

# Examining the impact of a social prescribing service for individuals living with and beyond cancer: A feasibility study







#### **Research Team**

Professor Deirdre Connolly, Principle Investigator, Discipline of Occupational Therapy, Trinity College, Dublin

Ms. Roisin Ryder, Health Development Coordinator, Fatima Groups United, Fatima Family Resource Centre

Ms. Adrienne Dempsey, Social Prescribing Link Worker, Fatima Groups United, Fatima family resource centre

Ms. Chloe O'Hara: Research Assistant, Discipline of Occupational Therapy, Trinity College, Dublin

Dr. David Robinson, Local Asset mapping project (LAMP), Mercer Institute for Successful Ageing, St. James' Hospital

Professor John Kennedy, Medical Oncology, St. James' Hospital

Dr. Cliona Grant, Medical Oncology, St. James' Hospital

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# Summary

Background: Early diagnosis and improved access to treatments has resulted in improved survival from cancer by 1% per year with currently over 150,000 cancer survivors in Ireland (Department of Health, (DOH), 2017). However, many cancer survivors experience continuing difficulties with pain, fatigue, anxiety, depression and cognitive difficulties following treatment that impact on engagement in work, leisure and social activities (Player, MacKenzie, Wills & Loh, 2014). Social prescribing is a community-based service that supports individuals with chronic diseases to access activities, services and supports in their community (South et al., 2008). It has potential to offer accessible, community-based support to individuals living with and beyond cancer to facilitate engagement in a variety of activities and services to reduce the impact of their diagnosis on health and well-being (Macmillan Social Prescribing Service, 2018). Research is required to test this possibility.

**Methodology:** The aims of this study were (i) to explore the impact of social prescribing on the health and well-being of individuals living with and beyond cancer and (ii) to examine the acceptability of social prescribing to individuals living with and beyond cancer. To achieve these aims a mixed methods study design was utilised which consisted of a pre-post quantitative design and individual semi-structured qualitative interviews.

Quantitative data were collected using self-reported outcome measures:

- The Frenchay Activities Index (FAI) (Holbrook & Skilbeck, 1983)
- The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983)
- The Multidimensional Assessment of Fatigue (MAF) (Belza, 1995)
- The European Organisation for Research and Treatment of Cancer Quality-of-Life
   Questionnaire Core-30 (EORTC QLQ-C30) (Aaronson et al., 1993)

Ethical approval for the study was obtained from St. James' Hospital Research Ethics Committee. Study participants were recruited through St. James's Hospital Oncology Day Ward and Outpatients Clinics; cancer-support services, local primary care teams and GP practices.

**Results:** Forty-three participants were recruited to the study and completed preintervention measures. Sixteen participants (37%) were lost to follow-up. Twenty-seven participants completed self-reporting questionnaires at post-intervention follow-up and engaged in a qualitative interview at the same time point. Descriptive statistics and inferential statistics were carried out using SPSS. Significant results were observed from baseline to ten-week follow-up in frequency of participation in leisure and work activities (p = 0.001), total activity participation levels (p = 0.005), depression (p = 0.025), fatigue-related distress (p = 0.045) and functional quality of life (p = 0.000).

Study participants reported a lack of follow-up care post-treatment to manage persistent symptoms and identified barriers to activity participation following cancer treatment, including health-related challenges and lack of information regarding suitable activities and support services. Social prescribing was considered an acceptable intervention to support individuals, particularly post-treatment, in identifying and attending both cancer-specific and community-based services and activities. Study participants identified the friendly and helpful personality of the link worker as an important element in facilitating activity engagement. They identified health benefits of improved mood and increased motivation from attending socially prescribed activities. Individuals who had previously engaged with cancer services identified the benefits of attending activities within community centres and with non-cancer populations, as this enabled them to feel a return to "normal living".

**Conclusion:** Social prescribing resulted in significant improvements in mental, physical and social health of individuals living with and beyond cancer in this feasibility study. It was considered an acceptable self-management intervention by study participants to facilitate access to a range of health-related activities in their community. Limitations of the study moderately small sample size for a mixed-methods study, and challenges recruiting to a relatively unknown community-based intervention. However, the findings of this study support a larger study to establish the effectiveness of social prescribing for improving the mental, physical and social health of individuals living with and beyond cancer. Cost

effectiveness of social prescribing and the resource implications for voluntary and community organisations is also required.

### Introduction

Social prescribing is a community-based service that supports individuals with health and social care needs to access activities, services and supports in their community (South et al., 2008). It enables healthcare professionals to refer individuals with chronic diseases to a link worker, who has knowledge and links to voluntary and third-sector organisations that can meet the needs of these individuals in the community (Bickerdike, Booth, Wilson, Farley & Wright, 2017). Social prescribing has emerged as an answer to burdened healthcare systems by stimulating the growth of stronger links between primary healthcare services and voluntary sector support (South, Higgins, Woodall & White, 2008).

A variety of social prescribing models have been recorded in the literature; some initiatives are provided by the voluntary sector in community centres, others are provided by health service commissioners in GP practices, and others still represent a partnership between the primary health and voluntary sectors in community wellbeing hubs (Dayson & Bennett, 2016). Despite the variety of available models, the process of social prescribing appears to be relatively similar across projects (Bickerdike et al., 2017). A social prescribing link worker, (also known as a community navigator, facilitator, co-ordinator or connector) meets with an individual to establish their activity preferences and interests. The link worker identifies opportunities within the individual's community to engage in preferred activities and supports the individual in attending the activity, including accompanying the individual to their chosen activity if required (Kilgarriff-Foster & O'Cathain, 2015).

