Prehabilitation services for people diagnosed with cancer in Scotland

Provan, Debbie; McLean, Gordon; Moug, Susan J.; Phillips, Iain; Anderson, Annie S.

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Prehabilitation services for people diagnosed with cancer in Scotland – current practice, barriers and challenges to implementation

Author names and affiliations

Ms Debbie Provan[a]

Mr Gordon McLean[b]

Professor Susan J Moug[c]

Dr Iain Phillips[d]

Professor Annie S. Anderson[e]

[a] Regional Lead for Living With & Beyond Cancer, West of Scotland Cancer Network

[b] Strategic Partnership Manager, Macmillan Cancer Support

[c] Consultant Colorectal Surgeon, Royal Alexandra Hospital, NHS Greater Glasgow & Clyde, Corsebar Road, PA2 9PN.

[d] Consultant Clinical Oncologist, NHS Lothian

[e] Professor of Public Health Nutrition, Centre for Research into Cancer Prevention and Screening , Level 7, Mailbox 7, University of Dundee, Ninewells Hospital and Medical School, Dundee, DD1 9SY

Corresponding author

Professor Annie S. Anderson

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Abstract

Background Prehabilitation is the practice of enhancing a patient's functional and psychological capacity before treatment commences. It is of interest in the cancer context because of the impact of treatments on quality of life and cancer survivorship. This work aims to document current practice, barriers and challenges to implementing prehabilitation to inform the development of a national framework.

Methods A mixed-methods approach was applied: an on-line survey was sent to stakeholders in cancer care across Scotland, supplemented by in-depth interviews. Key domains explored were the perceived importance of prehabilitation, availability, delivery and content of services, outcome measures, referral processes and funding.

Findings A total of 295 survey responses were obtained and 11 interviews completed. Perceived importance of prehabilitation was rated highly. There was uncertainty over the definition of prehabilitation and most respondents did not know if local services were available. Where services were described, a range of health professionals were involved, different outcome measures were utilised and frequency of referrals varied. Respondents highlighted short time frames between referral and treatment, concerns about patient engagement, the evidence base for action and funding priorities. Respondents also commented on which context a referral should be made and to whom, and the need for equity of service across the country.

Conclusions The current work found clear evidence of the perceived importance of prehabilitation in cancer patients. However, issues and key gaps were identified within current services (including issues arising from COVID-19) which must be addressed to enable wide-spread development and implementation of equitable programmes.

Introduction

Prehabilitation is the practice of enhancing a patient's functional, and psychological capacity before treatment commences. Ideally, prehabilitation interventions start at diagnosis, helping people to prepare for the next treatment stage in their journey of care[1]. Cancer prehabilitation has been defined by Sliver and Baima[2] as "a process on the cancer continuum of care that occurs between the time of cancer diagnosis and the beginning of acute treatment." It is of interest in the cancer context because of the well documented impact of treatments (chemotherapy, radiotherapy and surgery) on immediate and long-term quality of life and survivorship across all cancer types. Additionally, most older cancer patients are likely to have comorbidities (e.g. obesity, diabetes, cardiorespiratory disease) resulting in low levels of physical fitness that complicate treatment delivery and increase the likelihood of side-effects and complications that subsequently prolong their recovery.[3,4] These complications are even more likely in frail patients[5] and data on prehab interventions in co-morbid and older people are sparse[6].

As the first stage of a care pathway, prehabilitation has the potential to decrease length of hospital stay and postoperative complications as well as to improve aspects of neuro-cognitive function, quality of life and long-term health after completion of treatments[8,9,10,11] However, the impact of prehabilitation on long term patient outcomes is dependent upon such pre-treatment behaviour changes being supported in the rehabilitation period[12]. To date there is minimal data on the impact of prehab on non-surgical anti-cancer treatment, particularly in the use of systemic therapy for incurable cancer.

Current evidence suggests that three key factors should be considered within the design of prehabilitation programmes: physical activity[13], nutrition (individualised requirements in relation to under nutrition, otherwise keeping to a healthy balanced diet) and psychological support. Alcohol reduction and smoking cessation are also important to support the aims and objectives of prehabilitation, and programmes are already in place within the NHS to support behaviour change in these areas (but could become more visible within formal prehabilitation programmes). Consequently, it is thought that most prehabilitation work focuses on physical activity or fitness interventions given that many patients do not achieve the recommended baseline activity requirements for good health and there is much fewer trial data to support multimodal approaches which encompass all the three factors.

