Fear of Cancer Recurrence and Utilisation of the Irish Health Care System.

Laura Curran

17137144

Supervisor: Dr. David Mothersill

B.A. (Hons) Psychology

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Name: Laura Curran

Student Number: 17137144

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"Fate whispers to the warrior, 'You cannot withstand the storm.' The warrior whispers back, 'I am the storm,'” – Jake Remington.

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Abstract

The current study sought to identify if cervical cancer survivor's levels of fear of cancer recurrence changed over time since treatment; Furthermore, if a relationship exists between fear of cancer recurrence and health care usage. The hypotheses presented were that fear of cancer recurrence would decrease the greater time post treatment and that cervical cancer survivors with high levels of fear of recurrence will have high health care system usage. Participants (N=46) completed a survey containing demographics, the Fear of Cancer Recurrence Inventory and the Adapted CBMTG Healthcare Utilization Questionnaire online. An ANOVA tested the first hypothesis, reporting significant results across the three groups F (2, 43) = 3.3, p = .046, with a large effect size (eta squared = .13), in group three. Results of hierarchical multiple regression found that fear of cancer recurrence did not predict health care use. The results of the study identified high levels of fear of cancer recurrence up to six years post treatment suggesting early identification and interventions are required to assist recovery. Initiatives such as the National Cancer Control Programme (NCCP) survivorship programme could lend support by encompassing this population.

Keywords: Irish, Cervical Cancer, Fear of Cancer Recurrence, Health Care Utilisation

Contents

A young courtier, Damocles, who was given the kings throne and all his riches, quickly loses enjoyment in them when he notes a sword suspended by a single horsehair above his neck. *‘‘Damocles’ Sword”*; is an analogy used to describe the experiences of cancer survivors (Koocher, & O'Malley, 1981). They experience the new lease of life and celebration, however the persistent fear of a recurrence or metastatic disease coupled with hypervigilance to any new symptom experienced, soon feels like Damocles sword is hanging above their own neck (Zebrack, & Zeltzer, 2001). This body of work will examine the relationship between fear of cancer recurrence in cervical cancer survivors and their use of Irish health care systems, as excessive medical reassurance seeking behaviour may interfere with cancer survivors functioning (Otto et al. 2018). The literature review begins by providing a general overview of fear of recurrence before describing more specific studies on fear of cancer recurrence and health care use, concluding with an outline of cervical cancer in Ireland.

Cancer is the second leading cause of death, with approximately 9.6 million deaths attributed to cancer globally in 2018 (WHO, 2020). Countries of all income levels suffer with the substantial burden of cancer, however, with higher income countries increasing screening for early detection, reducing known risk factors and improving the treatment of cancer (Torre, Siegel, & Jemal, 2016) survival rates in the 5-year prevalence have increased to 43.8 million (WHO,2018). As the population of cancer survivors grows steadily, Aaronson, (2014) outlines how other problems related to the disease such as psychological distress and psychosocial health problems are occurring in this population and international cancer agencies have recognised the need for more ambitious research into cancer survivorship (Hewitt, Greenfield, & Stovall, 2006).

Literature Review

Fear of Recurrence

One of the most commonly reported problems experienced by cancer survivors is fear of cancer recurrence (Baker, Dennison, & Smyth, 2005). Fear of cancer recurrence has been defined as the fear or worry that cancer will return or progress in the same organ or in another part of the body (Vickberg, 2003). Current research suggests 33 – 56% of cancer survivors are reporting high levels of fear of cancer recurrence (Lebel, Rosberger, Edgar, & Devins, 2007; Vickberg, 2003). Simard, and Savard (2015) described how lower levels of fear of cancer recurrence would be considered a normal reaction to a cancer diagnosis and this vigilance was appropriate. However, they outlined how chronic intrusive thoughts about a possible recurrence and excessive need for reassurance would be clinically significant and that these higher levels of fear of cancer recurrence are generally associated with higher levels of depression and anxiety in cancer survivors.

Numerous studies support this idea, levels of fear of cancer recurrence significantly positively correlate with mental distress, fatigue and neuroticism and there is also a significant negative correlation with quality of life, self-esteem and coping (Skaali, Fosså, Bremnes, Dahl, Haaland, Hauge, & Dahl, 2009). Fear of recurrence has been reported as being highly prevalent among long-term breast cancer survivors and has significant association with depression and emotional functioning (Koch, Bertram, Eberle, Holleczek, Schmid-Höpfner, Waldmann, & Arndt, 2014). Also, Heins, Korevaar, Rijken, and Schellevis, (2013) reported that cancer patients attended their GP more than non-cancer patients for acute symptoms, infections, pain, fatigue, sleep disturbance and depression. However, none of the studies looked at health care use and all three studies questioned the validity of the scale they used for fear of cancer recurrence.

In the last Twenty years, efforts have been made to better understand fear of recurrence and to help survivors cope (Humphris, & Ozakinci, 2008) despite this, an agreed upon definition of fear of recurrence is still lacking and has therefore made assessing it challenging (Lebel, Ozakinci, Humphris, Thewes, Prins, Dinkel, & Butow, 2017). This leads to differences in items included in scales and creates a variability in reported prevalence rates of fear of recurrence (Llewellyn, Weinman, McGurk, & Humphris, 2008). The more often used definition, which views fear of recurrence from the patients perspective and is relevant across their cancer journey is the above mentioned Vickberg, (2003), in addition with the selection of the most appropriate assessment tool which is valid and reliable, may mitigate the challenge of assessing fear of recurrence.

Several standardised assessment tools exist, for example, Northouse, (1981) developed the fear of recurrence questionnaire, this was the first time that a fear of recurrence specific measure was reported in literature and the item wording was reviewed by clinical experts (Thewes, Butow, Zachariae, Christensen, Simard, & Gotay, 2012). The scale is a unidimensional measure shown to have good reliability with a Cronbach's α of 0.92 (Hilton,1989) however, Internal validity has not been assessed; while the Fear of Progression Questionnaire (Mehnert, Herschbach, Berg, Henrich, & Koch, 2009) with good internal and external validity and a Cronbach's α of 0.89, only measures fear of progression and omits the measure fear of recurrence. Studies have reported that in extreme cases, fear of recurrence is associated with anxiety disorders and post-traumatic stress symptoms. Highlighting, the importance of accurately measuring fear of recurrence in cancer survivors to effectively manage health care and interventions available to them (Black, & White, 2005; Simard, Savard, & Ivers, 2010).

Health Care Utilisation

Evidence exists in support of findings that cancer survivors who report higher fear of recurrence also have poor levels of health care satisfaction (Moyer, & Salovey, 1998; Shim, Shin, Oh, & Hahm, 2010). Furthermore, these lower levels of satisfaction in relation to the health information cancer patients received; symptom management, treatments and possible side effects were ultimately significant predictors of higher levels of fear of recurrence (Janz, Hawley, Mujahid, Griggs, Alderman, Hamilton, & Katz, 2011; Lee, Francis, Walker, & Lee, 2004). Yet, Hawkins, Smith, Zhao, Rodriguez, Berkowitz, and Stein, (2010) indicated that higher fear of recurrence predicted positive behaviour change, this was in relation to increased regular check-ups with health professionals; while others outlined the severity of fear of recurrence predicating the frequency of contact with health professionals (Cannon, Darrington, Reed, & Loberiza Jr, 2011; Mikkelsen, Sondergaard, Sokolowski, Jensen, & Olesen, 2009). However, none employed validated scales in the measure of fear of recurrence with the latter study simply asking if the participant feared a cancer relapse.

Sarkar, Sautier, Schilling, Bokemeyer, Koch, and Mehnert, (2015) did use a validated scale, the short version of the Fear of Progression Questionnaire (FoP-Q-SF), (Mehnert, Herschbach, Berg, Henrich, & Koch, 2009) with Cronbach's α of 0.87 to measure fear of recurrence, although the study showed fear of recurrence played a significant role in the unmet needs of the cancer patients their investigation into the relationship between fear of recurrence, anxiety, supportive care needs, and the use of health-care services it did not measure if fear of recurrence alone, related to health care use. In contrast, Lebel, Tomei, Feldstain, Beattie, & McCallum, (2013) did measure fear of recurrence by itself and measured it against health care use. They investigated the relationship between fear of recurrence and emergency room visits, overnight hospital stays, medication use, outpatient visits and specialists' visits. They recruited 231 participants who had previous diagnosis of breast, lung, colon, or prostate cancer within the last ten years. Participants completed the fear of cancer recurrence inventory (Simard, & Savard, 2009), to measure fear of recurrence and the CBMTG Healthcare Utilization Questionnaire (Schultz, 2011) to measure the use of the health care system via a survey package received by post. Hierarchical multiple regression analysis was employed to test the hypothesis that fear of cancer recurrence would significantly predict greater number of visits to an outpatient clinic, a medical specialist, other health care providers, an emergency department, or admissions to hospital in addition to total number of medications taken. The results indicated that patients who recorded higher levels of fear of recurrence did attend the Emergency room more frequently and consumed a greater amount of medication. They also reported that higher levels of fear of recurrence significantly predicted a greater number of outpatient's visits. The significance of which is compounded by Otto, Soriano, Siegel, LoSavio, and Laurenceau, (2018), as they highlighted that excessive medical reassurance seeking behaviour may interfere with cancer survivors functioning. In addition, Lebel et al., (2013), also identified younger female survivors as recording higher use of health care systems while also recording higher fear of recurrence, tentatively suggesting that fear of recurrence may be a better predictor in female populations.