There are a wide variety of activities that individuals may be referred to through a social prescribing service, including (but not limited to) exercise-based activities; arts groups such as painting or dance groups; counselling; computer technology classes; green activity/ecotherapy; volunteering; housing support; and self-help/peer support groups (Bickerdike, et al., 2017). There is emerging evidence that social prescribing may provide benefits to a range of health and wellbeing outcomes, including improved quality of life and emotional wellbeing (Chatterjee, Camic, Lockyer & Thomson, 2017; Moffatt, Steer, Lawson, Penn & O'Brien, 2017a).

In Ireland, cancer survivorship rates have increased — in the past decade, the percentage of people who survive five years post-diagnosis has risen from 45% to 61% (Department of Health, 2017). There are currently more than 150,000 cancer survivors in Ireland and it is estimated that by 2020, one in twenty people will be a cancer survivor (Department of Health, 2017). There has been some debate around the use of the term 'cancer survivor' and a definition of when a person with cancer becomes a 'survivor' (Hewitt, Greenfield & Stovall, 2006). According to the National Cancer Strategy 2017-2026, cancer survivorship is determined to begin at the time of diagnosis and continue until end of life and therefore that is the definition that shall be used throughout this review (Department of Health, 2017).

Cancer survivors experience continuing symptoms such as pain, fatigue, anxiety, depression and cognitive difficulties following treatment (Shneerson et al., 2013). These symptoms can impact on survivors' performance of daily activities, thus preventing them from engaging in activities of importance to them (Player, MacKenzie, Wills & Loh, 2014). This can affect survivors' quality of life and overall health and wellbeing (Shneerson et al., 2013). With economic and time constraints affecting the provision of post-treatment services, it is becoming difficult for hospital-based services in Ireland to meet the needs of cancer survivors (Naidoo, Hayes, Teo, Calvert, Horgan & O'Connor, 2013).

There appears to be no published studies within the current literature that explore the impact of social prescribing for individuals living with and beyond cancer, however, in the UK a summary evaluation report by the Macmillan Social Prescribing Service (2018) shows promising results. The service addresses the health and wellbeing needs of individuals with cancer by supporting access to community and voluntary services, improving quality of life and well-being and reducing demand on health services. Early findings from this social prescribing service for individuals living with and beyond cancer suggest that social prescribing could support cancer survivors to access community-based activities and services that may be beneficial to their health and wellbeing and may reduce some of the

difficulties associated with a cancer diagnosis. However, further research is warranted to determine the potential impact of social prescribing for individuals living with and beyond cancer and to gather the perspectives of service-users.

The purpose of this study therefore was to establish the feasibility of social prescribing as a community-based intervention to improve mental and physical health of individuals living with and beyond cancer. Specific objectives were:

- To examine the impact of a social prescribing service on the physical and mental health of individuals living with and beyond cancer
- To explore the feasibility and acceptability of a social prescribing service for individuals living with and beyond cancer

# Study context

A social prescribing service was established in the Fatima family resource centre, the F2 centre, in 2018. It offers social prescribing services to residents of Rialto and is delivered two days per week. The service receives referrals mainly from primary care teams in Dublin 8 and older adult services in St James' Hospital. This current study involved an expansion of the Fatima-based social prescribing service by two days/week to provide a social prescribing service specifically for people living with and beyond cancer.

# Study design

The Medical Research Council (MRC) recommends a phased approach in assessing the effectiveness of a complex intervention starting with a feasibility study and progressing to a definitive intervention study (Craig et al., 20008). Feasibility studies are carried out to test interventions, identify suitable outcome measures and to examine the acceptability of an intervention (Thabane et al. 2010). This study was therefore a feasibility study of social prescribing for individuals living with and beyond cancer.

The design for this study was a convergent parallel mixed methods design. This was considered suitable for the exploratory nature of the study (Creswell, 2011). The quantitative phase was a quasi-experimental design to measure self-reported physical and mental health outcomes following attendance at a social prescribing service. The qualitative phase explored participants' experiences and perspectives of social prescribing. Ethical approval was provided by St. James' Hospital Research Ethics Committee.

#### Sample

#### Eligibity criteria

- Individuals with a cancer diagnosis over 18 years who have completed cancer treatment/s
- Expressed an interest in accessing recreational, self-development, educational and/or exercise-focused activities in their community
- Living in Dublin 2, 4, 6, 8, 10, 12, 20, 22 or 24 postal areas

#### **Recruitment process**

As this was a feasibility study, a sample size was not calculated (Thabane et al. 2010). However, over the 12-month period of the study it was hoped to recruit approximately 50 - 60 people into the study. As social prescribing is relatively recent in Ireland, many of the SJH oncology staff were not familiar with the rationale for, or the referral pathway for social prescribing. Therefore, during the initial period of the PI and research assistant met with numerous oncology staff across all departments of SJH, including the SJH Daffodil Centre, to explain the purpose and process of social prescribing. They also discussed with staff at what stage of cancer treatment did they believe that social prescribing would be appropriate, and relevant, for individuals living with and beyond cancer. In other words, when might individuals be receptive to social prescribing and when might they be physically and/or emotionally ready to participate in social prescribing activities. Staff in all these departments were provided with participant information leaflets (PIL) on the study and requested to provide them to individuals who were eligible for inclusion in the study. Meetings also

occurred with primary care team (PCT) members in the eligible postal areas, including GPs in Rialto, and information leaflets were supplied to PCT members to give to eligible participants in their catchment areas. The PI and research assistant attended SJH oncology day wards, oncology outpatient clinics and psycho-oncology services weekly in order to meet potential social prescribing participants if requested. Contact details of the PI and research assistant were provided in the PIL and individuals were invited to make contact if interested in receiving further details of the study and/or to participate in the study.

