A review of the support services availed of by newly diagnosed cancer survivors who attended a cancer support centre.

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Abstract

Purpose

This audit aims to review and explore the support needs of those newly diagnosed with cancer who attended a cancer support centre over a two year period; 2018-2019. There are currently over 40 cancer support centres registered with the Charity Regulator in Ireland. As far as we are aware, this is the first study of its kind in Ireland to explore and analyse the support needs of newly diagnosed survivors who attended a cancer support centre.

Method

Prospective data in terms of gender, age demographic, diagnosis, socio-economic status and supports availed of were drawn from information retrieved from Jan 1st 2018 to Dec 31st 2019

Results

333 patients newly diagnosed with cancer attended the Cuisle Cancer Support Centre over the audit period. Women were more inclined to utilize the centre. The 50–59 age-group attended the centre most often. Women with breast cancer and men with prostate cancer accounted for the majority of contact in terms of diagnosis. Counselling and reflexology were the most common therapies availed of. Socio-economic status was challenging to determine but 12% of patients met with the welfare officer during the audit period. ‘Word of mouth’ and friend or family generated most referrals.

Conclusions

The Cuisle Cancer Support Centre embraces the opportunity to promote patient involvement in their self-management and living well beyond the cancer diagnosis. This audit will also demonstrate that the centre is not only a confidential, safe place for people to share their cancer experience but a contemporary, proactive, dynamic centre that promotes a positive survivorship message.

Keywords: cancer, support, survivorship.

INTRODUCTION

One in three people in Ireland will develop cancer during their lifetime; the National Cancer Strategy 2017-2026 predicts that the number of cases of cancer will increase over the period of the Strategy, and is expected to almost double by 2040 (DoH 2017). It is estimated that cancer treatment will have one or more physical and/or psychological consequences on 25% of cancer survivors with potential long-term effects on their wellbeing to a lesser or greater degree. The elderly, those who are poor, isolated or living alone are likely to have the greatest need (DoH 2017). As a result, the National Cancer Control Programme (NCCP), recommended that the development and implementation of dedicated survivorship programmes could have a profound impact on the quality of life of many who are living with the effects of a cancer diagnosis (DoH 2017).

The Cuisle Cancer Support Centre is a purpose built, state of the art centre which was established in 2004 in order to address the support needs of the local community affected by cancer in Co. Laois. The National Cancer Strategy (DoH 2017) recognises the necessity for high quality support services that provide much needed support to patients outside of the acute care setting. The strategy also highlighted that while the majority of cancer survivors live well and do not have significant on-going needs, many survivors face diverse and serious health care issues (DoH 2017). The Cuisle Cancer Support Centre provides a walk in and telephone/text service Monday-Friday 9am – 5pm. Interactive help online is available via the centre's website: www.cuislecentre.com and email (info@cuislecancersupportcentre.ie). The centre also has a social media presence in the form of Facebook, Instagram and Twitter where clients may contact the service via private message on those platforms if they so wish. A qualified oncology nurse is supported by a medical director and is available to all attendees. On contacting the service; clients are offered a confidential assessment by the nurse, their needs and expectations are discussed and an individual survivorship care plan is established. It is envisaged that this care plan compliments the patient's treatment summary as recommended by the NCCP (DoH 2017). Some of the therapies provided include; reflexology, counselling and psychotherapy, mindfulness, yoga, art, nutrition among many other programmes such as Thrive & Survive, staying well at home, bereavement support, men and women's groups which are all provided free of charge.

The Cuisle Cancer Support Centre aims to provide responsible, evidence-based information in confidence to people concerned about cancer. The service provides the public with access to a comprehensive range of information ranging from diagnosis, treatment to specific information relating to the cancer experience and survivorship. While we recognise that caregivers and family are greatly impacted by a loved one's cancer diagnosis; this study will however, focus on those who have been newly diagnosed themselves in terms of gender, age demographic, diagnosis, socio-economic status and supports availed of. Additionally, it is hoped that the audit will provide insight into what prompts the public to seek support.

