I would have more faith in, in his, you know, his saying 'that's fine' . . .

They've done tests and haven't, you know, they've all come back clear . . .

Not having a scan I think it will leave a

question mark over my head as to whether everything's okay.

Symptoms, and the methods of illness identification, are a focus for the elaboration of illness representations. The representation then serves as a guide for action (Leventhal et al., 1992).

Reassurance needs

Interviewer: What would you say that you gained through attending regular follow-up at the clinic?

[pause] Um, well just reassurance that, um, everything was okay, and that up to the point of [pause] when they say that's it you're okay.

I mean I'm quite happy as long as I can keep going to the clinic and see that I'm alright

It's the physical check and it's also, um, [pause] the reassurance, you know, if there was anything there they would be there to spot it, before it grows or anything.

The extracts above demonstrate a continuing and compelling need for reassurance within the follow-up appointments. The description of the reassurance sought indicates that women do not use self-detection methods for disease detection, but rely on clinic attendance and medical investigation. The purpose of this behaviour is the exclusion of disease, and subsequent reassurance of continued health (van Zuuren & Dooper, 1999). This behaviour is incongruent with the presentation of recurrent gynaecological cancer which is rarely asymptomatic. Indeed, definitive symptoms of recurrent gynaecological cancer include bleeding and discharge. These symptoms would present regardless of sexual activity/inactivity or menopausal status. Recurrent ovarian cancer has a slightly different presentation of gastrointestinal symptomatology. Evidence of disease detection behaviour illustrates a distinction between medical fact and patient vulnerability. These women have an extremely low risk of suffering any recurrence of gynaecological cancer. Their risk of suffering a symptom-free recurrence is even less likely. Despite this medical fact, women describe a continuing need to attend hospital appointments for reassurance that their cancer has not returned. Only one woman in the study felt confident in

her discharge from the follow-up clinic after a medically defined period of time (12 months). Interestingly, this woman was not convinced that she had even suffered with gynaecological cancer, believing her initial symptoms to be caused by taking medication following treatment for breast cancer. The persistence and commonality of vulnerability necessitate some exploration of implicit illness models, and their mediation of psychological response (Buick, 1997). It may be the illness representations developed during the cancer experience that maintain a sense of vulnerability and thus the continuing need for medical reassurance:

I want the reassurance of knowing that it hasn't reared its ugly head. There's always that, that thought that it, it could, um, come back again.

In the absence of self-diagnosis, which is dependent upon the recognition of indicative symptomatology, women are left without a guiding structure for medical action. The representation of cancer is that of an illness without symptoms or innocuous symptomatology and no clear warning signals:

I said to one of the insurance people look I'm cured, I've had my surgery, I'm cured you don't know what you've got growing inside you . . .

As a result, any symptomatology may be perceived as a potential threat to continued health. This perception of threat relates very much to the identity of cancer itself; once a woman has had a diagnosis of cancer the body is perceived as vulnerable. As such, the cancer no longer represents just a gynaecological threat, but a generalized threat to the woman:

If you've got a stomach bug or something untoward happens the questions always there are, you know, is it, is it the cancer coming back or is there a problem here so, er, you know there's always that uncertainty I think once you've had cancer.

But the anxiety part is thinking, it's something else that will come back to me.

. . . so that sort of follow-up is much more worth while, er, a check everywhere because it's not going to get cervical cancer again cause

I've, because it's gone, but it might come back lung cancer or skin cancer, you know so, so I think what, I would find most beneficial would be an all-over check

This will continue a sense of vulnerability to cancer recurrence throughout the period of recovery and sustain needs for medical reassurance.

Peer contact

You hear of people where it's gone and all of a sudden it's reoccurred, I think that's always at the back of your mind, to a degree.

