
BRIEF REPORT

LONG-TERM BREAST CANCER SURVIVORS: CONFIDENTIALITY, DISCLOSURE, EFFECTS ON WORK AND INSURANCE

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SUMMARY

As more women are diagnosed with breast cancer, more will survive the illness from a few years to a lifetime. This study sought to determine the experience of Canadian breast cancer survivors with respect to the impact of cancer on confidentiality, work and insurance.

Method: Women who had survived breast cancer without recurrence for at least 2 years completed a mail survey about the effect of their illness on confidentiality, disclosure, work and insurance.

Results: 378 (75.6%) women breast cancer survivors responded to the survey. Their mean age was 61.0 ± 10.9 years, and 67.6% had been recurrence free for more than 5 years. The majority of women rated hospital staff, family doctors, family, friends, and support groups at the highest possible level of confidentiality. Over 70% of survivors disclosed their diagnosis to friends, children, siblings, and partners, while over 50% disclosed to work colleagues and supervisors. However, over 40% felt cancer had altered their priorities or progress at work, and 5% were afraid to change jobs in case they became ill again. There was a lack of knowledge about insurance but, of the types of insurance identified, life insurance (17.9%), extended health insurance (7.7%), and private disability insurance (4.4%) were reported to have been refused or offered only with higher premiums as a result of a past diagnosis of breast cancer.

Discussion: A substantial minority of women perceived that cancer had substantially affected their personal and work lives. Although most felt their illness confidentiality was well protected and they disclosed freely to family, friends, and work, over 40% of women survivors reported that cancer had affected their work in various ways, and nearly 20% identified insurance problems. It appears that disclosure sometimes results in negative work and insurance experiences.

Conclusions: Health professionals and cancer survivors should engage in education about the potential positive and negative effects of disclosure, and advocacy against cancer-based work and insurance discrimination. Copyright © 2001 John Wiley & Sons, Ltd.

As more and more women are diagnosed with breast cancer, more will survive the illness from a

few years to a lifetime. There has been increasing literature on the general psychosocial and quality of life issues pertaining to breast cancer survivorship (Halstead and Fernsler, 1994; Maunsell *et al.*, 1995; Ganz *et al.*, 1996; Hassey Dow *et al.*, 1996; Osborne Lee, 1997; Ferrell *et al.*, 1998; Leedham and Ganz, 1999). Many authors have focused on the coping strategies of breast cancer survivors,

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and how women integrate the cancer experience into their lives. Without doubt, these studies have demonstrated the far-reaching effect of breast cancer, beyond the period of diagnosis and treatment.

Breast cancer affects the psychological well being of survivors, including realization of mortality, fear of recurrence, reprioritization of activities and goals, and changes in mood and mental health (Carter, 1993; Fredefte, 1995; Ganz *et al.*, 1996; Hassey Dow *et al.*, 1996; Ferrell *et al.*, 1998; Leedham and Ganz, 1999). However, some survivors describe their cancer experience in very positive terms, reporting greater appreciation for life, a deepening of faith (Hoffman, 1991; Ferrell *et al.*, 1998), and ability to determine what is important.

The impact of breast cancer on work, insurance, confidentiality and disclosure has not been as well documented. There is both the potential for, and evidence of, discrimination in the work place and with insurers, and for the negative effects of physical symptoms, such as fatigue and loss of concentration, on work (Fobair *et al.*, 1986; Mor, 1986; Houts *et al.*, 1989; Hoffman, 1991; Carter, 1994; Hoffman, 1990). This study will describe these experiences from the perspective of Canadian women who have survived breast cancer for periods from 2 to 47 years.

METHODS

Women breast cancer survivors believed to be disease-free for a minimum of 2 years were recruited from two cancer clinics and 28 community support groups from across Canada, and asked whether they would be willing to answer a questionnaire relating to survivorship. English speaking women over the age of 18 who were not cognitively impaired were eligible to participate. Individuals were excluded from the study if they had cancer at another site, or metastatic disease. Subjects recruited in clinics were identified by a review of clinic medical charts for eligibility and disease status. Those recruited from support groups were informed of participation and inclusion criteria by group leaders and/or by mail. The questionnaires were anonymous, and a stamped return envelope was included with each survey. The survey was approved by University Health Network's Research Ethics Committee, and in-

cluded items about demographics, experiences with cancer and its impact on life. The data were analyzed with the Statistical Package for the Social Sciences (SPSS). This paper will describe the women's reported experiences with confidentiality, disclosure, and effects on work and insurance.

