International Scholars Journals

African Journal of Nursing and Midwifery ISSN 2198-4638 Vol. 7 (1), pp. 001-004, January, 2019. Available online at www.internationalscholarsjournals.org © International Scholars Journals

Full Length Research Paper

The health and well-being of people with a previous diagnosis of cancer: A record-linkage study in Scotland

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Accepted 24 October, 2018

Routinely collected health care data (the Scottish Cancer Registry) were record-linked to representative survey data on health and health behaviours (the Government-funded Scottish Health Survey) to compare the health and well-being of cancer survivors in Scotland with people who had never had cancer; a methodological approach which has been under-utilised. After adjusting for age, sex and occupational classification, people with a previous diagnosis of cancer (even > 6 years previously) (n = were more likely to have poorer self-assessed health, reduced activity and psychological morbidity than people who had never had cancer (n = 25,631).

Key words: Cancer survivors, record-linkage, routine datasets, health and well-being.

INTRODUCTION

There are more people than ever before living with and beyond cancer, as noted in the United States (Ganz, 2009), in the UK (Maddams et al., 2009), and other developed countries (Phillips and Currow, 2010). In the UK, research shows that for most cancers, 10 year survival has improved between people diagnosed in the mid 1980s and those diagnosed in the late 1990s (Rachet et al., 2008; ISD, 2007). It is important to understand the needs of cancer survivors in relation to health and well-being, but aside from the expense of conducting primary research among this group, there can also be problems with identifying cancer survivors, and then obtaining sufficiently high recruitment and response rates (Ganz, 2009). A systematic review of studies examining quality of life of colo-rectal cancer survivors identified ten studies from North America, Japan and Europe, of which seven had response rates lower than 60% (Jansen et al., 2010), similar to those in a study of cervical cancer and breast cancer survivors in the US (Ashing-Giwa et al., 2010). To counteract this problem, Ganz (2003) suggested the use of national surveys and databases to monitor the long-term health of cancer survivors, but we have identified few studies with this explicit objective. The availability of linked administrative data in Scotland provides an opportunity to address this gap: we have therefore used the national Scottish Cancer Registry record-linked to Government survey data to compare certain aspects of health and well-being of people in Scotland who have had a diagnosis of cancer in the past with people with no such previous diagnosis.

MATERIALS AND METHODS

The Scottish Health Survey (SHeS) took place in 1995, 1998 and 2003 (and is annual from 2008). The survey collects comprehendsive information on health and health-related behaviour from a large sample of people that is nationally representative of the Scottish population (with different samples for each survey). Interviews are conducted face-to-face, with responses entered straight into

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a computer. Further information about the survey, including design and methods, is comprehensively documented (The Scottish Health Survey, 2010). The Scottish Cancer Registry (2010) records all new cases of cancer in Scotland and has been record-linked to the SHeS by the Information and Statistics Division, the body responsible for health data in Scotland. Linkage was probabilistic and based on name, addresses and date of birth. This was carried out for all respondents in the SHeS who agreed to this process (more than 90%) (Gray et al., 2009). Using date of diagnosis of cancer on the Scottish Cancer Registry, we identified all respondents to the SHeS survey who had had a cancer diagnosis prior to participation in the survey. Patients with non-melanoma skin cancers were excluded from this group; this cancer, treated within primary care, requires minimal clinical intervention, and is relatively common, and usually non-fatal (ISD, 2010).

The survey measured the following aspects of health and well-being:

1. Self-assessed health: respondents were asked whether their health was very good, good, fair, bad or very bad.
2. Reduced activity: respondents were asked whether they had reduced their 'usual activities' in the two weeks prior to interview, because of ill health, response being either yes or no.
3. Psychological morbidity: the general health questionnaire (GHQ-12) provides an indication of psychological morbidity and has been incorporated into the SHeS. Respondents were asked 12 questions, each soliciting a response of yes or no (scored 1 or 0). Anyone replying yes at least 4 times is likely to have a diagnosable mental health problem.

In logistic regression analyses, the measures of poor health and well-being were compared by sex, age and social classification defined by occupation (Rose, 1995), and also by whether (and when) the respondent had a previous diagnosis of cancer. Logistic regression analysis was used to calculate odds ratios, adjusted for all the aforementioned covariates (Table 1).

The study analysed anonymised data, therefore no specific ethical approval was required for this analysis.