Cervical Cancer

Each year, more than 530,000 women are diagnosed with cervical cancer worldwide and each year approximately 275,000 women die from this disease (Arbyn, Castellsagué, de Sanjosé, Bruni, Saraiya, Bray, & Ferlay, 2011). Cervical Cancer is the most common type of gynaecological cancer and second only to breast cancer in incidence of all female malignancies (WHO, 2012). One cause deemed necessary for growth of cancer in the cervix is a high risk strain of the human papillomavirus (HPV) which causes around 70% of cervical cancers (Bosch, F. X., Lorincz, Muñoz, Meijer, & Shah, 2002; Walboomers, Jacobs, Manos, Bosch, Kummer, Shah, & Muñoz, 1999). Many countries, Ireland included, have begun the introduction of a HPV vaccination programme, however the traditional route of prevention of cervical cancer has been cervical screening, this involves women attending their GP or nurse practitioner for cervical cytology tests in an attempt to detect and treat pre-cancerous lesions before they progress on to cervical cancer (O'Brien, & Sharp, 2013). Furthermore, a well organised, systematic screening in conjunction with an effective recall system were deemed to provide the optimum benefit (Arbyn, Rebolj, De Kok, Fender, Becker, O'Reilly, & Andrae, 2009; Raffle, Alden, Quinn, Babb, & Brett, 2003). Following a pilot programme run in the Mid-Western Health Board Region from 2000 (O'Neill, 2000), Ireland launched the national cervical screening programme 'Cervical Check' in September 2008 (O'Brien, & Sharp, 2013).

However, just ten years later, an independent scoping review of Cervical Check was commissioned in the wake of a crisis in the programme; women had not been notified of positive test results following an audit and subsequently went on to develop cancer and in some cases succumbed to the disease (Dyer, 2018). The scoping review by Scally, (2018), highlighted the "substantial weaknesses, indeed absences, of proper professional advisory structures," (p. V) and that the cervical screening system in Ireland was "doomed to fail at some point" and had problems that were "redolent of a whole system failure," (p. V). These critical findings are even more profound as women with cervical cancer, compared to those with other gynaecological cancers, have been shown to be more emotionally distressed and have a worse quality of life (Gonçalves, 2010). Evidence for how the 'doomed' Irish Cervical Check system has affected this population of women is non-existent to date.

The current study

Inconsistencies were observed in the literature, from what measurement tool is most appropriate for fear of recurrence to a lack of one consistent definition to describe it, any firm conclusion on fear of recurrences' effect on cancer survivors is lacking. Furthermore, health care systems differ across countries; these previous studies may not be generalisable as a consequence. Nevertheless, there is still evidence to support a relationship between fear of recurrence and the use of health care systems. This study will build on this literature via the use of the Vickberg (2003) definition for fear of recurrence and the validated and reliable Simard, and Savard, (2009) Fear of Recurrence Inventory (FCRI) to measure fear of recurrence.

Furthermore, literature is lacking in relation to Irish cervical cancer survivors, despite Ireland seeing an increase of 2% in incidence of Cervical Cancer up to 2015 and a year on year increase in survival rates, (National Cancer Registry Ireland, 2017). Moreover, there is now the realisation that the system the women of Ireland have been engaging with was not fit for purpose, with some expressing to the scoping review (Scally, 2018), their complete lack of confidence in the Irish health system and also, in some cases their treating clinicians (p. 5). Not only has fear of cancer recurrence been shown to increase health care use (Lebel et al., 2013) but also excessive medical reassurance seeking behaviour may interfere with cancer survivors functioning (Otto, et al. 2018), therefore identifying at what point post treatment survivors are experiencing high levels of fear of cancer recurrence is also salient.

Therefore, to address the gap in literature, this study will ask the question, 'Does fear of cancer recurrence predict cervical cancer survivors use of the Irish health system?' and address two aims. The first will examine at what point post treatment survivors experience higher levels of fear of cancer recurrence by determining if there are differences in fear of recurrence levels across three groups: 0- 3 years post treatment, 4-6 years post treatment and 7-10 years post treatment. The second will investigate if a relationship exists between fear of cancer recurrence in Irish cervical cancer survivors and their use of Irish health systems while controlling for differences in age at diagnosis, if the cancer was detected via the cervical screening system, having health insurance and years post treatment. On account of which, it is hypothesised

1. H_0 = Levels of fear of cancer recurrence will not differ over years post treatment.

   H_a = Levels of fear of cancer recurrence will decrease the greater the time post cancer treatment.
2. H_0 = Fear of Cancer recurrence will not predict cervical cancer survivors use of Health Care Systems.

   H_a = Cervical cancer survivors with high levels of fear of recurrence will have high health care system usage.

Methods

Participants

Participants were eligible to take part in this study if they had received a diagnosis of cervical cancer in the last ten (10) years which was then treated in an Irish hospital and if they were 18 years or older. The participants were also required to be in remission and not have a recurrence of cervical cancer or a metastatic cancer at the time of the completion of the questionnaire. The study employed a non-probability convenience sampling strategy to achieve a representative sample via an online support group for cervical cancer in Ireland with over 700 members. G*Power: Statistical Power Analyses (Faul, Erdfelder, Buchner, & Lang, 2009) was used to determine the sample size required for a statistically powerful analysis. As such, a sample size of 100 or more was required, to reduce the probability of a Type I error. Access to the questionnaires was available from November 21st, 2020 to January 13th, 2021 and a total of 65 responses were recorded (8.34% participation rate). No payments or incentives were utilised in the recruitment of participants.

A total of ten (10) participants were excluded from analyses due to cancer recurrence, current metastatic cancer and currently receiving cancer treatment. Furthermore nine (9) participants did not complete the questionnaires in their entirety. The final sample then comprised of forty-six (46) participants all female, with a mean age of 40.09 (SD = 5.64) ranging from 28 to 51. All participants were diagnosed and treated in Ireland with a mean age at diagnosis of 35.89 (SD = 5.65) ranging from 24 to 47. 60.9% had private health insurance (N = 28) and 56.5% of participants were diagnosed with Cervical Cancer via a Cervical smear test (N = 26).

Measures Materials

Demographic and health information.

Participants were asked to provide their age currently and also their age at diagnosis. They were also asked to indicate if they were a health insurance member and confirm that their diagnosis and treatment were completed in Ireland. Furthermore, participants were required to indicate if their cancer diagnosis was detected via a cervical smear test and to tick if they were still receiving treatment, in remission, have cervical cancer recurrence and/or have metastatic disease (cancer which has spread from the initial site of the cervix to any other part of the body). Finally, participants were asked to specify (in years) length of time since their cancer treatment (Appendix D).

Fear of cancer recurrence inventory (FCRI).

The Fear of Cancer recurrence Inventory (Simard, & Savard, 2009) is a 42-item questionnaire utilised in the measurement of cancer survivors concerns over cancer recurrence (Appendix E). The scale employs a five-point Likert scale from 0 (Never OR Not at all) to 4 (All of the Time OR A great deal). As reported by Simard, and Savard, (2009), the scale has demonstrated excellent internal consistency ($\alpha=0.95$), test – retest reliability, $r(287)= 0.89$, $p <0.001$, construct validity, ($r=0.68$ to 0.77), face validity and content validity (pg. 241); results echoed with the current sample indicating good internal consistency ($\alpha=0.86$). The total score of the FCRI ranges from 0 – 168, with higher scores indicating higher fear of cancer recurrence. Addition of individual scores from all 42 items generates the total score for fear of cancer recurrence with results of question 13 ‘I believe that I am cured, and the cancer will not come back’, as the only item to be reversed scored during analysis.

CBMTG healthcare utilization questionnaire.