BACKGROUND

More than 40,000 people are diagnosed with cancer in Ireland every year (NCRI 2019). With improving treatments, people are living much longer after their diagnosis. With better survival, cancer survivorship has become an emerging area of care (Kith 2017). Cancer Survivorship can now be defined as a distinct period that commences at diagnosis and continues throughout the patient's lifespan (Shapiro 2020). The National Coalition for Cancer Survivorship selected the words "cancer survivor" to convey two important messages: a message of hope for life after cancer, and a message to consider what happens beyond treatment (Ullman, 2014).

As cancer survivorship is an emerging concept; a literature review generated few studies evaluating the role of support centres in promoting survivorship. Much of the literature suggests that cancer patients have unmet needs in relation to their physical, financial, relationship, and emotional wellbeing. (Carey et al 2012, Harrison et al 2011, Hodgkinson et al 2007, Kahn et al 2011). Andrykowski et al (2008) highlight that having access to available cancer support services in the patient's community can be a valuable resource. Lepore (2001) suggests that cancer survivors cope better with the stress and burden of the cancer experience within a supportive social environment, one which facilitates the person to cognitively and emotionally process their cancer experience.

METHODOLOGY

Due to the confidential nature of the Cuisle Cancer Support Centre, basic client profile information such as the patient's age group, geographical location and gender are recorded on the MindaClient database. In order to evaluate client profile, prospective data for this review were drawn from the information retrieved on the database from Jan 1st 2018 to Dec 31st 2019. In order to determine caller profile and utilisation, data extrapolated from the database were limited to gender, age group, diagnosis, socio-economic status and support sought. Determining socio-economic status will be discussed in greater detail later but for the purpose if this study was based on the patients' employment status. Details on what prompted the contact to the Cuisle Centre were also retrieved in order to inform future awareness strategies. Some fields within the database were not recorded and will not feature in this review.

RESULTS –

333 patients newly diagnosed with cancer attended the Cuisle Cancer Support Centre over the audit period, 23% (n = 75) were men. The 50–59, and 60-69 patient age groups (female) utilized the service most often and accounted for 45% (n=105) of female contact (Fig. 1). The 50–59 age group of male patients tended to

utilize the Cuisle Cancer Support Centre most often, accounting for 29% (n=20) of male contact (Fig. 1). 43% (n=139) of patients who availed of the Cuisle Cancer Centre's services were employed. In keeping with the age-group demographic, 36% (n=116) were retired (Fig. 2).

Women with a diagnosis of breast cancer accounted for 54% (n = 137) of female contact with the centre (Fig. 3). One man with breast cancer utilised the centre during the audit period. Gender specifically, cervical and ovarian accounted for 6% (n=16) of female contact. 25% (n=19) of men who utilised the service had prostate cancer (Fig. 4). Contact from patients with colorectal cancer accounted for 7% (n=22) of all contact.

The Cuisle Cancer Support Centre offers 32 different types of touch/non-touch therapies and support programmes to patients and their families. Many avail of more than one support service, figures 5, 6 & 7 depict the 5 services most commonly availed of by patients. Counselling was availed of by 36% (n=121) of patients who attended the centre (Fig. 5). 50% (n=167) of patients availed of reflexology (Fig.6). It is important to highlight that most patients availed of these therapies more than once. Support programmes are run on a cyclical basis apart from the citizen's information service which is available as required. The centre ran four Thrive & Survive programmes during the time-frame and 12% (n=40) patients availed of citizens advice (Fig. 7).

When details of what prompted contact to the service were recorded; 24% (n=71) were 'word of mouth' or a friend; 15% (n=44) which highlights the nature of the service within the community (Fig. 8). Some 22% (n=64) of the public learnt of the service at their hospital, 14% (n=40) of survivors were referred by their General Practitioner (GP). Miscellaneous publicity accounted for the remainder of the contact and of those of heard of the service through social media 5% (*n*=16) or a leaflet, 1% (*n*=4).