There is a need for further research on prehabilitation including impact of programmes in non-surgical oncological treatments, definition of minimum and individualised 'exercise prescriptions', key goals of preoperative nutritional care, adherence and benefits in certain population subgroups such as frail older patients. Furthermore, the impact of prehabilitation programmes on mortality, disease prognosis and health economics need further exploration. However, work to date indicates that prehabilitation is safe, feasible and can be delivered alongside complex treatment pathways in different cancer sites including lung[14], colorectal[15] and upper gastro-intestinal[16]. A growing number of national and international reports now recommend prehabilitation as part of cancer pathways[7,17,18,] and whilst the principles of prehabilitation have been warmly welcomed within many NHS sites it is unclear what and how programmes are being delivered, by whom and to whom. This work aims to document current practice, barriers and challenges to implementing prehabilitation in

order to provide insight for the development of national frameworks for action and co-ordinated evaluation procedures in Scotland.

Methods

Under the auspices of the Short Life Working Group (SLWG) on Prehabilitation (commissioned by Scottish Government and led by Macmillan Cancer Support) a scoping study was undertaken to identify current cancer prehabilitation (and rehabilitation) work within Scotland. The current work focuses only on the prehabilitation aspects of the study.

A short on-line survey on was designed with the aim of *" identifying any prehabilitation initiatives (current or planned) and to consider future development needs in Scotland"*.

A mixed-methods approach was applied: an on-line survey was sent to stakeholders in cancer care across Scotland, supplemented by in-depth interviews The following aspects were considered in the survey: Perceived importance of prehabilitation, availability, delivery and content of services (including service development), outcome measures, referral processes and funding. The survey comprised 12 main questions, most of which were presented with pre-coded answer options plus space for free text. To rate perceived importance of prehabilitation interventions for people about to undergo cancer treatment a five-point Likert scale was utilised (where zero was of no importance at all and five was considered critically important). The survey was distributed to key stakeholders working across Scotland's three Cancer Networks (North Cancer Alliance, South and East Cancer Network and West of Scotland Cancer Network), the Cancer Coalition, Scotland's Perioperative Medicine

Group and the Scottish Primary Care Cancer Group which covered the main points of contact for onward distribution to all 14 Scottish Health Boards.

Respondents were also asked if they were prepared to undertake a telephone interview to expand details provided in the survey responses. This process was designed to clarify assumptions about responses and facilitate a greater understanding of what is being delivered, and the extent of barriers and enablers. Probing queries included suggestions for improvement, referral practices, and views on the relevance of prehabilitation in the cancer context. It was hoped that around 20 interviews could take place with health professionals who were planning or/and delivering services and to explore negative and positive comments expressed in the survey. However, the interviews were undertaken in the context of the COVID-19 pandemic and although fewer interviewees were attained the responses provided some insight into how prehab services were being delivered in this challenging context.

The survey was open for a duration of 4 weeks from November 19th – December 20th 2019 and a reminder email was sent out via the main distribution channels after two weeks to maximise return rate. When a mainland Board area showed a nil response at the mid-way stage, the survey co-ordinator made attempts through local contacts to highlight the survey and encourage engagement.

Interviews were undertaken by two independent investigators during April to July 2020. Interviewers took written notes which were then transcribed for analysis and interpretation which was initially conducted by two of the SLWG members and subsequently discussed by all members of the group.

Results

A total of 295 survey responses were obtained in the 4-week survey period. Most respondents (95%) were NHS employees 13% of which worked in primary care settings. Data were available for all Health Boards except Orkney and Shetland. The greatest number of responses came from the largest Boards (Greater Glasgow and Clyde (22.3%) and Lothian (21.9%)). Respondents came from a variety of professional backgrounds with 35% from medically qualified staff, 33% from allied health professionals and 15% from nurses.

Almost a third (29%, n=84) of survey respondents volunteered to be interviewed and provided contact details. As a result of COVID-19 restrictions and related NHS demands, 11 interviews were undertaken representing 6 health care professions (anaesthetics, dietetics, nursing, physiotherapy, radiography and speech and language therapy) working across 6 Health Board areas.