RESULTS

Five hundred questionnaires were distributed and 378 (75.6%) were completed and returned. Data were gathered on reasons for non-participation among those recruited in clinics—overwhelmingly, women refused to participate because their skills in English were inadequate. On average, the women had been diagnosed previously with breast cancer a mean of 8.6 ± 11.8 years previously: 31.0% were under 5 years since diagnosis, 49.3% were 5–10 years, and 18.3% were over 10 years since diagnosis. Their mean age was 61.0 ± 10.9 years, with a range of 35–88 years. The majority were born in Canada (64%), and 84% had children, 71% of them currently lived with their families, and 34% were homemakers. Fifty-seven percent had post-secondary education. Most survivors (87%) described their health during the past year as good to excellent, and 76% had no major health problems in the last year.

CONFIDENTIALITY AND DISCLOSURE

On a scale of 1 (worst) to 10 (best), women were asked to rate how they felt about the protection of their privacy and confidentiality by various institutions or people with respect to their breast cancer. The majority of women rated hospital staff, family doctor, family, friends, and support groups as 10, indicating maximal protection of privacy and confidentiality. Work colleagues and neighbours were also rated highly, with a mean rating of 9. A somewhat surprising 125 (33%) women spontaneously wrote that they were 'not at all concerned about confidentiality'.

Over two-thirds of women had disclosed their breast cancer to friends, children, siblings, or partners, while approximately half disclosed to work colleagues, bosses, or supervisors (Table 1). Reasons given for 'not telling' were that it might embarrass or upset others (22.7%), that they

Table 1. Breast cancer disclosure—who have you told (*n* = 378)?

	Number (%)
Friends	364 (96.8)
Children	304 (80.9)
Brothers/sisters	295 (78.5)
Husband/partner	288 (76.6)
Work colleagues	192 (51.2)
Parents	184 (48.9)
Boss/supervisor	154 (41.1)
Everyone	48 (34.6)
No one	1 (0.3)

didn't want to be the subject of gossip (117.4%), that it was too personal to tell (116.7%), that they worried about the stigma (13.6%), that it was awkward, uncomfortable, upsetting, or embarrassing (12.9%), that it might negatively affect relationships (8.3%), that it might affect job or career prospects (8.3%), that it might affect insurance (7.6%), that it was culturally inappropriate (7.2%), and that they didn't know how to tell (5.7%). The majority of women felt that disclosure had had a positive effect, including more support (73.8%), feeling closer to the people I told (56.3%), and receiving more information and advice from others (36.4%). However, some women felt it had no effect (17.8%), negatively changed the way other people perceived them (16.6%), resulted in insurance problems (9.8%), made people who were told less close (5.1%), caused work or job related problems (5.1%), or caused family problems (4.3%).

WORK

Although 43.7% of women felt the cancer in no way affected their work or career, 41.1% felt that it had altered their priorities and ambitions at work. Forty-one percent of women were no longer working, 25% reported a career change,

12.5% retired early as a result of cancer, 12.3% felt they were unable to fulfill their work or career potential, and 3.3% were too ill to work. Of concern were the 5.2% of women who felt afraid to change jobs in case they became sick, and the 3.0% of women who felt unable to fulfill their job potential because of perceived discrimination as a result of cancer. Conversely, 26.3% felt that cancer had made them more goal focussed and 6.5% reported a positive career change.

INSURANCE

A large number (approximately half of the women) didn't know or didn't answer the insurance questions, in comparison with other topics in the questionnaire (Table 2). Of the various types of insurance identified, life insurance (17.9%), followed by extended health insurance (7.7%), and private disability insurance (4.4%) were reported to have been refused or offered only with higher premiums.

DISCUSSION

Although these women were predominantly in good health at an average of 9 years after breast cancer diagnosis without recurrence, it is clear that some thought the cancer had greatly shaped their current lives. Clearly, most women felt their privacy and confidentiality were well protected by both the medical and social contacts, and over a third were not at all concerned about confidentiality. This lack of concern may have been related to them feeling that cancer wasn't, or shouldn't be, shameful. However, one wonders whether knowing the potential full impact of a breach of confidentiality on future work and other economic aspects of life, these women would be so unconcerned about confidentiality (Fobair *et al.*, 1986; Mor, 1986; Houts *et al.*, 1989; Hoffman, 1990, 1991; Rothstein, 1995).