The above illustrates the importance of peer contact in determining 'healthiness'. Social communication may be a critical determinant of health behaviour as peers give 'permission' for care seeking (Cameron et al., 1993). Peer contact is a supportive resource (Helgeson & Cohen, 1996), but it may not always be helpful, and may actually exacerbate anxieties about illness recurrence. Certain types of peer support are particularly unhelpful to cancer patients. Support groups including terminally ill cancer patients are unhelpful for those patients in recovery as they encourage downward comparisons and diminish optimism about the future (Helgeson & Cohen, 1996):

She had cancer of the bowels and she was only [pause] about three months. So that, you know, you know, she'd had no pain, no weight loss, no nothing. Which was the same as me, I kept putting myself in her position . . .

Women in recovery from early stage gynaecological cancer have a particularly low risk of future illness. Comparison with other groups of cancer patients elevates personal sense of risk and may compel women to seek out medical reassurances of continued health.

The self-regulatory process

Throughout the interview data, there are striking similarities within the accounts of the diagnostic period, and continuing vulnerability to gynaecological cancer recurrence. The SRM is helpful for an exploration of women's heightened vulnerability to cancer recurrence, despite medical reassurance to the contrary. As described, women seek medical reassurance to

reduce anxieties about cancer recurrence. Reassurance seeking produces a short-term reduction in anxiety, but may exacerbate general health anxieties. Salkovskis (1992) has suggested that both avoidance and excessive reassurance seeking exacerbate health anxiety.

Non-anxious patients who seek medical help respond to reassurance that illness has been 'ruled out'. Alternatively, those patients anxious about their health misinterpret reassuring messages, needing repeated reassurance. The process of 'normalization' and consequential maintenance of a 'healthy' identity prior to medical diagnosis may cause women to distrust their feelings of 'healthiness'. As a result, healthiness needs to be reassured through medical intervention (such as follow-up attendance).

The recollection of cancer as an 'invisible' disease prevents women from identifying those symptoms indicative, or not indicative, of gynaecological cancer. This allows health anxiety to build in the absence of relevant symptomatology. Individuals who feel vulnerable to a disease may be especially prone to symptom-induced anxiety (Cameron & Leventhal, 1995). Fear of cancer recurrence may also be stimulated by an external stimulus such as a media campaign or the death of a public figure from cancer (Diefenbach & Leventhal, 1996):

Every now and again if I hear of anything else or read in the papers, I mean [her husband] threatened to bin all those newspapers when, you know, Linda McCartney, all that was in there.

Once health anxiety is elevated, women employ coping methods to attempt to decrease anxiety. The absence of a specific schema to identify gynaecological symptomatology (assured by the lack of self-diagnosis) and reduced confidence in ascertaining 'healthiness' (assured by the period of 'normalization') directs women towards the medical intervention for the reassurance of good health.

However, the reassurance obtained from the follow-up appointment is temporary. As described above, the perceived inability to ascertain healthiness causes health anxiety to elevate in the absence of indicative symptomatology. To cope with this anxiety, women seek out reassurance in the form of routine follow-up appointments. The appraisal stage of the SRM is

concerned with the interpretation of sensation through comparison with past experiences. In this way, women experience health anxiety and recall the coping method employed to reduce this type of anxiety. In this case, the coping method employed to reduce health anxiety is medical reassurance via the follow-up clinic. Follow-up attendance is thus promoted, and health behaviour maintained (Diefenbach & Leventhal, 1996). Care seeking (such as follow-up attendance) is thought to represent a final effort to control distress after the failure of emotion-based coping procedures (Cameron et al., 1993).

Research investigating the follow-up process after treatment for gynaecological cancer has described elevated anxiety levels immediately prior to hospital appointments. This has led to suggestion that attendance at the follow-up appointment itself initiates an anxiety response (Auchinsloss, 1995). The SRM allows for an alternative explanation of this phenomenon. As described above, some women experience elevated health anxiety throughout their cancer recovery and seek medical reassurance for alleviation of this anxiety. However, this type of health behaviour does not permanently alleviate feelings of vulnerability to cancer recurrence. The possibility of a cancer diagnosis is elevated immediately prior to the follow-up appointment (as it is within this appointment that cancer recurrence may be diagnosed):

Just be about a week before you go, or I used to go for the check ups you'd start feeling a bit nervous about going in case, you know, anything else was found.