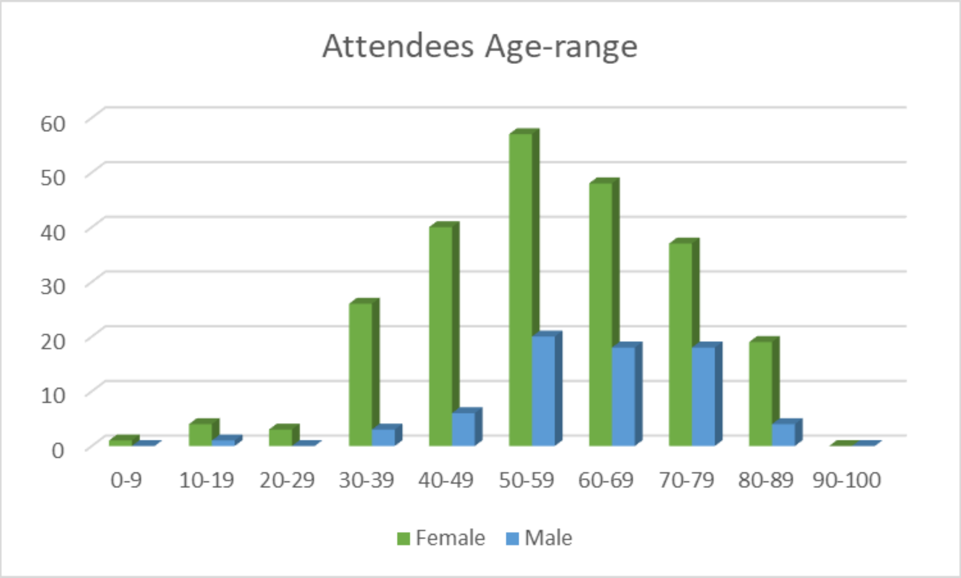

Figure 1. Newly diagnosed patient's age-range.

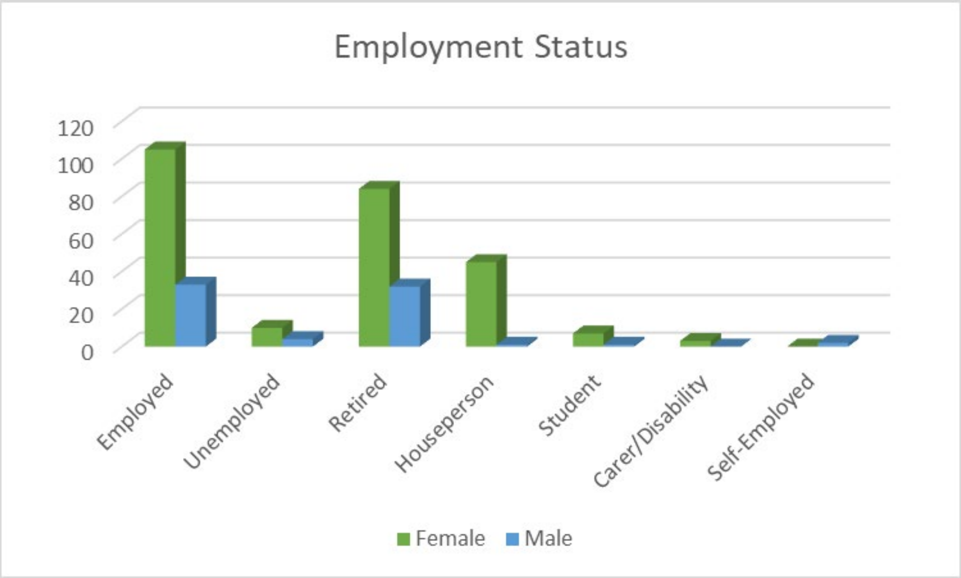

Figure 2. Employment Status for newly diagnosed patients who attended the centre.