This adapted questionnaire is based on the Canadian Blood and Marrow Transplant Group (CBMTG) Healthcare Utilization Questionnaire which is a project specific health care utilisation questionnaire by Schultz, (2011) which was created to measure the use of health care amongst different blood and marrow transplant patients (Appendix F). A validated, commonly used scale for measurement of health care utilisation does not exist; however, an adapted version of the Schultz, (2011) scale was used by Lebel, Tomei, Feldstain, Beattie, & McCallum, (2013) who generously shared the scale for the purpose of this study. As information in relation to participants medication consumption is not relevant for this study, only sections A and B from their adapted version were employed. These subscales assessed on how many occasions participants engaged in the use of out-patients clinics, specialists visits, other health care professionals such as family GP and psychologist, Accident and Emergency departments (A&E) or overnight 'in patient' hospital stays (hospitalisations). An increase was applied to the time frame for these visits from 'Over the past 6 months' to 'Over the past 12 months, to accommodate for the current Covid-19 pandemic. The overall combined score for the scale did not show high internal consistency, (α=0.29), the use of one criterion variable for total health care use was not suitable. Therefore, the five separate scales from within the questionnaire were used individually, producing five Criterion Variables; Out-Patients Visits, Specialists Visits, Other Health Care Visits, Accident and Emergency Visits (A&E) and Hospitalisations.

Design and Analyses

Additional hypotheses were generated at this point to accommodate to the aforementioned additional criterion variables, replacing the original second hypothesis 'Participants with high levels of fear of recurrence will have high levels of Health System usage', with:

- Hypothesis 2: Participants with high levels of fear of recurrence will have high levels of Out-Patients Visits
- Hypothesis 3: Participants with high levels of fear of recurrence will have high levels of Specialists Visits
- Hypothesis 4: Participants with high levels of fear of recurrence will have high levels of Other Health Care Visits
- Hypothesis 5: Participants with high levels of fear of recurrence will have high levels of A&E Visits
- Hypothesis 6: Participants with high levels of fear of recurrence will have high levels of Hospitalisations.

The present study used a quantitative approach employing a multivariate cross-sectional and correlational design availing of online survey research to collect data. Statistical analyses were conducted via IBM SPSS statistics version 27. Employing a one way between groups analysis of variance to test the first hypothesis, participants were placed into three groups according to their years post treatment, 0 to 3 years post treatment (Group 1), 4 to 6 years post treatment (Group 2) and 7 to 10 years post treatment (Group 3) and compared on their levels of fear of cancer recurrence. Hierarchical Multiple Regression analysis was implemented to test the second through to sixth hypotheses. Age at Diagnosis, Health Insurance, Cancer detected via smear test, years post treatment and total fear of cancer recurrence were used as predictor variables while Out-Patients Visits, Specialist Visits, Other Health Care Visits, A&E Visits and Hospitalisations were individually entered as criterion variables for the five regression analyses conducted.

Procedure

Data was collected online via the Survey Monkey platform, where the three anonymous, self-report questionnaires were used to generate a survey. Prior to allowing access to the survey, a trial run was completed by the student researcher to ensure the estimated time for completion provided by Survey Monkey was correct while assessing the usability of the layout. Once completed, this attempt was deleted from the results. A time of 10 minutes for completion of the survey was confirmed. The information sheet (Appendix A), in conjunction with a link to the survey, were posted to the private online cervical cancer group (access was gained as the student researcher is a member) on Facebook with all members having access to them. Once a member clicked the link they were shown the information sheet again detailing the nature of the study, it's purpose, eligibility requirements, how their information would be handled and the voluntary nature of the study along with their right to withdraw at any stage without prejudice. Furthermore, participants were advised at this stage, due to the unidentifiable nature of the information, withdrawal after they submitted their responses was not possible. Both the student researcher and supervisors contact information were also provided, should questions arise prior to commencement of the survey.

On the second page of the survey the participants completed a consent form (Appendix B) confirming their understanding of the information sheet and of the right to withdraw, their voluntary participation, and that they are over 18 years of age. Participants were asked, 'Do you give consent to take part in this study', consent was obtained if the participant clicked Yes, if a participant clicked No, they were automatically redirected out of the study and thanked for their time.

The third page of the survey collected information via the Demographic and Health Information sheet, followed by the Fear of Cancer Recurrence Inventory and then the Adapted CBMTG Healthcare Utilization Questionnaire. Finally participants were provided with a debriefing sheet (Appendix C) reiterating the nature and purpose of the study along with contact numbers for both the Marie Keating foundation and the Irish Cancer Society support lines in the event the engagement with the survey caused undue psychological distress. Participants were thanked for their time as at this stage their engagement with the study concluded. After the survey closed out on 13th January 2021, data was transferred from Survey Monkey to IBM SPSS statistics, a code book was generated, data entered, screened for errors and variables recoded and scored in preparation for statistical analyses.

Ethical Considerations

This study adhered to all ethical guidelines outlined by The National College of Ireland Ethical Guidelines and Procedures for Research involving Human Participants (2018) and The Psychological Society of Ireland Code of Professional Ethics (2010). Moreover, ethical approval for this study was granted by The National College of Ireland Ethics Committee. Transparency in relation to the purpose and nature of the study was highlighted to participants prior to obtaining informed consent, furthermore, on two occasions the participants right to withdraw without prejudice was reiterated. Although no harm was expected, helpline numbers for both the Marie Keating Foundation and the Irish Cancer Society were provided on two occasions, should a participant feel psychologically distressed following their engagement with this study.

Results

Descriptive Statistics

Descriptive statistics for categorical variables are presented in Table 1. 100% of participants were diagnosed and treated in an Irish setting (N = 46). 60.9% were health insurance members and 56.5% were diagnosed via a cervical cancer smear test.

Table 1

Frequencies for the current sample (N=46)

Variable	Frequency	Valid %
Diagnosed & Treated in Ireland	46	100
Health Insurance Member	28	60.9
Cancer detected via Smear Test	26	56.5

Mean (M), Median (MD), Standard Deviation (SD) and Range for all continuous variables were obtained and are presented below in Table 2. Preliminary analysis performed indicated that Age at Diagnosis and Total Fear of Cancer Recurrence followed the assumptions of normality; however, the results of the Kolmogorov-Smirnov statistic for Years post Treatment, Outpatients Visits, Specialists Visits, Other Healthcare, A&E visits and Hospitalisations were significant ($p < .05$) indicating not normally distributed data. Histograms indicated that the data was positively skewed and lower bound mean scores were observed in these variables; however, these variables are ‘count’ variables beginning at zero, indicating a Poisson distribution and as such, the distribution of scores will be treated as normal.

Table 2

Descriptive Statistics for all continuous variables (N=46)

Variable	Mean (95% Confidence Intervals)	Median	SD	Range
Age at Diagnosis	35.89 [34.21-37.57]	36.00	5.65	24-47
Years post Treatment	3.77 [3.05-4.50]	3.5	2.44	0.5-10
Outpatients Visits	4.59 [2.82-6.35]	3. 00	5.94	0-37
Specialists Visits	4.50 [1.78-7.22]	2.00	9.17	0-55
Other Healthcare	6.39 [3.52-9.27]	4.00	9.68	0-52
A&E Visits	0.46 [0.13-0.78]	.00	1.09	0-5
Hospitalisations	0.57 [0.21-0.92]	.00	1.21	0-5
Total FCRI	93.89 [89.19-98.59]	94.00	15.82	59-127

Hypothesis 1

To investigate the current study's first hypothesis, a one way between groups analysis of variance was conducted to explore the differences in Fear of Cancer Recurrence scores as the years lapsed post cancer treatment. Participants were divided into three groups according to their years post treatment, 0 to 3 years post treatment (Group 1), 4 to 6 years post treatment (Group 2) and 7 to 10 years post treatment (Group 3). There was a significant difference in levels of fear of cancer recurrence for the three groups, F (2, 43) = 3.3, p = .046, with the effect size indicating a large difference (eta squared = .13). Despite reaching statistical difference, Post -hoc comparisons using the Tukey HSD test indicated that the mean score for Group 1 (M = 95.91, SD = 16.63) was not significantly higher (p = .952) than Group 2 (M =

97.40, SD = 14.12) or Group 3 (M = 81.50, SD = 11.20). There was no statistically significant difference in mean scores between Group 3 or Group 4 (p = .052).

Analysis of hypotheses 2 to 6 was conducted using Hierarchical Multiple Regression, as healthcare use was measured on five separate scales, the p value was set at 0.01 using the Bonferroni correction (.05/5) to reduce the likelihood of a Type 1 error.

Hypothesis 2

Hierarchical multiple regression was performed to assess the ability of Fear of Cancer Recurrence to predict Out-Patients Visits, after controlling for age at diagnosis, cancer detected via smear test, health insurance and years post treatment. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity. Furthermore, the correlations between predictor variables (Age at Diagnosis, Cancer detected via smear, Health Insurance, Years post Treatment) were examined and these are presented in Table 3. None of the predictor variables significantly correlated with Out- Patients Visits and all correlations were weak ranging between r = -.29 to .23. Tests for multicollinearity also indicated that all Tolerance and VIF values were in an acceptable range. These results indicate that there was no violation of the assumption of multicollinearity and that the data was suitable for multiple linear regression analysis.