Perceived importance of Prehabilitation

Most respondents answered this item (95%) and almost half (47%) rated prehabilitation in the category of critical importance. Free text comments further underlined these values

> *"I have seen first-hand the difference this can make to the lives of patients and carers and would be more than happy to support taking this forward"* (Therapeutic Radiographer)

> *"I believe this is an essential part of the patients pathway that is missing."* (Physiotherapist)

Availability of services

A number of free text comments indicated that people were somewhat unaware of what constitutes prehabilitation; this was particularly evident amongst responses from primary care practitioners illustrated by the following quotes

"As a normal GP I have never heard of prehabilitation", (GP)

"I don't know what this is – looked it up", (GP2)

The questionnaire responses indicate that less than one-third of respondents (28%) could identify prehabilitation activities within their local area, 21% responded that there were no services and more than half (51%) did not know if services were available. Of those who identified services, 63% were located within the West of Scotland Cancer Network area, 29% in the South East Scotland Cancer Network area and 8% were in the North Cancer Alliance area.

Service content and delivery

None of the respondents that reported the availability of a programme described one that fully encompassed the 3 modalities recommended as part of a comprehensive prehabilitation programme i.e. physical activity/exercise, psychological support and dietary interventions[1]. However, one respondent indicated that patients due to undergo bone marrow or stem cell transplant are offered input from physiotherapy, dietetics and clinical psychology following clinic assessment (approximately 2-3 months pre-transplant).

Survey respondents identified **pilot programmes** including

- Royal Alexandra Hospital, Paisley – Patients with endometrial, colorectal cancer (focus on physical activity)
- NHS Ayrshire and Arran – Patients with upper GI cancer (focus on physical activity with holistic assessment and onward referral to dietetics and/or psychological support)
- Beatson West of Scotland Cancer Centre, Glasgow – Those diagnosed with brain tumours, prostate, upper GI or lung cancers (focus on physical activity)

Examples of **prehabilitation clinics** which had been initiated in the following areas:

- Beatson West of Scotland Cancer Centre, Glasgow – Patients with lung cancer undergoing radical radiotherapy
- Queen Margaret Hospital, Dunfermline – Patients with head and neck cancer

Two respondents reported a pilot project focusing on the psychological impact of cancer treatment which also provided information about lifestyle factors. One respondent noted clinical psychological support being offered to patients whilst three respondents reported signposting to Maggie's for both psychological and physical health reasons. The Macmillan 'Move More' programme• was mentioned frequently as a physical activity/exercise opportunity and ranged from being part of an 'official' prehabilitation offer to signposting or referral to local services. Similarly, some respondents mentioned signposting/referral to local gyms.

• Move More is a National programme developed by Macmillan Cancer support and delivered with Local Authority, Health and Leisure partners. The programme offers an individually-tailored programme of physical activity support throughout the cancer experience.Fully trained Cancer Rehabilitation (Level 4) fitness instructors and volunteers facilitate activities

The interview data (from dietitians) indicated that many patients are identified for referral after significant unintentional weight loss (one mentioned audit results indicating 7-20% weight loss between GP appointment and referral to a dietitian). Others mentioned a desire for more dietetic support within service design and delivery from non-dietetic colleagues. It was also noted that the focus of nutritional input tends to be on undernutrition but many patients have excess body weight and concerns about this (within the care continuum) are exacerbated by long waiting times for support.

In most cases the pre-operative advice described was being delivered as part of standard care or an 'Enhanced Recovery After Surgery' (ERAS) programme rather than a prehabilitation programme per se and comprised standard assessments or services (e.g. blood tests, standard information on medications, eating and drinking pre-surgery).

Table 1 indicates the staff groups involved in the delivery of prehabilitation activities across Scotland

Table 1: Staff delivering prehabilitation

Staff Group	**Number of Respondents (n=79)**
Nurse	48 (60.76%)
Physiotherapist	34 (43.04%)
Dietitian	24 (30.38%)
Fitness Instructor	16(20.25%)
Clinical Psychologist	9 (11.39%)

Volunteer/Buddy	7 (8.86%)
Occupational Therapist	6 (7.59%)
Counsellor	2 (2.53%)
NHS Technical Instructor/Support worker	2 (2.53%)
Other *	37 (46.84%)

*: Local Authority (n=2), Speech and Language Therapist (n=8), Physician (n=4), Radiographer (n=6), Dentist and Hygienist (n=4), Smoking Cessation (n=4), Anaesthetist (n=4), Move More (n=3), Benefits Advisor (n=1), Nutritionist (n=1), Charity (n=2), and Weight Management Service (n=1).