#### Data collection methods

The Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) is a 14-item self-report measure that assesses levels of anxiety and depression for use in a non-psychiatric outpatient setting. It consists of two subscales for anxiety and depression with each item rated on a 4-point scale (0 = not at all, 3 = yes definitely), with a maximum total score of 21 for each subscale, with higher scores indicating higher distress. This measure has been validated with a variety of cancer populations (Hartung, et al., 2016).

Quality of life scale: EORTC QLQ-C30. This is a self-report questionnaire that measures the impact of disease and clinical treatment on individual's quality of life (Aaronson, et al., 1993). It has strong psychometric properties relevant to different cancer-patient populations (Ringdal and Ringdal, 2000). The QLQ-C30 includes fifteen subscales grouped into three domains: Global Quality of Life, Functional Quality of Life and Symptoms.

The Frenchay Activities Index (FAI) measures frequency of engagement in community, social and instrumental activities of daily living. It consists of three subscales: domestic, leisure/work and outdoor activities (Holbrook and Skilbeck, 1983) Scores range from 0-45 with higher scores indicating greater activity engagement and has strong internal consistency ( $\alpha$ =0.83), criterion and construct validity and test-retest reliability (r=0.96).

Multidimensional Assessment of Fatigue (MAF) is a 16-item self-report measure of fatigue (Belza, 1995) across four dimensions: severity, distress, frequency, impact on activities of daily living, and global fatigue. Higher scores indicate greater fatigue. The MAF is suitable for individuals with cancer-related fatigue and has strong reliability and validity (Meek et al., 2000).

Quantitative data were collected by the researchers at the initial meeting of participants and the link worker (Time 1). Informed consent was obtained from study participants at the start of the meeting. Follow-up quantitative data were collected eight to ten weeks following the initial meeting with the link worker and research team (Time 2).

Qualitative data were collected through semi-structured interviews. Individual interviews are the most frequently used data collection method in qualitative studies (Stein et al., 2013). An interview guide asked participants to identify activities they attended in their community following their meeting/s with the link worker and if/how these activities impacted on their health and well-being. They were also asked of their experience of the social prescribing process.

#### Data analysis

Quantitative data were analysed using SPSS 21, the statistical package for social science program, (SPSS, Inc., Chicago). Descriptive and inferential statistics were used to describe the study participant demographics and analyse differences between outcome measures at the two assessment periods, (Portney & Watkins, 2009).

Qualitative data were analysed using a content analysis approach to identify commonalities and differences in participants' experiences and perceptions of social prescribing. Within a content-analysis framework, a deductive and inductive approach was used compare findings of this study to previously reported research on social prescribing (deductive analysis) and

to identify new findings related to social prescribing for cancer survivors (inductive analysis) (Elo & Kyngas, 2008).

# Results

Over the study period, 43 individuals agreed to participate in the study. These individuals were recruited from a variety of services with whom the PI and research assistant met during the initial study period (Table 1).

Table 1: recruitment sites for forty-three study participants

Recruitment Site	Frequency	Percentage
SJH Outpatient Oncology Clinics	29	68
SJH Oncology Day Ward	4	9
Cancer Support Service	4	9
Participant Information Leaflets in the Community	3	7
GP Practices	2	5
Primary Care Services	1	2
Total	43	100

All 43 participants completed baseline assessments however 27 individuals completed both pre and post-social prescribing questionnaires and participated in an interview. Sixteen participants were lost to follow-up. See Figure 1 for reasons for this.

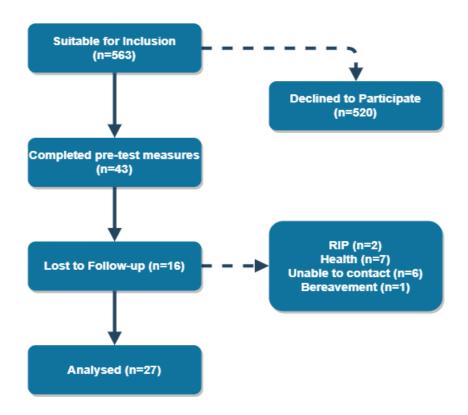


Figure 1: Study recruitment and attrition

#### Demographic profile

The majority of participants were female (n=19,70%). The mean age of participants was 57 years ( $\pm$  16.4). Most participants (n=15,56%) were living with at least one member of their family, while the remainder (n=12,44%) lived alone. Thirteen participants (48%) were married. Twelve participants (44%) had third level education and nineteen (70%) were not working at the time of the study.

#### Participants' cancer diagnosis and treatment

Breast cancer (n = 12, 44%) was the most common type of cancer diagnosis, both overall and among females, while bowel cancer (n = 3, 11%) was the most common cancer among male participants (Figure 2).