RESULTS AND DISCUSSION

There were 26,138 respondents across the three surveys. The percentage of respondents with a previous cancer diagnosis increased from 1.2% in 1995 to 2.3% in 2003, with this increase at least partially due to different age criteria applied in each of the rounds (16 to 64 years in 1995, 16 to 74 years in 1998 and all ages in 2003). However, when the results were compared with restrictions for age group and time since diagnosis to ensure comparability across surveys, the range of those with a previous cancer diagnosis became much narrower, with an increase of only 0.2% between 1995 and 2003 (although statistically significant: Chi squared = 15.3, $p < 0.001$). Chi-squared analysis showed no significant differences between the three rounds of the survey in terms of prevalence of self-assessed health ($p = 0.76$), reduced activity related to health ($p = 0.45$), or psychological morbidity ($p = 0.52$), therefore results from the three surveys were combined for further analyses to increase statistical power.

In total, there were 25,631 respondents with no previous diagnosis of cancer. There were 507 respondents who had had a previous diagnosis. The most commonly occurring initial cancer diagnoses were breast cancer (30.2% of the total number), cancer of the digestive organs (15.2%), malignant neoplasms of lymphoid, haematopoietic and related tissue (10.1%), cancer of male genital organs (9.9%), cancer of female genital organs (9.7%), cancer of the urinary tract (8.3%) and cancer of respiratory and intrathoracic organs (5.1%).

Women were at increased risk of reduced activity and psychological morbidity (Table 1). Poorer health outcomes were also associated with decreasing social classification and increasing age. After adjusting for sex, age and social classification, it appeared that the poorest health was experienced by people with a recent diagnosis of cancer (within the previous 2 years). Over half of these people reported fair, bad or very bad health, over one third experienced reduced activity in the previous fortnight and over one quarter had psychological morbidity; with odds ratios indicating more than twice the risk of all outcomes when compared with people who had never had cancer. People diagnosed between 2 and 4 years ago also had a high risk of poor self-assessed health, although the risks were lower for reduced activity and psychological morbidity. However, it is notable that even people diagnosed with cancer more than 6 years previously were still at increased risk (albeit lower increased risk) of poor health outcomes, with 43% reporting fair, bad or very bad health, 23% reporting reduced activity and 19% with possible psychological morbidity; as com-pared to 23, 15 and 14% respectively among people never previously diagnosed with cancer.

This finding for Scotland that people who have had a previous diagnosis of cancer are more likely to fare poorly on measures of health and well-being than people who have never had cancer, confirms results of studies of health and well-being and quality of life, conducted in other countries (Hewitt et al., 2003; Arndt et al., 2006; Smith et al., 2009). We are confident that these results are valid. Record-linking the Scottish Cancer Registry (which is of high quality) with a comprehensive Government-funded survey of representative samples of the Scottish population provided an effective, yet economical, method of providing a simple snapshot of the health and well-being of cancer survivors, without the expense of conducting primary research. Additionally, the experiences of almost all people with a previous diagnosis of cancer were included, rather than a potentially biased and relatively small proportion of people who agree to take part in primary research (Ganz, 2003). Although there is the possibility of a small degree of selection bias in terms of the 90% of respondents who agreed to their data being record-linked for our study, this is likely to be smaller in magnitude than the bias arising from self-selection for primary research.

While our results arise from a heterogeneous sample of people with a previous diagnosis of cancer and their experiences may differ by diagnosis and by treatment

Table 1. Adjusted odds ratios (OR) for all covariates for the three outcomes of self-assessed health, reduced activity and psychological morbidity.