Table 3

Correlations between all continuous variables

Variable	1.	2.	3.	4.	5.	6.
1. Outpatients Visits	-					
2. Age at Diagnosis	.01	-				
3. Detected via Smear	.23	-.12	-			
4. Health Insurance	-.13	.01	.02	-		
5. Years Post Treatment	-.29	-.14	.14	.01	-	
6. Total FCR	.01	-.03	-.06	-.06	-.18	-

Note: Statistical significance = p < .01

Step 1 of the hierarchical multiple regression included the entry of four predictor variables: Age at Diagnosis, Cancer detected via smear, Health Insurance and Years post Treatment. This model was not statistically significant F (4, 41) = 2.19; p =.087, and explained 17.6% of variance in out-patients visits. Following the entry of total fear of cancer recurrence at Step 2 the total variance explained by the model as a whole, was 17.9% (F (5,40) = 1.74; p =.148). Fear of cancer recurrence explained an additional 0.3% of the variance in out-patients visits after controlling for Age at Diagnosis, Cancer detected via smear, Health Insurance and Years post Treatment, R squared change = .003, F change (1, 40) = .124, p =.726, remaining not statistically significant in the final model. (see table 4 for full details)

Table 4

Hierarchical Multiple Regression Model predicting Out-Patients Visits

Variable	*R*	R^2	R^2 *Change*	*B*	*SE*	*β*	*t*	*p*
Step 1	.420	.176						
Age at Diagnosis				-.009	.151	-.008	-.058	.954
Detected via Smear Test				3.23	1.71	.272	1.89	.066
Health Insurance				-1.60	1.71	-.134	-.944	.351
Years Post Treatment				-.802	.350	-.330	-2.29	.027
Step 2	.423	.179	.003					
Age at Diagnosis				-.012	.153	-.011	-.076	.940
Detected via Smear Test				3.20	1.72	.271	1.86	.071
Health Insurance				-1.65	1.73	-.137	-.953	.346
Years Post Treatment				-.824	.360	-.399	-2.29	.027
Total FCR				-.019	.055	-.052	-.353	.726

Note: R^2= R-squared; R^2 *Change* = R-square change; B = unstandardized beta value; SE = Standard errors of B; β = standardized beta value; Statistical significance = $p < .01$

Hypothesis 3

Hierarchical multiple regression was performed to assess the ability of Fear of Cancer Recurrence to predict Specialists Visits, after controlling for age at diagnosis, cancer detected via smear test, health insurance and years post treatment. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity. Furthermore, the correlations between predictor variables (Age at Diagnosis, Cancer detected via smear, Health Insurance, Years post Treatment) were examined and these are presented in Table 5. None of the predictor variables significantly correlated with Specialists Visits and all correlations were weak ranging between r = -.18 to .14. Tests for multicollinearity also indicated that all Tolerance and VIF values were in an acceptable range. These results indicate that there was no violation of the assumption of multicollinearity and that the data was suitable for multiple linear regression analysis.

Table 5

Correlations between all continuous variables

Variable	1.	2.	3.	4.	5.	6.
1. Specialists Visits	-					
2. Age at Diagnosis	.14	-				
3. Detected via Smear	.14	-.12	-			
4. Health Insurance	-.01	.01	.02	-		
5. Years Post Treatment	-.11	-.14	.14	.01	-	
6. Total FCR	.12	-.03	-.06	-.06	-.18	-

Note: Statistical significance = p < .01

Step 1 of the hierarchical multiple regression included the entry of four predictor variables: Age at Diagnosis, Cancer detected via smear, Health Insurance and Years post Treatment. This model was not statistically significant F (4, 41) = .649; p =.631, and explained 6% of variance in Specialists Visits. Following the entry of total fear of cancer recurrence at Step 2 the total variance explained by the model as a whole, was 7.2% (F (5,40) = .617; p =.687). Fear of cancer recurrence explained an additional 1.2% of the variance in Specialists Visits after controlling for Age at Diagnosis, Cancer detected via smear, Health

Insurance and Years post Treatment, R squared change = .012, F change (1, 40) = .520, p =.475, remaining non statistically significant in the final model. (see table 6)

Table 6

Hierarchical Multiple Regression Model predicting Specialists Visits

Variable	*R*	R^2	R^2 *Change*	*B*	*SE*	*β*	*t*	*p*
Step 1	.244	.060						
Age at Diagnosis				.244	.250	.150	.978	.334
Detected via Smear Test				3.20	2.81	.175	1.14	.262
Health Insurance				-.139	2.82	-.007	-.049	.961
Years Post Treatment				-.439	.578	-.117	-.760	.452
Step 2	.268	.072	.012					
Age at Diagnosis				.254	.251	.156	1.01	.319
Detected via Smear Test				3.28	2.83	.179	1.16	.254
Health Insurance				-.015	2.83	-.001	-.005	.996
Years Post Treatment				-.362	.591	-.097	-.613	.543
Total FCR				.065	.090	.112	.721	.475

Note: R^2= R-squared; R^2 *Change* = R-square change; B = unstandardized beta value; SE = Standard errors of B; β = standardized beta value; Statistical significance = p < .01

Hypothesis 4

Hierarchical multiple regression was performed to assess the ability of Fear of Cancer Recurrence to predict Other Health Care Visits, after controlling for age at diagnosis, cancer detected via smear test, health insurance and years post treatment. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity. Furthermore, the correlations between predictor variables (Age at Diagnosis, Cancer detected via smear, Health Insurance, Years post Treatment) were examined and these are presented in Table 7. None of the predictor variables significantly correlated with Other Health Care Visits and all correlations were weak ranging between r = -.33 to .14. Tests for multicollinearity also indicated that all Tolerance and VIF values were in an acceptable range. These results indicate that there was no violation of the assumption of multicollinearity and that the data was suitable for multiple linear regression analysis.

Table 7

Correlations between all continuous variables

Variable	1.	2.	3.	4.	5.	6.
1. Other Health Visits	-					
2. Age at Diagnosis	-.05	-				
3. Detected via Smear	.12	-.12	-			
4. Health Insurance	-.33	.008	.02	-		
5. Years Post Treatment	.02	-.14	.14	.01	-	
6. Total FCR	.08	-.03	-.06	-.06	-.18	-

Note: Statistical significance = p < .01

Step 1 of the hierarchical multiple regression included the entry of four predictor variables: Age at Diagnosis, Cancer detected via smear, Health Insurance and Years post Treatment. This model was not statistically significant F (4, 41) = 1.46; p =.231, and explained 12.5% of variance in Other Health Care Visits. Following the entry of total fear of cancer recurrence at Step 2 the total variance explained by the model as a whole, was 12.9% (F (5,40) = 1.19; p=.333). Fear of cancer recurrence explained an additional 0.4% of the variance in Other Health Care Visits after controlling for Age at Diagnosis, Cancer detected via smear, Health Insurance and Years post Treatment, R squared change = .004, F change (1, 40) = .190, p=.665, remaining non statistically significant in the final model. (see table 8 for full details)

Table 8

Hierarchical Multiple Regression Model predicting Other Health Care

Variable	*R*	R^2	R^2 *Change*	*B*	*SE*	*β*	*t*	*p*
Step 1	.353	.125						
Age at Diagnosis				-059	.254	-.035	-.234	.816
Detected via Smear Test				2.25	2.87	.116	.783	.438
Health Insurance				-6.51	2.87	-.332	2.27	.028
Years Post Treatment				-.001	.588	.000	-.002	.998
Step 2	.359	.129	.004					
Age at Diagnosis				-.053	.257	-.031	-.208	.836
Detected via Smear Test				2.29	2.90	.119	.791	.434
Health Insurance				-6.44	2.90	-.328	-2.22	.032
Years Post Treatment				.046	.604	.012	.076	.940
Total FCR				.040	.092	.066	.436	.665

Note: R^2= R-squared; R^2 *Change* = R-square change; B = unstandardized beta value; SE = Standard errors of B; β = standardized beta value; Statistical significance = $p < .01$

Hypothesis 5

Hierarchical multiple regression was performed to assess the ability of Fear of Cancer Recurrence to predict A&E Visits, after controlling for age at diagnosis, cancer detected via smear test, health insurance and years post treatment. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity. Furthermore, the correlations between predictor variables (Age at Diagnosis, Cancer detected via smear, Health Insurance, Years post Treatment) were examined and these are presented in Table 9. None of the predictor variables significantly correlated with A&E Visits and all correlations were weak ranging between r = -.33 to .20. Tests for multicollinearity also indicated that all Tolerance and VIF values were in an acceptable range. These results indicate that there was no violation of the assumption of multicollinearity and that the data was suitable for multiple linear regression analysis.