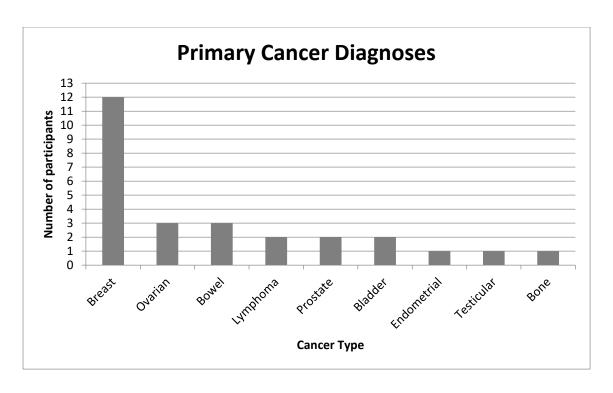


Figure 2: Frequency of primary cancer diagnoses

Participants were asked to indicate the time since receiving their primary cancer diagnosis (Table 2). Most participants (n=14, 51.9%) had received their cancer diagnosis up to five years prior to participation in the study, with a minimum time of two months and a maximum period of eight years.

Table 2: Years since primary cancer diagnosis

	Number of participants	Frequency
<1 year	8	29.6%
1-5 years	14	51.9%
>5 years	5	18.5%
Total	27	100%

Participants were asked if they were attending any community activities prior to commencement of the study. Twelve participants (44%) reported that they were participating in community-based activities (Table 3).

Table 3: Activities attended prior to social prescribing

Activity Type	Number of participants	Frequency
Attending cancer support	3	11.1%
services		
Arts, crafts & music	3	11.1%
Physical activity	2	7.4%
Volunteering	2	7.4%
Relaxation-based	1	3.7%
Education	1	3.7%
None	15	55.6%
Total	27	100%

Twenty-seven participants completed outcome measures prior to and eight weeks following their final contact with the link worker. All measures showed improvements in total and category scores following social prescribing. There were statistically significant improvements in the total score of the Frenchay Activities Index (FAI) (p=0.005). On examining the FAI categories, participation in the 'work/leisure' activities demonstrated statistically significantly improvements (Table 4).

Table 4: T1 and T2 median scores and statistical significance difference testing outcomes

Measure	Time 1 (T1) median score	Time 2 (T2) SP scores	p-value	
	(IQR)	(IQR)		
FAI				
Domestic	13 (4)	14 (3)	0.317	
Leisure/Work	8 (2)	10 (3)	0.001*	
Outdoors	11 (2)	11 (2)	0.282	
Total FAI	32 (6)	35 (6)	0.01*	
HADS				
Anxiety	8 (8)	5 (6)	0.10	
Depression	5 (5)	2 (4)	0.025*	
EORTC QLQ-C30		,		
Fatigue severity	5 (3.5)	4 (4)	0.11	
Fatigue-related	4 (5)	2 (3)	0.04*	
distress				
Interference of	3.11 (4)	2 (2.4)	0.21	
fatigue with ADL				
Global Fatigue Index	24.56 (19.8)	17.89 (16.4)	0.12	

Table 3: Self-reported outcome measures

The HADS consists of two scales: Anxiety and Depression. A score of above seven in either category indicates 'caseness' of anxiety or depression. There was a statistically significant improvement in the 'Depression' scale of the HADS before and after social prescribing and the median anxiety score reduced from above to below the cut-off score for 'caseness' after social prescribing. On examining fatigue-related outcomes of social prescribing, the category of 'Distress caused by Fatigue' reduced significantly.

<sup>\*</sup>Statistically significant at p<0.005

The functional category of the EORTC QLQ-C30 includes physical, emotional, role, cognitive and social functioning. This category improved significantly before and after social prescribing (Table 5).

Table 5: Category scores of the EORTC QLQ-C30 at T1 and T2

	Baseline (T1) (n=27) Median (IQR)	Post-Intervention (T2) (n=27) Median (IQR)	Change in median scores	p-value
EORTC Global Health Status Scores	66.67 (33.33)	75 (16.66)	8.33	0.5
EORTC Functional Scores	75 (23.66)	90.33 (15.33)	15.33	<u>&lt;0.00</u>
EORTC Symptom Scores	16.05 (17.91)	15.43 (12.96)	-0.62	0.431
EORTC Summary Scores	80.32 (20.16)	85.87 (14.92)	7.26	0.18

# **Qualitative findings**

Twenty-seven individuals completed semi-structured interviews exploring their perspectives on the impact of social prescribing and activity engagement on their health and their experiences of social prescribing. Following data analysis, four themes were identified:

- Barriers to activity engagement prior to attending social prescribing
- Outcomes of social prescribed activities
- > Barriers to participation in social prescribed activities
- > Experiences of a social prescribing process

#### Barriers to activity engagement prior to attending social prescribing

Interview participants discussed reasons why they were not participating in activities prior to engaging in social prescribing. Reasons discussed ranged from difficulties encountered following cancer treatment, financial difficulties and not wanting to access cancer-specific services to engage in activities post treatment.

#### Treatment related

Fatigue was the main issue reported by participants. Participants described how they were trying to manage their fatigue but its impact on their ability to participate in social and leisure activities.