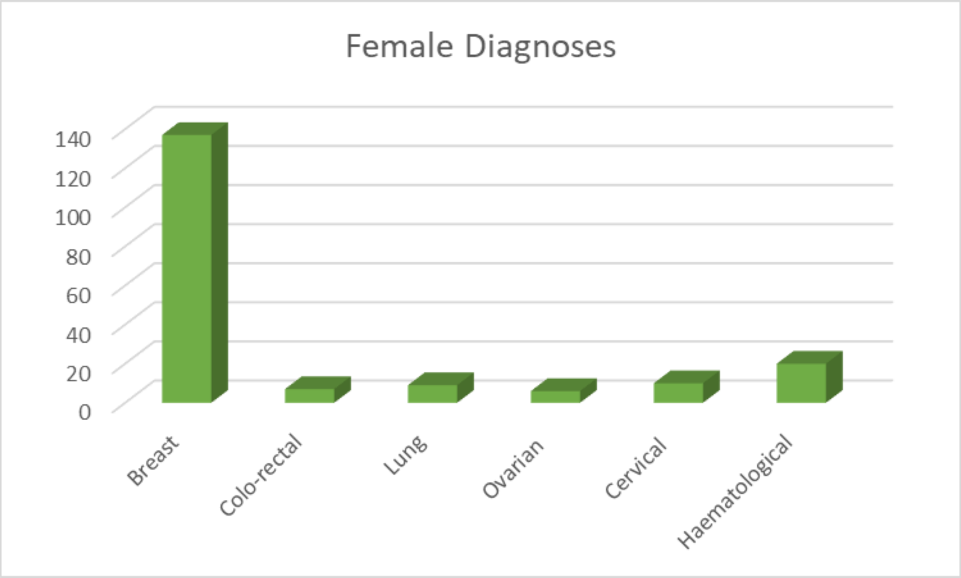

Figure 3. The 5 most common diagnoses for females who attended the Centre.

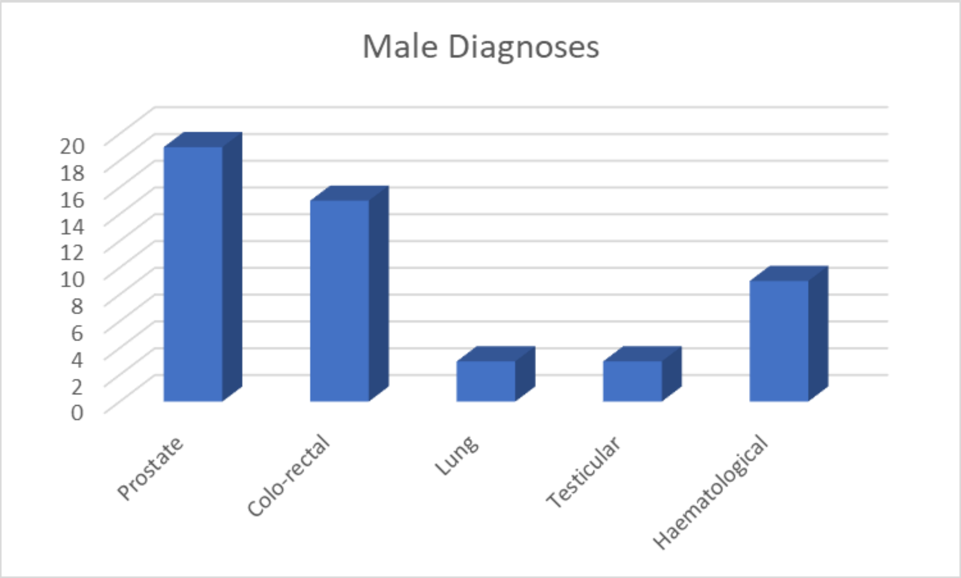

Figure 4. The 5 most common diagnoses for men who attended the Centre.