Table 9

Correlations between all continuous variables

Variable	1.	2.	3.	4.	5.	6.
1. A&E Visits	-					
2. Age at Diagnosis	02	-				
3. Detected via Smear	.20	-.12	-			
4. Health Insurance	.20	.01	.02	-		
5. Years Post Treatment	-.33	-.14	.14	.01	-	
6. Total FCR	.08	.46	-.06	-.06	-.18	-

Note: Statistical significance = p < .01

Step 1 of the hierarchical multiple regression included the entry of four predictor variables: Age at Diagnosis, Cancer detected via smear, Health Insurance and Years post

Treatment. This model was not statistically significant F (4, 41) = 2.67; p =.046, and explained 20.6% of variance in A&E Visits. Following the entry of total fear of cancer recurrence at Step 2 the total variance explained by the model as a whole, was 20.8% (F (5,40) = 2.10; p=.085). Fear of cancer recurrence explained an additional 0.2% of the variance in A&E Visits after controlling for Age at Diagnosis, Cancer detected via smear, Health Insurance and Years post Treatment, R squared change = .002, F change (1, 40) = .081, p=.777, remaining non statistically significant in the final model. (see table 10)

Table 10

Hierarchical Multiple Regression Model predicting A&E Visits

Variable	*R*	R^2	R^2 *Change*	*B*	*SE*	*β*	*t*	*p*
Step 1	.454	.206						
Age at Diagnosis				-,001	.027	-.005	-.033	.974
Detected via Smear Test				.531	.307	.244	1.73	.091
Health Insurance				.437	.307	.198	1.42	.162
Years Post Treatment				-.162	.063	-.364	-2.57	.014
Step 2	.456	.208	.002					
Age at Diagnosis				.000	.028	-.002	-.017	.987
Detected via Smear Test				.534	.311	.245	1.72	.093
Health Insurance				.443	.311	.200	1.42	.163
Years Post Treatment				-.159	.065	-.356	-2.45	0.19
Total FCR				.003	.010	.041	.285	.777

Note: R^2= R-squared; R^2 *Change* = R-square change; B = unstandardized beta value; SE = Standard errors of B; β = standardized beta value; Statistical significance = p < .01

Hypothesis 6

Hierarchical multiple regression was performed to assess the ability of Fear of Cancer Recurrence to predict Hospitalisations, after controlling for age at diagnosis, cancer detected via smear test, health insurance and years post treatment. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity. Furthermore, the correlations between predictor variables (Age at Diagnosis, Cancer detected via smear, Health Insurance, Years post Treatment) were examined and these are presented in Table 11. None of the predictor variables significantly correlated with Hospitalisations and all correlations were weak ranging between r = -.29 to .26. Tests for multicollinearity also indicated that all Tolerance and VIF values were in an acceptable range. These results indicate that there was no violation of the assumption of multicollinearity and that the data was suitable for multiple linear regression analysis.

Table 11

Correlations between all continuous variables

Variable	1.	2.	3.	4.	5.	6.
1. Hospitalisations	-					
2. Age at Diagnosis	-.01	-				
3. Detected via Smear	.06	-.12	-			
4. Health Insurance	.26	.01	.02	-		
5. Years Post Treatment	-.29	-.14	.14	.01	-	
6. Total FCR	.08	-.03	-.07	-.06	-.18	-

Note: Statistical significance = p < .01

Step 1 of the hierarchical multiple regression included the entry of four predictor variables: Age at Diagnosis, Cancer detected via smear, Health Insurance and Years post Treatment. This model was not statistically significant F (4, 41) = 2.00; p =.113, and explained 16.3% of variance in Hospitalisations. Following the entry of total fear of cancer recurrence at Step 2 the total variance explained by the model as a whole, was 16.5% (F (5,40) = 2.16; p=.187). Fear of cancer recurrence explained an additional 0.2% of the variance in Hospitalisations after controlling for Age at Diagnosis, Cancer detected via smear, Health Insurance and Years post Treatment, R squared change = .002, F change (1, 40) = .098, p=.756, remaining non statistically significant in the final model. (see table 12).

Table 12

Hierarchical Multiple Regression Model predicting Hospitalisations

Variable	*R*	R^2	R^2 *Change*	*B*	*SE*	*β*	*t*	*p*
Step 1	.404	.163						
Age at Diagnosis				-.009	.031	-.043	-.293	.771
Detected via Smear Test				.231	.349	.096	.662	.512
Health Insurance				.629	.349	.258	1.80	.079
Years Post Treatment				-.154	.072	-.313	-2.15	.037
Step 2	.404	.165	.002					
Age at Diagnosis				-.009	.031	-.040	-.273	.787
Detected via Smear Test				.235	.353	.098	.666	.510
Health Insurance				.635	.353	.260	1.80	.080
Years Post Treatment				-.150	.074	-.304	-2.04	.048
Total FCR				,004	,011	.046	.312	.756

Note: R^2= R-squared; R^2 *Change* = R-square change; B = unstandardized beta value; SE = Standard errors of B; β = standardized beta value; Statistical significance = p < .01

Discussions

The goal of this body of work was to address the gap in currently available literature by examining the relationship between fear of cancer recurrence in Irish cervical cancer survivors and the use of Irish health care system. Two separate aims were investigated, the first examined at what point post treatment survivors experience higher levels of fear of cancer recurrence and the second sought to identify if a relationship exists between fear of cancer recurrence in Irish cervical cancer survivors and their use of Irish health systems while controlling for differences in age at diagnosis, if the cancer was detected via the cervical screening system, having health insurance and years post treatment.

Results of this study did indeed support the first hypothesis that levels of fear of cancer recurrence would decrease the greater the time since treatment, therefore the null hypothesis was rejected. Group three, who were seven to ten years post treatment reported lower levels of fear of cancer recurrence than those in the first two groups ranging from zero to six years post treatment. These results are in contrast to those observed in previous research (Mehta, Lubeck, Pasta, & Litwin, 2003) in which they identified initially lower levels of fear of cancer recurrence after treatment as they stated patients may have felt some control over their own health following their choices in relation to treatment and surgeries. Furthermore, fear of cancer recurrence remained fairly consistent over time for all three groups, and still posed a substantial burden six years after treatment. Although seven to ten years after treatment reported lower levels of fear of cancer recurrence, the results were only 11 points lower on mean scores reported for the first two groups.

To test the second aim, it was hypothesised, Cervical cancer survivors with high levels of fear of recurrence will have high health care system usage. However, identification of the low internal consistency of the health care utilisation questionnaire led to each question generating its own scale resulting in additional hypotheses 2 (H2) through 6 (H6). Each of these five hypotheses were not supported by the results as higher levels of fear of cancer recurrence did not predict increased Out-Patients Visits, Specialist Visits, Other Health Care Visits, Accident and Emergency Visits or Hospitalisations. In all instances, as the alternative hypothesis was not supported, the null hypothesis was accepted. The results of the current study reveal that there is no relationship between Fear of Cancer Recurrence and Health Care Use in Irish Cervical Cancer survivors.

These results are wholly inconsistent with previous research, Lebel et al., (2013) reported higher levels of fear of cancer recurrence resulting in more frequent A&E visits and Outpatients Visits, particularly in female cancer survivors. Cannon et al., (2011), also reported cancer survivors with greater fear of cancer recurrence engaging in care seeking behaviour and an increasing need to see a health care provider, they described these increased check-ups as a positive behaviour change. Yet, the current study found no relationship between fear of cancer recurrence and health care use. These results are surprising as medical appointments are an integral part of the care plan for cancer survivors, however a large number of participants were reporting zero across all health care usage which is reflected in their mean scores.

High levels of fear of cancer recurrence were recorded in the current study which is well documented to correlate with mental distress, fatigue, neuroticism, lower quality of life, self-esteem and coping (Skaali, et al., 2009), yet they are not engaging in the same reassurance seeking from medical and psychosocial professionals, a behaviour identified in other cancer survivors (Cannon et al., 2011; Hawkins et al., 2010; Lebel et al., 2013; Sarkar et al., 2015). In previous studies, different cancer survivors (prostate, lung, breast and colorectal) were examined simultaneously and none of the population were cervical cancer survivors, this study is the first to examine this population exclusively which could explain the differences observed in results.

Implications

Existing literature in relation to cervical cancer survivors is scant; furthermore, in an Irish context this literature is non-existent. The solitary results of the current study are significant with high levels of fear of cancer recurrence being reported by cervical cancer survivors, up to six years post treatment therefore, additional research is required within this health system domain. Furthermore, programmes such as The National Cancer Control Programme (NCCP) survivorship programme, are tasked with providing community cancer support centres that offer assistance inclusive of psychological support for survivorship (Grealy, & Love, 2020). Should the NCCP expand the parameters of is survivorship support to include those who are a number of years post treatment they could address the higher levels of fear of cancer recurrence in this group. Also, from a clinical perspective, early detection of clinical levels of fear of cancer recurrence would enable the development of interventions to effectively treat it, allowing cervical cancer survivors to heal and not still experience adverse effects six years after their treatment.