"The fatigue was a big thing. Definitely it's been like one of the most prominent things in my life, physically, since my diagnosis." (P43)

"I have a lot of friends but I find it difficult to connect and say 'let's meet' because again that requires a previous arrangement and I don't know, maybe I agree with a friend to meet her in four days and then I'm tired." (P38)

One participant discussed how losing her hair following chemotherapy treatment restricted her from attending activities:

"I'd say it's probably mostly for women but when you have a bit of hair on your head you feel like you can attend activities, even if it's not too much but it looks like you just cut it very tight. You feel more able to start becoming yourself again in that sense." (P16)

Anxiety and fear of cancer recurrence was reported by participants as having an impact on activity participation. One participant described fearing that 'a pain or ache' (P35) might signify a deterioration in their health.

"It just leaves you that if you've a pain or ache, the first thing you think is, 'Oh, is the cancer back?' But it's just your mind." (P35)

"The fear, oh my god, the terror of it coming back. That stayed with me a long, long time after the treatment was finished." (P40)

Some participants spoke about how cancer resulted in feeling socially isolated and misunderstood. One participant described how talking about their cancer resulted in other people being uncomfortable:

"Because I find with the cancer, when you stop and talk to people, you want to talk about your cancer but it puts fear into people I think. That's the way it was coming across to me." (P37)

Reluctance to attend cancer-specific services

Some participants discussed their preference not to attend cancer-specific support services.

One participant described how she did not want to attend her local cancer support service due to difficulty accepting her diagnosis:

"The mere fact of going in through the door said to me, 'oh yeah, you have cancer, you know that don't you?' Now nobody said that, it was in my head, but I didn't like the idea of that." (P9)

Other participants discussed taking a self-management approach to coping with their cancer:

"I definitely didn't avail of any supports. It was something I figured was best to combat on my own, which probably wasn't the best thing. I definitely think I got through it quite well but there were probably counselling services and whatnot that I should have availed of but didn't. Out of stubbornness maybe, I don't know." (P43)

Another participant identified how one-to-one supports such as counselling and acupuncture were beneficial. However, this person preferred to attend non-canceractivities in the community for social outlets.

"I actually went to counselling and I had acupuncture and a few different things. But I never wanted to sit in a support group. I joined a choir that wasn't based around cancer." (P39)

### **Outcomes from attending social prescribed activities**

Participants spoke about the impact of activities they attended following social prescribing. They described how these activities improved their physical and mental health. They also identified increased social interaction, improved motivation and discussed how engaging in activities provided a structure to their daily routine.

#### Physical health

Some participants reported improvements in fatigue and how this facilitated an ability to complete other tasks:

"I have more energy. And when I'm finished these classes I can go home and I can do a lot more work in the house, you know what I mean? You're more energetic." (P13, attended yoga, tai chi, meditation and dance classes)

Another participant reported that attending weekly art classes helped to reduce fatigue over time:

"So I feel like just getting into the habit of going on a weekly basis and easing myself into it that way, it's helped the fatigue even itself out so I'm at a place now where it's not a big deal. But definitely at the start I think the fatigue was still an issue but by going every week I think it helped it kind of go away I guess." (P22)

Sleep patterns are often affected following cancer treatment (Cleeeland et al., 2013). However, three participants reported that relaxation-based activities such as mindfulness and reflexology positively impacted their sleep quality. For example:

"All that activity has helped me sleep, and the relaxation and mindfulness and that has helped me sleep." (P14)

"I couldn't tell you exactly what reflexology does or doesn't do but I know I go there for an hour and I have an amazing night's sleep afterwards. If anything that's worth it like. Because sometimes my sleep is shocking." (P29)

#### Mental health

Improved mental health was also identified as a benefit of engaging in community activities. Participants described feeling less anxious:

"I think my mental health is definitely improved since, I don't feel as anxious and as stressed as I possibly did, no, I definitely don't." (P29)

Another participant identified feeling more positive and relaxed from attending mindfulness and relaxation classes:

"I don't feel as many negative thoughts as I would have had before I went, when I'd be sitting thinking of this, thinking of that. I feel I'm more relaxed."

(P35)

"Well my mood is better. I'm more optimistic I think, more motivated, confident in talking to people about it, just in passing or in conversation. It gave me a mood boost, sort of development of a direction." (P43)

#### **Increased** motivation

Social prescribing was reported by participants as having a positive impact on motivation to engage in activities. Prior to engaging in the service, some cancer survivors reported having difficulties with motivation:

"It pushed me and gave me the motivation to do something, definitely." (P38)

"I struggled with motivation before this so I like never did it on my own accord before, when I could have, but I didn't. I wanted to volunteer for a long time, been telling people I was going to for a long time, but never materialised. But it gave me motivation when I found out you could help me with that. Extra motivation, networking, contacts as well was a big thing. I don't know anyone else who does it." (P43)

Daily routines can often become disrupted following completion of cancer treatment (Palmadottir, 2010). However, participants discussed how attending activities provided a structure to their day:

"It's kind of a reference point and then you can look at the calendar like, 'Okay I have this and then this.' And then things can sort of hang on from there. I have some routine and so I know what's going to happen." (P44)

"It gets you out because you'd be, 'oh my god how am I going to get out of bed this morning?', because you would have aches and pains. But then when you get out and get going, it's great. You are not going to benefit from staying in the bed. And you are not going to be benefit from staying in the house you know whereas you have to get washed and changed and dressed and get out to go participate." (P14)

#### Social interaction

Social prescribing was identified as offering participants an opportunity to meet new people and engage in social interactions:

"I'm definitely meeting new people and strangers who I've never met before and I really like that, I just think meeting new people is so fun. Usually I'm quite introverted and I don't mind being on my own but it's nice at the same time to be doing activities with somebody too." (P22)

Another participant described how engaging in activities made her feel that she was returning to her life prior to the cancer diagnosis.