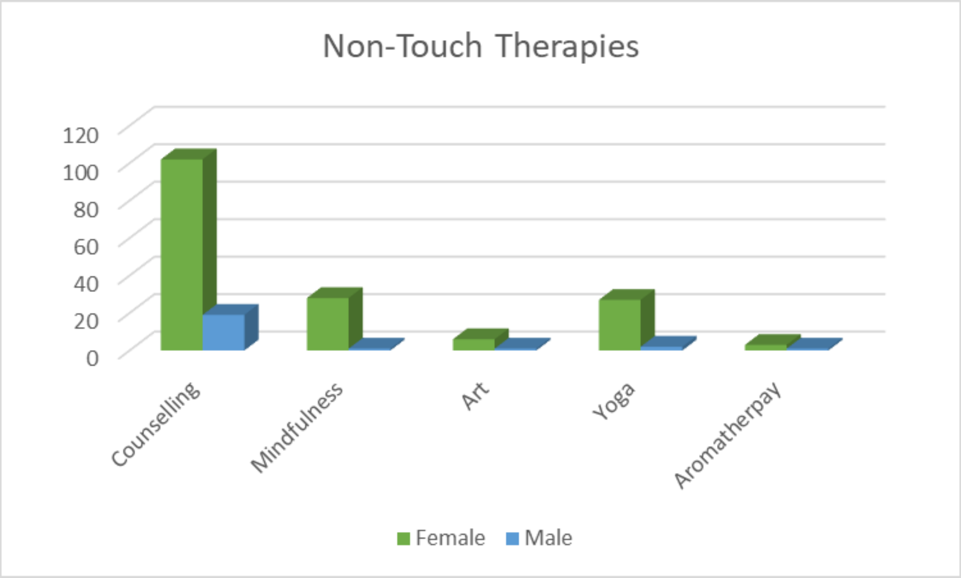

Figure 5 . The five most common non-touch therapies availed of by newly diagnosed patients.

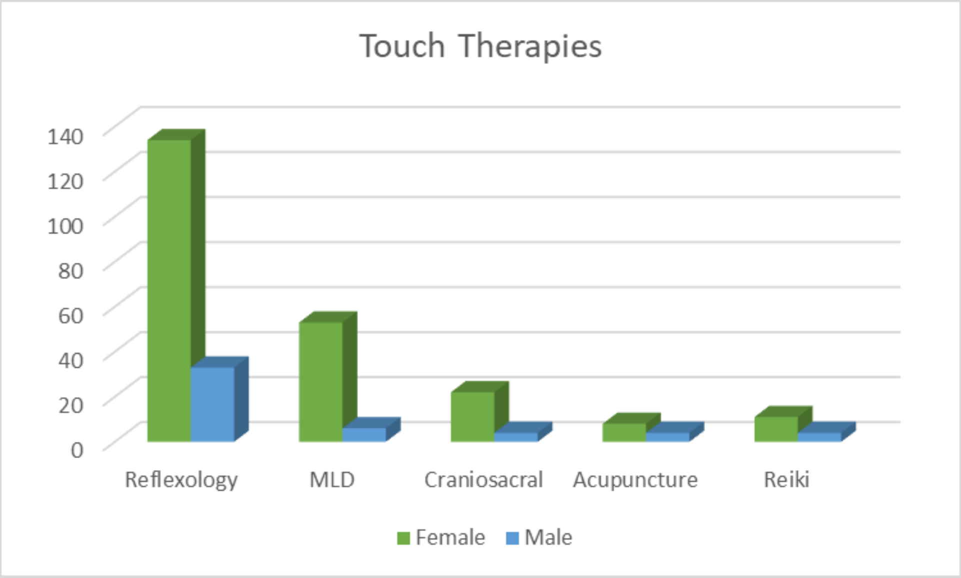

Figure 6. The five most common touch therapies availed of by newly diagnosed patients.

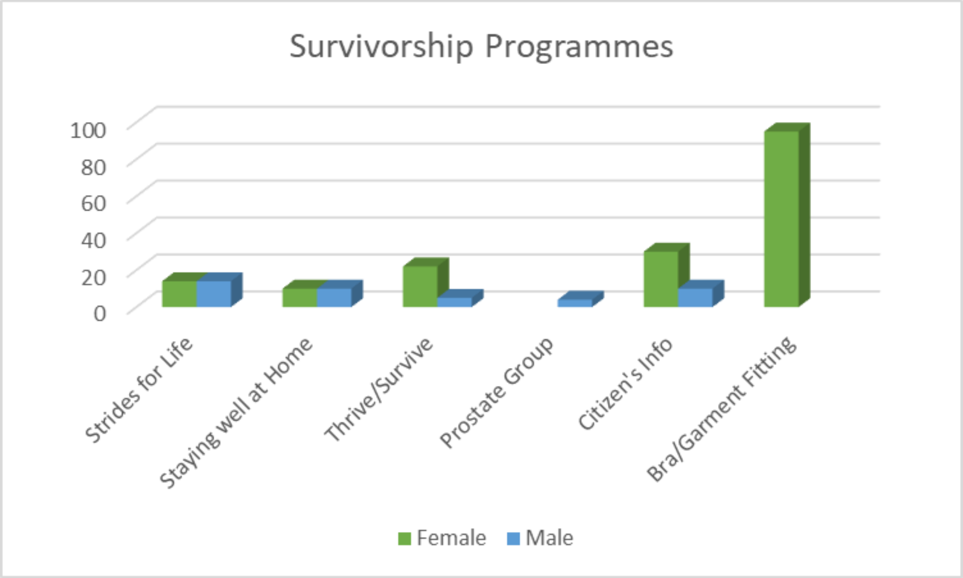

Figure 7. The five most common support programmes availed of by newly diagnosed patients.