Table 2. Insurance refusals or premium increases in breast cancer survivors

	Yes (%)	No (%)	Don't know (%)	No answer (%)
Extended health insurance	25 (7.7)	155 (45.7)	41 (12.1)	117 (34.5)
Private Disability Insurance	14 (4.4)	94 (29.7)	41 (13.0)	167 (52.8)
Life Insurance	61 (17.9)	101 (29.7)	37 (10.9)	141 (41.5)

A remarkable majority of women chose to freely disclose their breast cancer to family and friends, and this usually resulted in more support, greater closeness, and more information and advice from confidants. For nearly 20% of women, however, the disclosure was less positive and altered the perception of others, produced difficulties with insurance, work, and family, and diminished closeness with people they told. In addition to the women who had negative experiences following disclosure, it is possible that women who chose not to tell certain people may accurately have predicted the potentially negative reactions and sequelae of disclosure on relationships, job, and insurance.

As 56% of women felt that cancer had affected their work or career in various ways, it may be helpful for women newly diagnosed with cancer to be aware of the potential impact of cancer upon work. While the effect on work was sometimes personal, in that it affected the woman's priorities or ambitions, systemic issues probably affected the over 12% of women who felt unable to fulfill their work and career potential, made a career change, decided to retire early, or were afraid to change jobs in case they became sick. It has been estimated that 25% of the 6 million persons in the United States with a cancer history experience disparate treatment in employment solely because of their medical histories (Mor, 1986; Houts *et al.*, 1989; Hoffman, 1990, 1991). Most employers do not realize that over half of all cancer patients will survive over 5 years, that cancer is not contagious, and that survivors of cancer have the same productivity as other workers (Rothstein, 1995). An early study of 1351 Bell Telephone employees with a cancer history found that 77% returned to work after diagnosis and treatment (Stone, 1975). A later study found that a higher percentage of white collar survivors (78%) than blue collar survivors (63%) remained in their jobs 1 year after cancer diagnosis (Mor, 1986). However, discriminatory treatment including dismissal, denial of new jobs, demotions, loss of benefits, subtle bias, undesirable transfers, isolation and hostility in the workplace, and mandatory medical examinations unrelated to job performance are still reported (Wheatley *et al.*, 1974; Stone, 1975; Wellisch, 1984; Fobair *et al.*, 1986; Mor, 1986; Houts *et al.*, 1989; Hoffman, 1990, 1991; Rothstein, 1995). Although the stigma of cancer is far less than it was in past years, it seems that the effect of disclosing breast cancer may still sometimes be problematic

in some personal and work situations. Decisions to deny employment opportunities based on misconceptions about cancer rather than ability may violate legal rights. Meanwhile, a recent guide suggests that a survivor should not volunteer his/her cancer history in a job interview unless it directly affects the ability to perform that job and instead stress ability and qualifications for the job (Hoffman, 1990). Both health professionals and cancer survivors must engage in education and advocacy to combat cancer-based job discrimination.

Difficulty in obtaining life insurance was problematic for 17.9% of the women. Although a small number of women experienced difficulties with insurance refusals or premium increases for extended health (7.7%) or private disability insurance (4.4%), it may be that some women assumed they were ineligible and simply did not apply. As basic health insurance is universally provided in Canada, extended health insurance is primarily used for private and semi-private hospital accommodation, prescription drugs, dental and visual services, and extended nursing care. Although a small number of women reported insurance difficulties, the large number who reported that they didn't know, or didn't answer, all of the insurance questions is in keeping with the work of others and ourselves, which shows that women are poorly informed about insurance issues and are often unaware of what health insurance is available or provided through their or their spouses' work (Wheatley *et al.*, 1974; Rothstein, 1995; Leedham and Ganz, 1999). The non-response to these questions (up to 65%) was in sharp contrast to all other questions in this survey, which had non-response rates of under 5%. Most women are also unaware that the insurance companies share health information, and that a past history of breast cancer may have a negative impact on premiums or on acquiring new insurance. Insurance problems may therefore have been unknowingly under-reported in this survey.

Limitations to the generalizability of this study include the fact that Canada has a universal government sponsored health care system, that recall bias may be present, and that 24% of women did not respond. Most non-responders cited language barriers as the reason for not participating. It is possible that women from minority groups and recent immigrants to Canada would experience breast cancer survivorship in different ways, and this should be a future area of exploration.

CONCLUSION

In conclusion, it is clear that most women who survive breast cancer do not experience difficulties related to disclosure about cancer, but a significant minority report negative effects on relationships with friends, family, work, and insurance. It is likely that women in healthcare systems where private insurance is required for ongoing medical expenses will face greater difficulties. It may be helpful for women with newly diagnosed breast cancer to be aware of the potentially negative effect that may result from indiscriminate disclosure of cancer history or risk, and to selectively confide only in those people or agencies who are likely to be supportive or helpful in the longer term.

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