"I feel I'm going back to myself kind of, the outgoing person I was, by going to these things." (P35, attended relaxation classes)

### Self-initiated engagement in activities

Seven individuals participating in the study attended more than one activity recommended by the social prescribing link worker. They described how attending one activity encouraged them to attend other activities following positive experiences and discovering other activities on offer within that setting:

"Sometimes you hear about a place but you don't realise how much it has to offer, not until you start going and using the services. I didn't know what to expect even going. I just said if I like it, I like it, and I'll go again. But I started one thing and then I put my name down for other things." (P35, attended mindfulness in cancer support centre, followed by reflexology and yoga)

"By attending one thing then I thought I can do something else you know, it'd be nice to come up here and take up something else up here." (P13, attended yoga in a community centre and then attended tai chi, meditation and dance).

#### Barriers to activity attendance

Participants described some challenges accessing activities that the link worker identified for them to attend.

One participant wanted to attend a yoga class near her home but the class was consistently full. She therefore carried out internet-based yoga at home but reported that it did not have the social impact of a group-based yoga class:

"I did enjoy the yoga at home and feel that it benefited me a little bit. But it wasn't like a class setting, so I wasn't meeting anybody, which was part of what I was looking forward to was, meeting new people." (P20)

Health challenges arose for some participants that resulted in difficulty attending certain activities. For one participant, limited mobility combined with poor weather restricted him from attending his preferred activities:

"There was quite a lot on offer but as I said it just came at a bad time of the year. The weather did affect me, and the weather affects my well-being. The nights were bad, the weather was bad. And as I say my walking is not great and I don't like walking into the breeze going up to the community centre. Because of that I have to walk into town to get a bus and then when I get off the bus, I still have to walk. So I said 'feck it I won't go'." (P4)

For another participant the lack of availability near her home of Mindfulness required her to take a taxi to the class which presented some difficulties:

"Well it was just a little bit awkward for me to get at. And I haven't got any transport really since June and so I have to rely on taxis and I was a while waiting down there to get a taxi back." (P33)

#### **Experiences of the Social Prescribing service**

Study participants spoke about their experiences of support received from the link worker from the initial meeting, attending activities and receiving ongoing support throughout the process.

## The initial meeting

Participants reported positive outcomes from meeting with the link worker and receiving ongoing support. Some participants admitted that they did not know what to expect at the initial meeting with the link worker or what the process of social prescribing entailed. The initial meeting was reported to have helped in clarifying the purpose of the service. Participants found it useful to receive resources they could take away and review in their own time:

"I really enjoyed it. You gave me a lot of really good resources and a lot of options. I didn't really know going into it the wide variety of things that were available in the area... I had a look at all of the leaflets that you had given

me and different online resources that were emailed to me and I just had a think about what I'd really like to do and what was closest to me." (P20)

Participants spoke about the benefit of feeling comfortable speaking about cancer-related symptoms and side effects of treatment. The link worker was described as offering reassurance related to cancer treatment symptoms such as fatigue:

"That was like a weight lifted off my shoulders. Because then I said, 'Well this is normal.' So I can't pull the house apart in one day, but I'm satisfied now to be able to pull a couple of rooms apart. Because it's normal. So I was happy, I was delighted with that. That is one of the main things that stuck out from that meeting." (P40)

As the social prescribing service was advertised as being cancer-specific, one participant reported feeling they could talk freely about their cancer diagnosis and treatment and that the link worker would understand:

"I was coming here and knew it was for cancer, so I knew I could talk about it without any barriers. I knew I wouldn't put fear into you because you are dealing with it and I could talk about it no problem. Believe it or not I felt a big lump off my shoulders going out after the meeting to be able to talk about it." (P21)

As part of social prescribing, the link worker typically offers to meet the individual at their chosen activity the first time they attend. This was offered to all participants in the study, although only two individuals availed of the option. Both participants identified that it helped to reduce their anxiety:

"But she has a lovely manner and she met me there when I went because I was a bit insecure the first day going. Because I didn't know what to expect." (P43)

"So she said 'will you come and I'll go down with you' and when she said I'll come down with you, I said 'okay, I'll go.'" (P4)

#### Ongoing support

Participants discussed ongoing support received from the link worker by phone to check in on their progress and to send further information about activities as appropriate.

"She'd just ask me how everything was going and would I be interested in anything else. You knew she was doing all the legwork. Yeah it was very good." (P34)

The link worker also sent information vie email and telephone texts:

"I received emails and different things from the link worker, just different new courses or new activities that she came across, so I definitely knew that support was always there and if I had an issue, or if I needed help working on something, that I could just give her a call or let her know what I was doing, things like that." (P20)

"She's very helpful. She texted me about some of these things taking place. She made sure I knew what was going on and asked did I want to go and told me what time they started at. She phoned me once or twice but normally it would be text saying there's such a thing happening this week."

(P4)

#### **Discussion**

The aim of this study was to evaluate the feasibility of a community-based social prescribing service for individuals living with and beyond cancer and to examine the acceptability of social prescribing to those who attended the service.