Strengths. Limitations and Future Research

The foundational aspect of this study is the main strength. To the authors knowledge, no previous work has investigated Irish cervical cancer survivors, their levels of fear of cancer recurrence and/or their relationship with health care use. A search of ‘Lenus’, the leading source for Irish research in health and social care was conducted, with zero results returned in relation to cervical cancer survivors. This study is not just filling a gap in literature, it is laying the flagstone. Not only have cervical cancer survivors been shown to be more emotionally distressed and have a worse quality of life (Gonçalves, 2010), but also, Irish cervical cancer survivors have expressed their distrust for the Irish health care system, (Scally, 2018). Lack of trust in health care has been associated with poorer health outcomes, a reduction in adherence to medical recommendations and a reduction in trusting behaviours

(Gopichandran, 2013; Graham, Shahani, Grimes, Hartman, & Giordano, 2015). Therefore, identifying attitudes of cervical cancer survivors toward health care is both imperative and justified.

Furthermore, the current study was conducted during the Covid- 19 Pandemic which as a strength is a snapshot into cervical cancer survivor's behaviour in relation to health care use during a pandemic and results recorded can act as comparisons. However, at the same time, it is a limitation, due to the inaccessibility of healthcare during the pandemic. Non-essential health services were suspended for a time with only acute cancer services being provided from the end of April 2020 (Rialtas Na hÉireann, 2020). Data also supports a drop off in available health care usage during the pandemic, McDonnell et al., (2020) identified a 27 – 62% reduction in attendance in Accident and Emergency departments. Therefore, results observed in the current study may not be accurately reflecting the health care use of this population. Future research conducted in post pandemic Ireland may provide more accurate results in relation to health care use.

Additional limitations identified include, the low recruitment rate for the study (8.34%), therefore, results may not be generalisable to all Irish cervical cancer survivors. This low recruitment rate, also calls for the significant F ratio recorded for H1 to be treated with caution, owing to the result likely been driven by the drastically low number of participants in the seven to ten years post treatment group. Furthermore, the 'CBMTG Healthcare Utilization Questionnaire', had incredibly low internally consistency (α=0.29) and did not account for online access to health care which experienced rapid expansion during the Covid-19 Pandemic (Mann, Chen, Chunara, Testa, & Nov, 2020). Future research should include the collection of online and telemedicine data as a form of health care usage. Finally, the naturalistic, cross-sectional design of the study prevents the inference of causality; a longitudinal study, measuring health care use in a continuous manner would be a more appropriate measure to adequately address the research question posed in this study.

Conclusion

The current study expands current literature in relation to fear of cancer recurrence and cancer survivors and it fills a gap in literature investigating the relationship between fear of cancer recurrence and health care use. The study found no relationship between fear of cancer recurrence and health care use in cervical cancer survivors in Ireland, however, high levels of fear of cancer recurrence were identified up to six years post treatment. These high levels of fear of cancer recurrence have been associated with mental distress, fatigue, neuroticism, lower quality of life, low self-esteem and low coping abilities (Skaali, et al., 2009) which needs to be addressed in order to remove ‘‘*Damocles' Sword*” from above the necks of cervical cancer survivors and allow these women heal. Implementing early detection of clinical levels of fear of cancer recurrence and development of interventions to effectively treat it, coupled with greater access to the NCCP survivorship resources are two examples to assist recovery. Future studies may benefit from identifying attitudes of cervical cancer survivors towards the health care system, measuring health care use in a continuous manner, and conducting the research in a post pandemic Ireland.

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Appendix A

Participant Information sheet

Fear of Cancer Recurrence and Utilisation of the Irish Health Care System

I would like to invite you to take part in a research study. Please read the below information before you decide if you would like to participate. It is required that you understand why the research is being done and what it would involve for you. Take your time to read the information, and please feel free to ask any questions you may have. Once you have completed this information page of frequently asked question, if you decide not to take part, I thank you for your time and there is no further engagement required. If you choose to take part, please just click the link to the questionnaires in the post and follow the instructions.

Who are you? What this study is about?

My name is Laura Curran and I am a final year BA (Hons) in Psychology student of the National College of Ireland. I am conducting this study as part of my final year project. The overall aim of this study is to investigate if a relationship exists between fear of cancer recurrence and a Cervical Cancer survivor use of the Irish Health Care System.

What will taking part involve?

This study is conducted using an online survey system. If you choose to take part, you click the link to the questionnaires in the original post in the private group forum. You will be asked to complete a consent form before continuing onto two separate questionnaires. They take no more than 15 minutes to complete. You will not be required to have any further involvement outside of the completion of the questionnaires.

Who has been Invited to Take Part?

We are asking females over the age of 18 years who have received a diagnosis of Cervical Cancer in the last ten (10) years to take part. You must have received your diagnosis and treatment in Ireland, be now cancer free, not have a recurrence of Cervical Cancer or a metastatic cancer at the time of the completion of the questionnaire.

Am I required to take part?

This study is completely voluntary, you do not have to take part if you do not want to. If you do choose to take part, you can withdraw from the study at any stage without the need to explain why and without prejudice. All you have to do is close out of the questionnaire. The information collected is completely anonymous and once you complete both the questionnaires, you will ask to press the submit button. You will be unable to withdraw from the study once you complete this step.

What are the possible risks and benefits of taking part?

As this study is building on current research, there is the possible benefit that the study may highlight areas that further support should be given to Cervical Cancer Survivors. Another possible benefit is this study could lead to additional research in the actual economic costs of cervical cancer to the Irish Health System.

It is important to note that there is a small risk of your engagement with the questionnaires reminding you of difficult times during your own Cancer journey. Should you feel sad, fearful or overwhelmed following this, please contact any of the below organisations for assistance.

Irish Cancer Society	Email: cancernurseline@irishcancer.ie	Ph. 1800 200 700
Marie Keating Foundation	Cancer support contact number	Ph. 01 6283726

Will my information be confidential?

Confidentiality will be assured for all who participate. The survey will only require your age and year of diagnosis and the questionnaires do not require any identifiable information. The surveys can be completed on your own time in the privacy of your own home if you wish. There is no requirement for the researcher to meet or speak with you.

However; If for any reason there is a strong belief that there is a risk of harm to a participant or if a serious crime has been committed, all data will be made available to the relevant authorities.

How will information you provide be recorded, stored and protected?

Your information will be recorded, stored and protected in line with the European Communities (Electronic Communications Networks and Services) (Privacy and Electronic Communications) Regulations 2011 (http://www.irishstatutebook.ie/eli/2011/si/336/)

The online survey platform will store your information in an accredited data centre before securely transferring it to the researcher using encryption algorithms and strength. Your unidentifiable information will be stored in an electronic file for analysis with only the researcher and their supervisor having access.

What will happen to the results of the study?

Once the information from the Questionnaires have been collated, they will be included in the researcher’s final year project and submitted to the National College of Ireland for review.

Please feel free to contact either of the below for further information:

Laura Curran	David Mothersill
Student researcher	Supervisor
X17137144@student.ncirl.ie	david.mothersill@ncirl.ie

Thank you for your time.

Appendix B

Consent Form

Fear of Cancer Recurrence and Utilisation of the Irish Health Care System

1. I voluntarily agree to participate in this research study.

2. I understand that even if I agree to participate now, I can withdraw at any time up to submitting the information by clicking out of the questionnaire or refuse to answer any question without any consequences of any kind.

3. I have read the information sheet provided and understand the purpose and nature of the study I have also had the opportunity to ask questions I may have had.

4. I understand that participation involves the completion of an online study with two questionnaires that should take no more than 15minutes to complete and that there is no further involvement required from me.

5. I understand that I will not benefit directly from participating in this research and no monetary reward will be received by me.

6. I understand that all the information I provide for this study will be treated confidentially.

7. I understand that if I inform the researcher that myself or someone else is at risk of harm, they may have to report this to the relevant authorities.

8. I understand that there is a risk that the study could remind me of my cancer journey and remind me of upsetting feelings. I understand I can contact either the Irish Cancer Society or the Marie Keating foundation in relation to this.

9. I understand that consent forms will be retained in an electronic file until the exam board confirms the result of the student researcher's final year project and only the student researcher and supervisor having access to it during this time. They will then be destroyed in line with the European Communities (Electronic Communications Networks and Services) (Privacy and Electronic Communications) Regulations 2011 (http://www.irishstatutebook.ie/eli/2011/si/336/)

10. I understand that I am free to contact any of the people involved in the research to seek further clarification and information from their details below:

Laura Curran	David Mothersill
Student researcher	Supervisor
X17137144@student.ncirl.ie	david.mothersill@ncirl.ie

Do you give consent to take part in this study?

Yes *No*

Appendix C

Participant Debrief sheet

Fear of Cancer Recurrence and Utilisation of the Irish Health Care System

Thank you for taking the time to participate in this study. This sheet will provide you with an outline of the details of the study you have just completed.

The purpose of this study is to investigate if a relationship exists between fear of cancer recurrence and a Cervical Cancer survivor use of the Irish Health System. You were asked to participate in this study as you were over 18 years of age, had a Cervical Cancer diagnosis in the last ten years and were diagnosed and treated in the Irish Health System. You completed two questionnaires during the study and are not required to engage any further with this study. The data you submitted will be used in a final year BA (Hons) in Psychology project for the National College of Ireland.