Variable	Total	Very bad/bad/ fair health (%)	Adjusted OR (95% CI)	Reduced activity in last 2 weeks (%)	Adjusted OR (95% CI)	GHQ-12 > 4	Adjusted OR (95% CI)
Years since diagnosis							
No cancer	25,631	5940 (23.2)	1.00 (Ref)	3898 (15.2)	1.00 (Ref)	3681 (14.4)	1.00 (Ref)
0-2 years	130	74 (56.9)	2.55 (1.77-3.67)	48 (36.9)	2.60 (1.80-3.73)	37 (28.5)	2.30 (1.55-3.41)
2-4 years	81	47 (58.0)	2.94 (1.85-4.68)	19 (23.5)	1.28 (0.75-2.17)	21 (25.9)	1.77 (1.06-2.95)
4-6 years	59	26 (44.1)	1.69 (0.98-2.90)	16 (27.1)	1.75 (0.98-3.13)	7 (11.9)	0.75 (0.34-1.65)
6+ years	237	102 (43.0)	1.53 (1.16-2.01)	55 (23.2)	1.33 (0.98-1.82)	45 (19.0)	1.29 (0.92-1.80)
Gender							
Male	11,766	2793 (23.7)	1.00 (Ref)	1617 (13.7)	1.00 (Ref)	1415 (12.0)	1.00 (Ref)
Female	14,372	3396 (23.6)	0.96 (0.90-1.02)	2419 (16.8)	1.26 (1.17-1.35)	2376 (16.5)	1.40 (1.30-1.51)
Age							
Under 20 years	4,080	372 (9.1)	1.00 (Ref)	411 (10.1)	1.00 (Ref)	172 (4.2)	1.00 (Ref)
20-29 years	3,447	559 (16.2)	1.97 (1.70-2.28)	451 (13.1)	1.31 (1.13-1.51)	545 (15.8)	4.41 (3.66-5.32)
30-39 years	5,051	916 (18.1)	2.35 (2.06-2.69)	701 (13.9)	1.41 (1.23-1.60)	863 (17.1)	4.95 (4.14-5.92)
40-49 years	4,379	954 (21.8)	3.04 (2.66-3.48)	689 (15.7)	1.64 (1.44-1.88)	755 (17.2)	5.16 (4.31-6.19)
50-59 years	4,163	1347 (32.4)	5.02 (4.41-5.73)	799 (19.2)	2.05 (1.79-2.33)	744 (17.9)	5.22 (4.35-6.26)
60-69 yrs	3,251	1267 (39.0)	6.45 (5.64-7.37)	630 (19.4)	2.02 (1.76-2.32)	484 (14.9)	4.06 (3.36-4.91)
70+ years	1,767	774 (43.8)	8.01 (6.90-9.29)	355 (20.1)	2.09 (1.79-2.45)	228 (12.9)	3.40 (2.75-4.22)
Social classification							
I Professionals	1,308	113 (8.6)	1.00 (Ref)	153 (11.7)	1.00 (Ref)	127 (9.7)	1.00 (Ref)
II Managerial and technical	6,826	1152 (16.9)	2.01 (1.63-2.47)	1011 (14.8)	1.21 (1.01-1.46)	840 (12.3)	1.20 (0.99-1.47)
III N Skilled non-manual	4,883	960 (19.7)	2.56 (2.07-3.16)	741 (15.2)	1.21 (1.00-1.46)	730 (14.9)	1.39 (1.14-1.71)
III M Skilled manual	5,746	1628 (28.3)	3.94 (3.21-4.84)	889 (15.5)	1.33 (1.10-1.60)	806 (14.0)	1.52 (1.25-1.86)
IV Partly skilled	4,244	1289 (30.4)	4.70 (3.82-5.79)	696 (16.4)	1.38 (1.10-1.60)	699 (16.5)	1.70 (1.39-2.08)
V Unskilled	1,722	671 (39.0)	5.93 (4.76-7.41)	338 (19.6)	1.58 (1.28-1.94)	338 (19.6)	1.97 (1.57-2.45)
Unclassified	948	254 (26.8)	4.75 (3.70-6.10)	139 (14.7)	1.31 (1.02-1.68)	160 (16.9)	2.12 (1.64-2.74)

Ref - reference group.

(some may be disease-free, others still receiving active treatment), this study has demonstrated the feasibility of using routinely collected datasets to monitor the health of cancer survivors. This could also be achieved in other countries that have well-developed cancer registries and the ability to link to other healthcare datasets. In Scotland, with the Scottish Health Survey occurring regularly and more data accumulating, sub-group analyses by cancer diagnosis will also become possible. In addition, this study provides pointers for future research: we need to investigate the incidence, prevalence and severity of long-term physical and psychological effects of a cancer diagnosis, why poorer health outcomes persist among cancer survivors even long after diagnosis, who is particularly at risk, and how health policies might address these inequalities.

ACKNOWLEDGEMENTS

We thank MacMillan Cancer Support for funding this study. We also acknowledge the staff of the Information and Services Division, Scotland for their help in supplying the data.

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