# Impact of social prescribing on health and well-being of individuals living with and beyond cancer

The findings of the study indicate that a community-based social prescribing (SP) service is feasible for individuals living with and beyond cancer. Twenty-seven people participated in the service and attended a range of community-based activities which they accessed with assistance from the link worker in the SP service. Following attendance at their activities of choice, participants had statistically significant improvements in how frequency they engaged in activities, specifically in work and leisure activities. They also had statistically significant improvements in depression and experienced statistically significant less fatigue-related distress following their involvement in the service. As this is a feasibility study, it cannot establish whether social prescribing or some other factor resulted in these significant improvements. Therefore, the findings of this study support the need for a more rigorous study that can determine the extent to which social prescribing can improve the health and well-being of individuals living with and beyond cancer.

This feasibility study also demonstrates the acceptability of a social prescribing service to individuals living with and beyond cancer. Participants reported improved mental, physical and social health as a result of attending community-based activities which they accessed with support from the link worker in the social prescribing service. They experienced increased motivation to participate in activities and discussed how attending community-based activities provided them with a structure and routine to their day. Individuals living with and beyond cancer valued support from a link worker in identifying, and accompanying them to their preferred activities. They also identified benefits of attending non-cancer

specific services. These findings indicate acceptability of social prescribing to individuals living with and beyond cancer.

### Impact of physical and mental health

Cancer and cancer treatment results in a range of mental and physical health difficulties (Stanton 2012). In this current study Individuals living with and beyond cancer who engaged with the social prescribing service reported experiencing symptoms including fatigue, cognitive challenges, low confidence, and sleep disturbances. Participants described the impact these symptoms had on their daily activity participation, including their ability to socialise and to engage in leisure activities. Following their participation in social prescribing, participants' frequency in which they engaged in social and leisure-related activities increased significantly as measured by the Frenchay Activities Index (FAI). Some participants reported that through attending one activity in their local communitycentre, they became more aware of other activities offered in the centre and signed up for these activities independently of input from the link worker. Perhaps social prescribing gave some participants the impetus and confidence to explore other activities without the support of the link worker. Increased activity participation aligns with other studies that have examined the impact of social prescribing (Bertotti et al., 2017; Chatterjee et al. 2017, Moffatt et al. 2017). However, a more rigorous study, such as randomised control trial, is required to provide definitive evidence of this outcome of social prescribing.

Fatigue is a persistent and debilitating cancer-related symptom which can endure for many years following cancer treatment (Jones et al., 2016). It interferes with many activities of daily living and is reported as a symptom that prevents some cancer survivors from returning to work following successful completion of treatment and negatively impacts on quality of life (Aaronson et al., 2014). In cancer patients, disturbed sleep, which contributes to fatigue, is rated the second most bothersome symptom based on cancer type and treatment status (Cleeland et al, 2013). Some of the participants in this current study identified difficulty sleeping which resolved following their involvement in their preferred activities. It is likely that improved sleep patterns contributed towards reducing fatigue as

participants reported significantly less fatigue-related distress. Fatigue is positively impacted through engagement in physical activities (Jones, 2016). The participants in this study engaged in a wide range of physically-demanding activities such as dance, yoga, art, tai-chi etc which could have contributed to reduced fatigue.

In this current study participants mood, as measured with the HADS outcome measure, improved significantly. In their interviews, participants identified experiencing anxiety following treatment citing one reason for this being fear of cancer recurrence. Following participation in social prescribing participants described how their mood improved and that they experienced less negative thoughts. Many other studies report improved mood following social prescribing (Chatterjee et al., 2017). The causal mechanism for improved mood in social prescribing is yet unknown. Some suggestions include that improved mood is as a result of person-centred interactions between the individual attending the service and the link worker or as a result of the individual attending targeted activities that impact on mood or both. Further research on mechanisms of change are required to verify this (Bickerdike et al., 2017). A contributing factor to improved mood could be related to how meeting with the link worker motivated participants in this current study to follow through on previously identified goals (such as volunteering as indicated by a participant in this study), but was never realised due to the onset of a cancer diagnosis and treatment. Improved mood could also be explained by structure provided to daily routines through attending scheduled community-based activities.

In a recent systematic review Pescheny et al., (2019), reported reduced social isolation as a frequent positive outcome reported in studies of the impact of social prescribing. In this current study participants referred to increased social interaction as a reason to participate in social prescribing rather than completing activities alone. Social prescribing offered participants a chance to meet people while also participating in health-related activities. One participant described this as "returning to her previous self", i.e. before she was diagnosed with cancer. Previous studies have identified reduced social confidence and difficulty re-engaging in social activities following completion of cancer treatment (Aaronson

et al., 2014). The potential of social prescribing assistance in resolving some of these difficulties is a finding that warrants further investigation.

Cancer survivors identified the link worker as a key factor in their experience of social prescribing. The role of the link worker has been highlighted repeatedly as a key mechanism to promote positive change (Bertotti et al., 2018; Friedli et al., 2012; Wildman et al., 2019a). Participants described the link worker as helpful, supportive, pleasant, accommodating, and offering reassurance. The link worker offered emotional support and reassurance to cancer survivors, which has been found to be important in supporting services users who lack self-esteem and experience anxiety to engage in the process of social prescribing (Wildman et al., 2019b).