Respondents commented on service design and timing and 195 free text comments were received. These highlighted the short time frames allowed by referral to treatment time targets. It was noted that future models would need to be cognisant of this and pathways redesigned to allow maximum gain from intervention without delays to definitive treatment. This issue was clearly of concern as the following quotes illustrate:

> *"Many of our patients decline physically and mentally because of the disease itself and therefore any delay to treatment of the disease may actually worsen their condition rather than improve it"* (Consultant, Haematologist)

> *"Issues arise around a growing population, with longer life expectancy and more complex surgery and treatment, with no increase in staff time and number. This increases the stress on staff and increases the time people may wait for input"* (Speech and Language Therapist)

Respondents also commented on the need for national or local **guidance** outlining what constitutes prehabilitation, in which context a referral should be made and to

whom it should be made. Some respondents also commented on a need for equity of service across regions/Scotland.

Two less common themes in relation to service delivery were **patients not wanting to participate** and **lack of evidence**. The former raises questions about approach to prehabilitation i.e. core or optional component of treatment and the latter may represent information that is essential during awareness raising activity. Free text responses indicated some scepticism over patient engagement

> *"barriers would be attendance if they are feeling unwell, having to attend multiple appointments",* (Dietitian)
>
> *"Barriers include denial and disbelief around causation of cancer/ill-health and need for psychoeducation/MI to enable shift in energy and focus of control.",* (Clinical Nurse Specialist)
>
> *"The main barrier in [NHS Board] is patient engagement."…* (Consultant Surgeon)

Outcome Measures

Respondents were asked to describe the outcome measures being used to determine the effectiveness of the prehabilitation. In total, 73 (25%) people responded to this question and 14% described outcome procedures including objective measures of fitness (6-minute walk test or timed sit to stand), muscle strength (hand-grip dynamometer), weight and body mass index and patient reported outcome measures (EQ5D, FACT-L, self-efficacy and fatigue). Subjective self-reported measures such as the Godin Leisure Time Exercise Questionnaire and lifestyle change trackers were also mentioned, as were service level outcomes (i.e.

post-operative morbidity and mortality, and bed days/length of hospital stay). A small number of respondents reported experiential measures generated through feedback and satisfaction questionnaires. Some screening (i.e. Malnutrition Universal Screening Tool (MUST)) and assessment tools (i.e. Holistic Needs Assessment (HNA)) were also noted. Around a third (33%) said they did not know which measures were being used, whilst 12% stated that no measures were being used

Referrals

Of those that stated prehabilitation activities were available locally, 38% stated that they would refer people to relevant programmes, although only 27% reported referring *every* patient. A further 38% did not currently refer, 15% were providers of prehabilitation services and 10% reported that the question was not applicable.

Funding

Of the 81 respondents who stated that prehabilitation activities were available in their local area, 80 commented on the type/duration of funding available. There were few (16%) reports of permanent funding and considerable uncertainty around financial support. In relation to funding sources, two respondents highlighted some degree of support from Macmillan, one from Maggie's cancer charity and one an un-named charity. Responses also included information on dates of projects ending, costs for incentive spirometers covered and non-specific support for prehabilitation (delivered as part of a service package)

Free text responses also indicated concerns about costs and financial priorities

> *"Prehabilitation should only be supported with healthcare funding once there is sufficient evidence of significant benefit."* (Consultant Surgeon 2)

"evidence of major benefit should come first before major funding, not the other way around" (Consultant Surgeon 2)

"Patient support and preconditioning is essential but an area generally covered by volunteer and other support groups. I am not sure funding for this should detract from funding for treatment. There is a finite pot of money and treatment gets more successful, provided we can continue to afford it." (Consultant Surgeon 3)

A number of respondents indicated that whilst prehabilitation is important, implementation is dependent on funding (to both sustain current provisions and to set up additional services or develop appropriate pathways of care). Several comments related to the role of allied health professionals in prehabilitation noting that current models of care do not generally take account of the resource requirements for these services.