As previously advised, this study was completed online therefore once you clicked on submit you are unable to withdraw from the study. Confidentiality can be assured with consent forms and study data stored separately online and will be destroyed in accordance with European Communities (Electronic Communications Networks and Services) (Privacy and Electronic Communications) Regulations 2011 (http://www.irishstatutebook.ie/eli/2011/si/336/) once the exams board has graded the final year project.

Should your engagement with the questionnaires remind you of difficult times during your own Cancer journey and you are feeling sad, fearful or overwhelmed following this, please contact any of the below organisations for assistance.

Irish Cancer Society	Email: cancernurseline@irishcancer.ie	Ph. 1800 200 700
Marie Keating Foundation	Cancer support contact number	Ph. 01 6283726

Once again thank you for your participation, should you have any further question, please use the contact details below.

Laura Curran	David Mothersill
Student researcher	Supervisor
X17137144@student.ncirl.ie	david.mothersill@ncirl.ie

Appendix D

Demographic and Health Information

Current Age: ________

Do you have health insurance?

☐ Yes
☐ No

Age at Diagnosis: ___________

Was your diagnosis and treatment carried out in an Irish Hospital?

☐ Yes
☐ No

Was your cervical cancer detected via a routine smear test?

☐ Yes
☐ No

Please check all that apply to you:

☐ I am still receiving treatment
☐ I am in remission
☐ I have Cervical Cancer recurrence
☐ I have metastatic disease (disease has spread to other parts of the body)

I am:

☐ 0-3 years post Cervical Cancer treatment
☐ 4-6 years post Cervical Cancer treatment
☐ 7-10+ years post Cervical Cancer treatment.

Appendix E

Fear of Cancer Recurrence Inventory

Most people who have been diagnosed with cancer are worried, to varying degrees, that there might be a recurrence of the cancer. By recurrence, we mean the possibility that the cancer could return or progress in the same place or in another part of the body. This questionnaire aims to better understand the experience of worries about cancer recurrence. Please read each statement and indicate to what degree it applied to you DURING THE PAST MONTH by circling the appropriate number.

0	1	2	3	4
Never	Rarely	Sometimes	Most of the Time	All of the time

The following situations make me think about the possibility of cancer recurrence:

1. Television shows or newspaper articles about cancer or illness 0 1 2 3 4
2. An appointment with my doctor or other health professional 0 1 2 3 4
3. Medical examinations (e.g. annual check-up, blood tests, X-rays) 0 1 2 3 4
4. Conversations about cancer or illness in general 0 1 2 3 4
5. Seeing or hearing about someone who is ill 0 1 2 3 4
6. Going to a funeral or reading the obituary section of the paper 0 1 2 3 4
7. When I feel unwell physically or when I am sick 0 1 2 3 4
8. Generally, I avoid situations or things that make me think about the possibility of cancer recurrence 0 1 2 3 4

0	1	2	3	4
Not at all	A Little	Somewhat	A Lot	A Great Deal

9. I am worried or anxious about the possibility of cancer recurrence 0 1 2 3 4
10. I am afraid of cancer recurrence 0 1 2 3 4
11. I believe it is normal to be worried or anxious about the possibility of cancer recurrence 0 1 2 3 4
12. When I think about the possibility of cancer recurrence, this triggers other unpleasant thoughts or images (such as death, suffering, the consequences for my family) 0 1 2 3 4
13. I believe that I am cured and that the cancer will not come back 0 1 2 3 4
14. In your opinion, are you at risk of having a cancer recurrence?

0	1	2	3	4
Not at all at risk	A Little at risk	Somewhat at risk	A Lot at risk	A Great Deal at risk

15. How often do you think about the possibility of cancer recurrence?

0	1	2	3	4
Never	A Few times a Month	A Few times a Week	A Few times a Day	Several Times a Day

16. How much time do you spend thinking about the possibility of cancer recurrence?

0	1	2	3	4
I don't think about it	A few seconds	A few minutes	A few hours	Several hours

17. How long have you been thinking about the possibility of cancer recurrence?

0	1	2	3	4
I don't think about it	A few Weeks	A few Months	A few Years	Several Years

0	1	2	3	4
Not at all	A Little	Somewhat	A Lot	A Great Deal

When I think about the possibility of cancer recurrence, I feel:

18. Worry, Fear or Anxiety 0 1 2 3 4
19. Sadness, discouragement or disappointment 0 1 2 3 4
20. Frustration, anger or outrage 0 1 2 3 4
21. Helplessness or resignation 0 1 2 3 4

My Thoughts or fears about the possibility of cancer recurrence disrupt:

22. My social or leisure activites (e.g. outings, sports, travel) 0 1 2 3 4
23. My work or everyday activities 0 1 2 3 4
24. My relationships with my partner, my family, or those close to me 0 1 2 3 4
25. My ability to make future plans or set life goals 0 1 2 3 4
26. My state of mind or mood 0 1 2 3 4
27. My Quality of life in general 0 1 2 3 4

0	1	2	3	4
Not at all	A Little	Somewhat	A Lot	A Great Deal

28. I feel that I worry excessively about the possibility of cancer recurrence 0 1 2 3 4
29. Other people think that I worry excessively about the possibility of cancer recurrence 0 1 2 3 4
30. I think that I worry more about the possibility of cancer recurrence than other people who have been diagnosed with cancer 0 1 2 3 4

0	1	2	3	4
Never	Rarely	Sometimes	Most of the Time	All of the time

When I think about the possibility of Cancer Recurrence, I use the following strategies to reassure myself:

31. I call my doctor or other health professional 0 1 2 3 4
32. I go to the hospital or clinic for and examination 0 1 2 3 4
33. I examine myself to see if I have any physical signs of cancer 0 1 2 3 4
34. I try to distract myself (e.g. do various activities, watch television, read, work) 0 1 2 3 4
35. I try not to think about it, to get the idea out of my mind 0 1 2 3 4
36. I pray, meditate or do relaxation 0 1 2 3 4
37. I try to convince myself that everything will be fine or I think positively 0 1 2 3 4
38. I talk to someone about it 0 1 2 3 4
39. I try to understand what has happened and deal with it 0 1 2 3 4
40. I try to find a solution 0 1 2 3 4
41. I try to replace this thought with a more pleasant one 0 1 2 3 4
42. I tell myself to "stop it" 0 1 2 3 4

Appendix F

Health Care Utilisation Questionnaire

Adapted CBMTG Healthcare Utilization Questionnaire (Schultz, 2011)

(A) Health Care Visits

Please read about the following types of health care visits before completing this form:

1) Outpatient clinic visit: Visits which occur in a clinic where patients can be assessed by a doctor, a specialist, or other health care professional AND/OR have a procedure such as blood work, dressing change, IV medication, blood transfusion, biopsy, etc. Usually the doctors and health care professionals have specialized training in the field of cancer and/or hematopoietic stem cell transplant. An outpatient visit may involve anything from a brief assessment to several procedures and/or several assessments.
2) Specialist visit: A visit to a doctor with specialized training (haematologist, cardiologist, surgeon, psychiatrist, dermatologist, etc) at a location other than an outpatient clinic.
3) Other health care visit: A visit to any of the following health care professionals: family doctor, nurse practitioner, pharmacist, psychologist, physiotherapist, naturopath, massage therapist, chiropractor or dietician at a location other than an outpatient clinic.
4) Emergency Room (A&E) visit: A visit to the Emergency Department of a hospital.

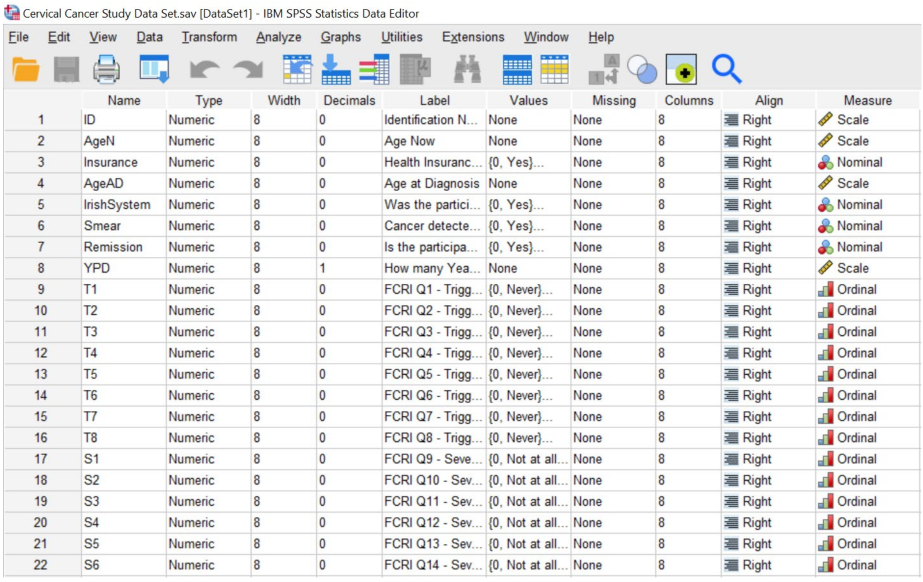
During the past 12 months:

1. How many times have you had an outpatient clinic visit? ______
2. How many times have you had a specialist visit? ______
3. How many times have you had any other health care visit? ______
4. How many times have you had an Emergency Room visit? ______
5. (Not admitted overnight — If admitted count as a "hospitalisation".)