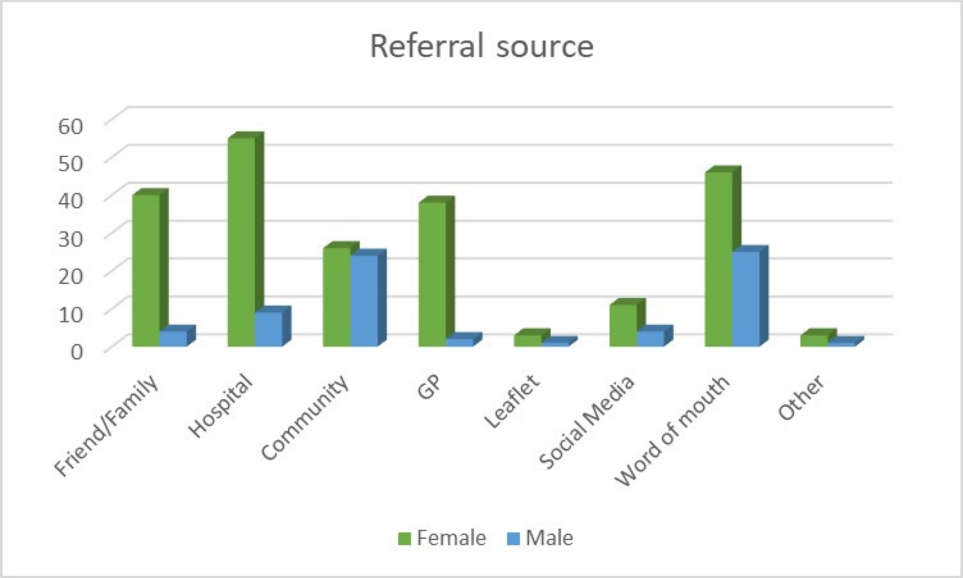

Figure 8. Details of what prompted newly diagnosed patients to attend the centre.

DISCUSSION

Davidson and Lloyd (2001) outline that gender, culture, ethnicity and number of socio-economic variables including education, occupation, income and access to care influence information access. Given the variables that influence health and the diverse nature of society, it must be considered what strategies are appropriate to promote cancer survivorship. The literature revealed that overall women were generally more inclined to engage in help seeking behaviour. (Banks, 2001, Chapple & Ziebland 2002, Gough, 2013, White, 2001). In keeping with these findings, 77% (*n*=258) of patients who attended the Cuisle Cancer Support Centre during the timeframe, were female in comparison with 23% (*n*=75) of males. This is concerning as National Cancer Research Ireland (NCRI) found that the age adjusted risk for developing cancer is overall 22% higher in men than for women (excluding non-melanoma skin cancers), (NCRI 2019). Banks (2001) found that men are aware of strategies to improve their health but are reluctant to access information. Scholfield et al (2000) found that men were more inclined to seek help for physical health related issues rather than mental or emotional wellbeing and Denner (2000) found that men tended to lean on their partners and friends for support. Indeed 57% (n=43) of men who attended the centre were married, 25% (n=19) of those were referred by a friend or family. Galdes et al (2004) however, cautions against stereotyping men as all behaving in the same way and having no interest in their health. We also need to consider that more people are seeking health information online and for men the internet is often the first place they will look for help (Pollard 2007). Indeed our Facebook insights showed that our Cuisle Cancer Support Centre page reached 30% of men in May 2020. Anecdotally, we find that men tend to radiate more toward the proactive survivorship support systems such as Strides for Life, Staying Well at Home and Thrive & Survive. Oancea & Cheruvu (2016) outline that survivorship care plans show short and long term benefits to cancer survivors' overall psychological well-being. The NCCP (DoH 2017) hopes to implement treatment summary and survivorship care plans which are completed by the cancer specialist in partnership with the patient. A treatment summary includes an explanation of the patient's cancer diagnosis, dates of treatment and treatment description (ASCO 2015). A survivorship care plan consists of follow-up care instructions and is important for cancer survivors to prevent, manage, and treat any complications that may arise as a result of their cancer history (Oancea & Cheruvu 2016). Survivorship care plans could appeal to men's proactive nature and ties in nicely with promoting patients to be active participants in the care in line with the vision of the NCCP (DoH 2017). Our goal as a centre would be to create a supportive relationship with the patient and their loved ones to be part of their survivorship care plan in partnership with their specialists.