Concern was also expressed about the risk of exacerbating inequalities as illustrated in the following quotes

"NHSScotland should provide and equitable service for all in every region. Still lots of variation in each area and without a standardised referral pathway and standardised services in place, inequity will continue to exist and poorer outcomes achieved for many." (Physiotherapist 2)

"Travel and cost of classes can be prohibitive"
(Physiotherapist 3)

"We are providing a very remote service to a scattered population so isolation, poverty, lack of transport and broad band links have a big impact on cancer patients." (Dietitian 2)

Insights from the COVID-19 context

The impact of COVID-19 was discussed during the interviews, with all respondents noting a significant impact on delivery. Interviewees noted that fewer patients were coming through for treatment and there was less notice of planned admissions (therefore limiting time for targeted input). Those who described 'surgery school' or pre-treatment group interventions explained that service delivery had now ceased; the exception to this was a therapeutic radiographer providing a 'fear of recurrence' project. In some cases, facilitators were able to continue project delivery using a popular online group video-chat platform. Services that previously offered one-to-one face-to-face prehabilitation or usual care interventions had largely moved to video-consultations but in some cases the collection of outcome measures was adversely affected. Similarly, those using telephone consultations was felt to be suboptimal in terms of motivation, objective assessment and monitoring. The negative impact of shielding and need to look at home-based support was also raised.

Discussion

The current work found clear evidence of the perceived importance of prehabilitation in health and well-being amongst NHS staff working with cancer patients in Scotland. The survey and interviews provide a single lens on prehabilitation which may not be representative of any single professional group but provides a wide array of experiential data from professions working within this field. It is not possible to comment on the response rate to the survey because the method of cascading the survey through stakeholder networks does not allow for contact number collection. However, it is useful that responses were attained from 12 of the 14 health boards in Scotland. Lack of data from Orkney and Shetland boards may signify lack of activity in these areas and further investigation is merited. It is clear that issues and key gaps exist within current services and these must be addressed to enable wide-spread development and implementation of equitable programmes.

Whilst there is growing awareness of prehabilitation as a term there are clearly uncertainties about definition and application indicating a strong need for clarity through training and awareness raising. It is notable that no service was described that encompassed all recommended elements of prehabilitation. Those that responded to the survey generally described services led by individuals or small teams which primarily focussed on the provision of a single discipline-led component. Prehabilitation provision appeared to focus more on a pathway ending in surgical treatment and it is also not clear where prehabilitation may overlap with early palliative care for those who are not fit for treatment.

This small-scale work has limited the opportunity to capture, report and understand the impact of prehabilitation services on clinical outcomes. The findings of the current survey highlight the substantial amount of work (and long-term ring-fenced funding) that is required before multi-modal, multi-phasic interventions can become the norm providing comprehensive prehabilitation services across the country.

Current literature suggests that physical activity interventions are the most common components on prehab interventions but nutrition and psychological aspects remain to be developed. Around 70% of adults over 50 (when most cancers are diagnosed) in the UK have a BMI >25 kg/m^2 and this brings under and over weight associated challenges to initial and long-term management plans[20]. Further work is also required to understand the impact of co-existing cancer associated weight loss syndromes, such as muscle loss (sarcopenia) and systemic inflammation (cancer cachexia)[21]

Whilst it is recognised that further research is needed on the impact of dose, duration, intensity and stage of interventions and the underlying mechanisms involved[22] there is a significant body of evidence that justifies service development, and evaluation of implementation procedures at the present time[11,23,24]. In addition to health outcomes, two issues are crucial in evaluating services. The first is a cost benefit analysis and the second is patient experience, notably equity of access, engagement procedures and acceptability of services.

Published research demonstrates that some cancer patients who participate in prehabilitation can achieve better outcomes, particularly when these services are delivered as part of a rehabilitation continuum that extends beyond treatment. Following the debilitating impact of COVID-19 on the delivery of NHS services and patient care[25], there is a clear need to enhance cancer care. The combination of worsening lifestyle habits and concern over mental well-being arising during the COVID-19 pandemic will undoubtedly have contributed to a general deconditioning within the population. Coupled with late presentation (due to fear in accessing health services) and screening delays the need to harness effective interventions for people diagnosed with cancer has become even more important[26]. A move to tele/digital services during the pandemic provides significant insight to engaging and reaching a far wider population group at a key stage prior to surgery without adding additional travel burdens to those brought about by specialised oncological investigations. These issues have been flagged within the Scottish Government 'Framework for Rehabilitation & Prehabilitation During & Post COVID-19'[27] and work is now required to develop and implement effective services for improved cancer care.

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Table 1: Staff delivering prehabilitation

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Physiotherapist	34 (43.04%)
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