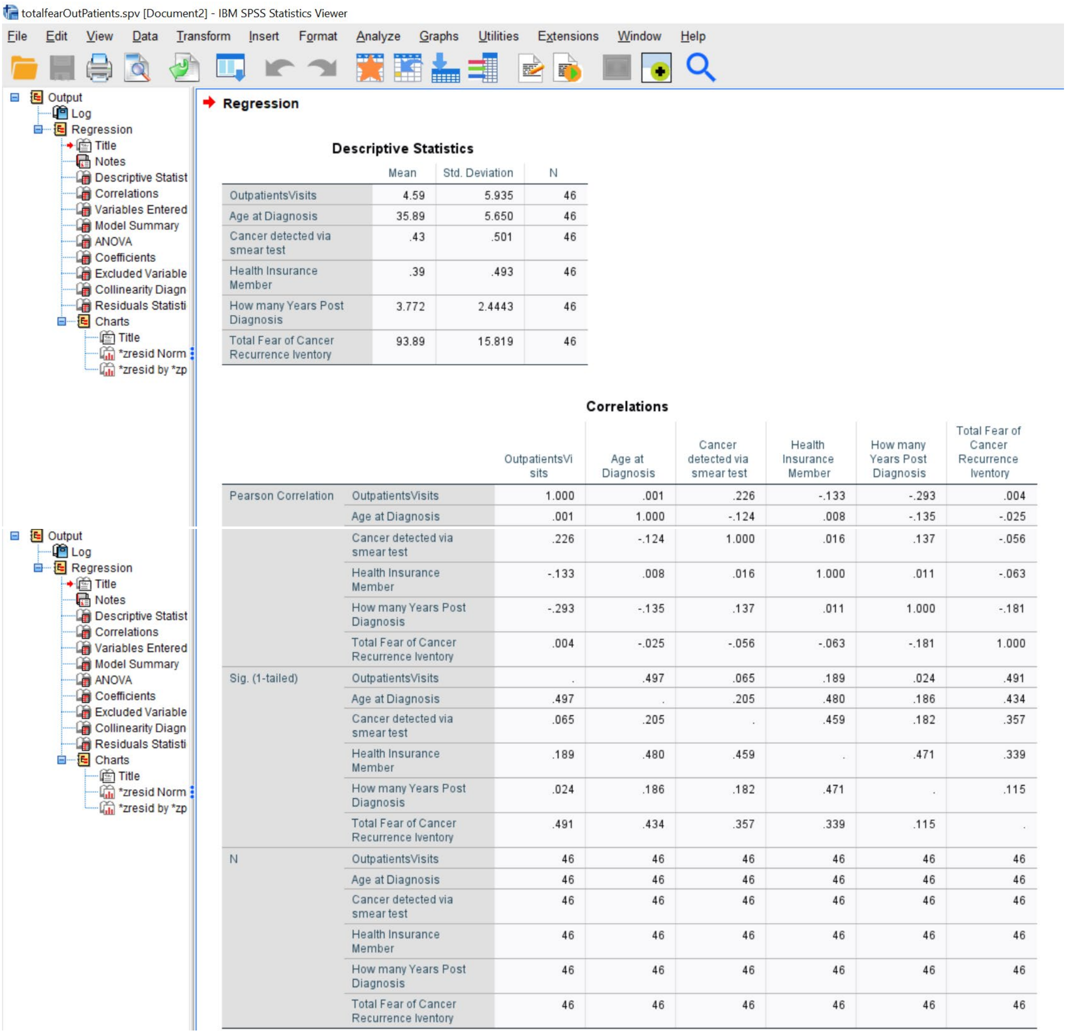
B) Hospitalisations How many times have you been admitted to a hospital overnight? ______

Appendix G

Evidence of data and SPSS output with full data file available on request.



	Name	Type	Width	Decimals	Label	Values	Missing	Columns	Align	Measure
1	ID	Numeric	8	0	Identification N...	None	None	8	Right	Scale
2	AgeN	Numeric	8	0	Age Now	None	None	8	Right	Scale
3	Insurance	Numeric	8	0	Health Insuranc...	{0, Yes}...	None	8	Right	Nominal
4	AgeAD	Numeric	8	0	Age at Diagnosis	None	None	8	Right	Scale
5	IrishSystem	Numeric	8	0	Was the partici...	{0, Yes}...	None	8	Right	Nominal
6	Smear	Numeric	8	0	Cancer detecte...	{0, Yes}...	None	8	Right	Nominal
7	Remission	Numeric	8	0	Is the participa...	{0, Yes}...	None	8	Right	Nominal
8	YPD	Numeric	8	1	How many Yea...	None	None	8	Right	Scale
9	T1	Numeric	8	0	FCRI Q1 - Trigg...	{0, Never}...	None	8	Right	Ordinal
10	T2	Numeric	8	0	FCRI Q2 - Trigg...	{0, Never}...	None	8	Right	Ordinal
11	T3	Numeric	8	0	FCRI Q3 - Trigg...	{0, Never}...	None	8	Right	Ordinal
12	T4	Numeric	8	0	FCRI Q4 - Trigg...	{0, Never}...	None	8	Right	Ordinal
13	T5	Numeric	8	0	FCRI Q5 - Trigg...	{0, Never}...	None	8	Right	Ordinal
14	T6	Numeric	8	0	FCRI Q6 - Trigg...	{0, Never}...	None	8	Right	Ordinal
15	T7	Numeric	8	0	FCRI Q7 - Trigg...	{0, Never}...	None	8	Right	Ordinal
16	T8	Numeric	8	0	FCRI Q8 - Trigg...	{0, Never}...	None	8	Right	Ordinal
17	S1	Numeric	8	0	FCRI Q9 - Seve...	{0, Not at all...	None	8	Right	Ordinal
18	S2	Numeric	8	0	FCRI Q10 - Sev...	{0, Not at all...	None	8	Right	Ordinal
19	S3	Numeric	8	0	FCRI Q11 - Sev...	{0, Not at all...	None	8	Right	Ordinal
20	S4	Numeric	8	0	FCRI Q12 - Sev...	{0, Not at all...	None	8	Right	Ordinal
21	S5	Numeric	8	0	FCRI Q13 - Sev...	{0, Not at all...	None	8	Right	Ordinal
22	S6	Numeric	8	0	FCRI Q14 - Sev...	{0, Not at all...	None	8	Right	Ordinal



Regression

Descriptive Statistics

	Mean	Std. Deviation	N
OutpatientsVisits	4.59	5.935	46
Age at Diagnosis	35.89	5.650	46
Cancer detected via smear test	.43	.501	46
Health Insurance Member	.39	.493	46
How many Years Post Diagnosis	3.772	2.4443	46
Total Fear of Cancer Recurrence lventory	93.89	15.819	46

Correlations

		OutpatientsVisits	Age at Diagnosis	Cancer detected via smear test	Health Insurance Member	How many Years Post Diagnosis	Total Fear of Cancer Recurrence lventory
Pearson Correlation	OutpatientsVisits	1.000	.001	.226	-.133	-.293	.004
	Age at Diagnosis	.001	1.000	-.124	.008	-.135	-.025
	Cancer detected via smear test	.226	-.124	1.000	.016	.137	-.056
	Health Insurance Member	-.133	.008	.016	1.000	.011	-.063
	How many Years Post Diagnosis	-.293	-.135	.137	.011	1.000	-.181
	Total Fear of Cancer Recurrence lventory	.004	-.025	-.056	-.063	-.181	1.000
Sig. (1-tailed)	OutpatientsVisits	.	.497	.065	.189	.024	.491
	Age at Diagnosis	.497	.	.205	.480	.186	.434
	Cancer detected via smear test	.065	.205	.	.459	.182	.357
	Health Insurance Member	.189	.480	.459	.	.471	.339
	How many Years Post Diagnosis	.024	.186	.182	.471	.	.115
	Total Fear of Cancer Recurrence lventory	.491	.434	.357	.339	.115	.
N	OutpatientsVisits	46	46	46	46	46	46
	Age at Diagnosis	46	46	46	46	46	46
	Cancer detected via smear test	46	46	46	46	46	46
	Health Insurance Member	46	46	46	46	46	46
	How many Years Post Diagnosis	46	46	46	46	46	46
	Total Fear of Cancer Recurrence lventory	46	46	46	46	46	46