The National Cancer Survivorship Needs Assessment (Mullen & Hegarty 2019) suggests that further research is warranted to examine the unmet needs of cancer survivors in terms of socio-economic status. Our audit used employment to status to determine socio-economic status. Other international studies

(Barbeau et al 2004, Adlrich et al 2013) used postcode, level of education, income level and occupation to evaluate socio-economic status. Postcode does not generally determine socio-economic status in Ireland. The Central Statistics Office (2011) classifies the entire population into 10 socio-economic groupings based on the level of skill and education required for their occupation (for those at work, unemployed or retired). All others are classified based on the person they are dependant on (CSO 2011). Figure 2 classifies the employment status of patients who attended the Cuisle centre between 2018 – 2019. The Pobal Haase Pratschke (HP) Deprivation Index is compiled from various censuses and presents an area-based deprivation measure for Ireland. A score is given to the area based on a national average of zero and ranging from approximately -35 (being the most disadvantaged) to +35 (being the most affluent). The results indicate that the absolute deprivation score for County Laois declined from -1.2 in 2006 to -9.3 in 2011 (LCDC 2016). Information regarding socio-economic status can be a sensitive subject and may not always be immediately apparent. We are aware of our responsibility as a support centre though to gather this information in order to reach all socio-economic groups. We are also cognoscente that 52% (n=173) of the survivors who attended during the audit period live rurally. Generally we will outline to patients what support services are available to them including welfare advice or citizen's information. 12% (n=40) patients met with the welfare officer during the audit period. The Cuisle centre also provides an outreach education service to the local schools, prison, travelling community and men's shed in order to promote our service to all socio-economic groups.

The audit revealed that 36% (n=121) of patients who attended the Cuisle centre availed of professional counselling. The Irish Cancer Society kindly funds a free professional counselling which is available to anyone who has been affected by a cancer diagnosis. Figure 7 illustrates the most commonly availed of support programmes availed of at the Cuisle centre. Thrive & Survive is a Stanford University evidence based self-management structured programme with the aim of supporting cancer survivors to deal with the impact of cancer and improve their quality of life. This programme is supported by the NCCP and the Cuisle centre held four separate 6 week programmes during the audit period. Other survivorship programmes which are facilitated include; an early menopause workshop, a prostate group and a living life/secondary cancer programme where patients can avail of the opportunity to share in the knowledge and experience of a healthcare professional and others who have been through diagnosis and treatment.

Figure 3 illustrates that women with breast cancer accounted for 45% (n=105) of all patients who utilised the Cuisle Centre and fell within 50–69 age groups (Fig. 1). This is in keeping with the NCRI (2019) that cancer prevalence is highest for breast cancer (23% of all cancer survivors). In addition to the aforementioned menopause workshop, the Cuisle Centre offers Manual Lymphatic Drainage (MLD) a prosthesis and bra fitting service to assist patients in their recovery. Patients with haematological cancers accounted for 9% (n = 29) of patients and given the variety; further specific analysis is indicated. As stated earlier all patients are assessed by a qualified oncology nurse on arrival at the centre and a survivorship care plan is put in place. Generally patients wish to discuss their diagnosis and/or treatment options, some are concerned regarding the implications on their quality of life. We always remind patients that we do not have access to their clinical notes and specific questions should be directed to their clinical specialist doctor or nurse. The necessity for a standardized treatment summary and survivorship care plan is apparent and we look forward to the implementation of same as recommended by the Cancer plan (DoH 2017).