The reassurance of these elevated recurrence fears means that there is a great relief of anxiety. The alleviation of anxiety negatively reinforces this health behaviour in the presence of future health anxiety. In this way, the common-sense model is correct psychologically (there is a reduction in anxiety levels upon attending follow-up) even though the health behaviour may be irrelevant to the control and cure of the condition (Leventhal, Diefenbach, & Leventhal, 1992).

Reformation of illness identity

This study employs the self-regulatory model to interpret why some women have a continued

need for follow-up in the absence of medical benefit. It is important that health research attends to long-term needs for follow-up so that women's continued vulnerability to gynaecological cancer recurrence can be addressed. Can the self-regulatory model help to redefine follow-up health behaviours? The process of 'normalization' prior to medical diagnosis of cancer is proposed to be responsible for the formation of an 'invisible' illness identity. Yet, within the interview material, women recollect symptom-free diagnosis alongside descriptions of indicative cancer symptomatology. It is possible that women do not reconcile their experiences of cancer symptomatology with the cancer diagnosis. Discussion of the period prior to medical confirmation of disease may enable women to achieve this reconciliation. This may then allow for adjustment of the cancer identity as symptom-free. This is particularly important during recovery from early stage gynaecological cancer as the symptoms indicative of recurrence are medically defined. Furthermore, most women who suffer a recurrence detect it independently of the medical appointment. With regard to recurrent endometrial cancer, 75 percent of women are symptomatic at the time of diagnosis (Shumsky et al., 1994) and 82 percent of cervical cancer recurrences are symptomatic (Anskink et al., 1996). Knowledge about important symptomatology should help decrease health anxiety in the absence of indicative cancer symptoms. The specialist nurse within the gynaecological cancer clinic would be an ideal candidate to provide education about gynaecological cancer recovery.

Differentiation of follow-up/discharge preference

Despite the similar descriptions of illness identity within the sample, some women describe a preference for discharge from follow-up appointments. With a similar process of 'normalization' and illness identity formation it may be expected that all women would request continued routine follow-up appointments. However, the formation of an illness representation is not reliant on illness identity alone. There are five dimensions to illness representations. It may be that those women who feel able to discharge from follow-up appointments have alternative timeline, or consequence

beliefs to those women with a maintained desire for follow-up. Indeed, as Leventhal and Nerenz (1983) warned, illness representations are not always well integrated and may be inconsistent (Heijmans and DeRidder, 1998). This would allow some women to develop similar illness identities yet develop alternative coping strategies. Personality characteristics such as preference for information (monitoring) or avoidance of information (blunting) may differentiate between coping behaviours after the formation of illness identity.

Conclusions

This article sought to investigate why some women maintain health anxiety and follow-up need during recovery from gynaecological cancer. In the absence of predictive psychological or clinical factors, illness identities were explored. A full examination of the integrated illness representations of women who adapt to gynaecological cancer recovery without request for medical reassurance is beyond the scope of this current research, but will be investigated in future studies.

It is thought that it is the illness identity of cancer that maintains women's fears of symptom-free cancer recurrence. The fear of symptom-free cancer recurrence in turn increases the need for medical reassurance. The self-regulatory process reinforces a negative cycle of health behaviour, maintaining women's cancer fears for a period unsupported by medical evidence. If women's recovery from early stage gynaecological cancer is to improve, it is necessary to investigate further the role of illness representations and the self-regulatory process. This work goes some way to illustrate the impact of medical and psychological inconsistencies for a specific disease type. In improving the understanding of such inconsistency, it may be possible to understand the experience of illness further, and achieve both medical and psychological recovery.

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