Some participants who started attending activities discontinued following one/two attendances due to difficulty accessing their chosen activities. One participant was unable to secure a place in a yoga class despite repeated efforts, due to lack of availability. Another participant had mobility issues which impeded him from attending his chosen activities. Successful social prescribing is dependent on the availability of adequate and suitable services to which the link worker can refer to ensure individuals can participate in their activities of choice. Wildman et al., (2018), reported that gaps in activities and supports included a lack of affordable and accessible services. Many community-based services in Ireland are provided by the Voluntary and Community Sector who rely to a large extent on external funding for delivering and developing services. This makes sustainability of services vulnerable in times of austerity. A steady funding stream is therefore critical to ensure access to high quality and sustainable services to whom the link worker can refer individuals on to.

#### Feasibility of Social Prescribing for individuals living with and beyond cancer

#### Recruitment

One of the primary aims of this study was to assess the feasibility of social prescribing for individuals living with and beyond cancer. The study recruited 43 people over a 12-month period with 27 people completing all study measures. However, the research team cannot calculate an overall study recruitment rate as it is not known how many people were considered eligible by SJH oncology staff and primary care team members and therefore the number of people provided with participant information leaflets though out the study period.

In the initial stages of the study the PI (DC) and research assistant (COH) attended SJH oncology day wards to inform individuals, attending for long-term chemotherapy treatment, whom nurses had identified as potentially suitable for social prescribing, about the study. However, most of these individuals declined to participate citing reasons such as fatigue, family commitments, work etc. After approximately three months attending the oncology day wards three times/week with very few referrals to SP, a decision was made by the research team to discontinue attending. The finding from this is that perhaps SP is not suitable for individuals receiving long-term chemotherapy treatment, but further exploration, and discussion with individuals with cancer, is required to verify this finding.

During the study period, DC and COH attended twice-weekly SJH outpatient oncology clinics. Oncologists involved in the study identified eligible participants and provided them with a participant information leaflet (PIL) on the study. DC and COH were available to meet potential participants during clinics visits if requested. Contact details of the PI and research assistant were provided in the PIL and individuals were invited to make contact if interested in receiving further details of the study and/or to participate in the study. Over a ninemonth period, it is estimated that 563 eligible individuals attended the clinics. Of these, 28 people agreed to participate in the study, giving a 'recruitment rate' of almost 5% which is disappointing for an intervention that has potential to improve health and well-being.

However, this is an estimation based on average numbers attending the outpatient oncology clinics. The research team do not have the exact number of all individuals who received information about the study. Nor do they have data on these individuals such as age, employment status, physical and mental health status etc., all of which are factors that could impact on a person's willingness, interest, availability and suitability to engage in social prescribing. Therefore a 5% 'recruitment rate' should be interpreted with this caveat.

The majority of participants in this study were women with breast cancer. A recent review of self-management studies identified breast cancer survivors as the main participants in self-management interventions (Boland et al., 2018). Therefore, future studies of social prescribing must consider alternative methods to recruit men and individuals with other types of cancer. The majority of individuals who agreed to participate in this study were more than one-year post-cancer diagnosis. This would indicate that this is potentially a time at which individuals living with and beyond cancer are ready to re-engage in community-based activities to support their physical, mental and social health. The numbers in this study did not enable comparisons between individuals at different times from cancer diagnosis. A larger study is needed to investigate this finding further.

# **Recommendations for future studies**

- ❖ Based on the positive findings of this feasibility study a randomised control trial is indicated to determine the effectiveness of social prescribing on the mental, physical and social health of individuals living with and beyond cancer
- Social prescribing is a complex intervention which consists of many interacting components that when combined may improve health and well-being of individuals living with and beyond cancer. These interacting components begin with the initial meeting with a link worker and are potentially present through to an individuals' attendance at community-based services and activities. Future studies should include a qualitative process evaluation to identify which component/s of the social prscribing service lead to changes in mental, physical and social health of individuals living with and beyond cancer
- The findings of this feasibility study suggest that individuals attending outpatient oncology clinics who are more than a one-year period from receiving their cancer diagnosis are most likely to benefit from a social prescribing service. Larger studies are, however, needed to compare individuals with varying lengths of time to establish the optimal time for social prescribing in order to identify where it might be best located within a national pathway of cancer survivorship
- ❖ An economic evaluation of social prescribing is required including healthcare utilisation, medication use, resources and capacity of community and voluntary agencies to provide support services and activities for individuals living with and beyond cancer

### Conclusion

Cancer survivors can experience continuing difficulties post-treatment which can have negative impacts on their participation in daily activities and quality of life. Cancer survivors report a need for follow-up care post-treatment and support to increase their activity

participation. The findings of this study indicate that social prescribing has potential to increase activity participation, mood and quality of life of cancer survivors. Furthermore, it was considered an acceptable intervention by cancer survivors by offering reassurance related to post-treatment symptoms, and both immediate and longer-term support to access community-based resources. Limitations to this study include a small sample size, the absence of a control group and challenges conducting research in 'real-life' clinical settings.

The National Cancer Control Programme (NCCP) recently completed a scoping review of the needs of adult cancer survivor needs (NCCP, 2019). Recommendations arising from this review stated that "accessible, integrated and equitable pathways need to be developed to address side-effects of treatment and their management" (NCCP, 2019:10). They also contended that supportive interventions are essential to meet the needs of survivors and to improve their quality of life. This feasibility study indicates that social prescribing is a community-based, low-cost intervention that has potential to improve the physical, mental and social health of individuals living with and beyond cancer and could be a suitable intervention that is accessible to individuals regardless of their social and/or economic resources. The findings of this study support a definitive intervention study of the effectiveness of social prescribing as a self-management intervention for individuals living with and beyond cancer.

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