Word of mouth prompted 24% (n=71) of patient referrals to the Cuisle Centre. As stated previously, the Cuisle centre has been part of the local community since 2004 and on questioning patients 'just knew of the service' or a friend/family member had recommended them (15% n=44). Referrals from community palliative care teams and public health nurses and other therapists are represented as 'community' in the audit and accounted for 17% (n=50) of referrals. We maintain good relationships with all our colleagues in the acute and community settings and encourage visits to the Cuisle centre and provide a bi-annual newsletter with updates on our services. Social media is also an important platform for us to reach and maintain relevance with both patients and healthcare colleagues. There is however a dearth of research into this area and particularly in relation to outcomes from social media interaction and more research is warranted. We always remain cognoscente of our responsibility to maintain confidentiality and adhere to General Data Protection Regulations (GDPR) guidelines. 35% (*n*=104) of the patients identified the GP or healthcare professional at the hospital as the person who prompted them to contact the service. Anecdotally, particular GP's and healthcare professionals favor referral and positive patient feedback generates more referrals.

RECOMMENDATIONS

The impact of socioeconomic status and deprivation on death rates from some cancers in Ireland is undeniable (DoH 2017). Future studies need to examine how a range of factors such as ethnicity, age, sexuality, socioeconomic status influence engagement with support services. Reducing health inequalities and ensuring equitable access to all patients in Ireland irrespective of age, geographic location and socioeconomic status is a key priority of the Cancer Plan (DoH 2017). The audit provides no insight into as to who may underutilize the service in terms of race, ethnicity or sexual orientation. The audit was not designed to elicit these data, but future evaluation should address this shortcoming in order to sufficiently inform all social groups in the community. Data collection relies on the quality of the data input and this significantly influences the information retrieved. We recognise the limitations of our database and plans are in place to enhance data collection in order to extrapolate pertinent, informative, quality unambiguous data particularly in relation to socio-economic status. The Cuisle centre plans to implement a cancer support evaluation study later this year may be feasible to attain this information through optional disclosure within a questionnaire. Additionally, further research is indicated to determine if psychological, social and physical outcomes are influenced as a result of utilising a support service such as this.

The NCRI (2019) found that Prostate cancer accounted for 23% of all cancer survivors in Ireland yet only 25% (*n* =19) of men with prostate cancer attended the Cuisle centre during the audit period. Strategies to reach men are currently under consideration such as working with our healthcare professional colleagues, the NCCP and Men's Health Ireland. Further research should explore differences and similarities between groups of men and within individual men. Clearly, there is much research opportunity in the area of communication and support using the forum of social media. It must be acknowledged also that inequalities regarding internet access and use exist.

Efforts are in place to promote our role in partnership with healthcare providers to enhance the patient's survivorship journey in line with the Irish Government's Slainte Care initiative; Right Care, Right Place, Right Time (DoH 2019). The Cuisle Centre maintains good relationships with healthcare professionals working in the acute centres and local community and plan to continue to promote our work and build relationships through site visits at clinical and non-clinical level. Further research is warranted to examine health professional's attitudes and behaviors towards cancer support centres.

It is important to highlight that this study was limited to newly diagnosed patients who attended the Cuisle Centre during the audit period. An additional 351 former patients attended and 488 carers and relatives with a total of 1172 attendees over the two year period. Further research is warranted to explore the support needs and outcomes for relatives and carers who attended the centre.

CONCLUSION

The majority of attendees to the centre were women but those men who did attend radiated towards the survivorship programmes. Counseling and reflexology were the most common therapies availed of. 12% of patients sought welfare advice and this audit has highlighted the necessity for the centre to reach all socio-economic groups. 'Word of mouth' and friends or family generated most referrals. The NCCP (Mullan & Hanan 2019) published a Cancer Survivorship Needs Assessment with the aim of developing an appropriate model of survivorship healthcare for Ireland. The report agreed with international consensus that the traditional model of oncologist and cancer centre follow-up care is not sustainable and nurse-led models and programmes appeared to address survivorship care components (Mullen & Hanan 2019). We would envisage broadening the survivorship care plan incorporating social prescribing and linking in with GPs and both local and national health promotion activities. The Cuisle Centre would embrace the opportunity to work with the DoH, the NCCP, the Irish Cancer Society, our healthcare professional colleagues and other support centres to promote patient involvement in their self-management and living well beyond the cancer diagnosis.

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Declarations of competing interest

None declared

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