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A physical exercise programme for palliative care patients in a clinical setting: Observations and preliminary findings

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Introduction: Reduced physical function and increased dependency have a significant negative impact on the quality of life of people who are terminally ill. Previous research indicates that participation in physical exercise can reduce distressing symptoms and improve physical functioning and quality of life in palliative care patients with a diagnosis of cancer. We describe the preliminary evaluation of an outpatient rehabilitation and exercise programme implemented in a hospice setting specifically designed for patients with a palliative diagnosis, and aimed at improving and maintaining physical functioning.

Methods: Eligible patients completed a programme of 10 gym-based exercise sessions including exercises to strengthen arms, legs, and core muscles, and to improve balance and cardiovascular fitness. This was further supported by a home-based exercise programme. Assessments of physical performance, fatigue, and quality of life were completed at baseline and immediately post-completion of the exercise programme.

Results: Improvements were observed in physical performance, fatigue, and overall quality-of-life scores post-intervention. There were high levels of attrition and many patients were lost to follow-up.

Discussion: While acknowledging the limitations of our design and small sample size, our findings contribute to the literature around the benefits of exercise for patients receiving palliative care. We recommend that exercise programmes implemented in clinical practice for palliative care patients should be individually tailored and supported by educational initiatives promoting the benefits of exercise to patients, families, and healthcare providers, and promoting early referral. Future work should explore the mechanisms by which such programmes might support improvements in quality of life, and how outcomes may differ for patients with different demographic and disease characteristics.

Keywords: Exercise, Palliative care, Quality of life, Rehabilitation

Background

Reduced physical function and increased dependency have a significant negative impact on the quality of life of the terminally ill.^{1,2} Patients receiving palliative care experience many symptoms, and loss of physical function and fatigue are repeatedly reported as being among the most distressing of these symptoms.² Although the number of randomized controlled trials is small,³ there is evidence that physical activity in palliative care has the potential to alleviate or help manage these distressing symptoms in some patients,^{3,4} including reductions in the intensity of fatigue,⁵ improved quality of life,⁶ and improved physical performance and activity.⁷ Palliative patients are interested in participating in individualized exercise

programmes, but with varying preferences in regard to content, location, and type.⁸

For patients receiving palliative care, the focus as highlighted by the World Health Organization definition, is on improving or maintaining quality of life. Palliative care patients present with complex symptoms and problems that have physical, psychosocial, and spiritual aspects, and it is therefore unlikely that any one intervention will ever be a definitive answer to improving the quality of life of patients. However, for patients who are interested in participating in exercise interventions, options should be available to provide specialist knowledge, exercise counselling, and opportunities for participation in such interventions.

In response to this accumulating research evidence, Marie Curie Hospice in Belfast, with support from Sport Northern Ireland, launched an outpatient

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rehabilitation and exercise programme specifically designed for patients with a palliative diagnosis, aimed at improving and maintaining physical functioning. In line with UK strategy which promotes the improvement of quality of palliative and end-of-life care for *all patients irrespective of condition*,^{9–11} the service was not limited to patients with a cancer diagnosis – unlike previously published literature which has reported the benefits of physical exercise for palliative cancer patients only.

Here, we report our experience of implementing an exercise programme for patients receiving palliative care in a clinical setting, and the preliminary findings of an evaluation with a small sample of patients.

Methods

The programme

The exercise programme was designed to help patients to independently manage and maintain a level of exercise that had maximum benefit for them, incorporating exercises to strengthen arms, legs, and core muscles, and to improve balance and cardiovascular fitness. Although the programme was designed to involve 10 weekly sessions lasting approximately 1 hour each, in practice it was necessary to facilitate a flexible pathway for patients through the service. Hence, sessions were rescheduled when necessary to facilitate the patient or in response to the patient's changing health condition. A risk assessment was completed and approved by the senior management team at the hospice prior to initiating the service. Policy and procedures were developed and approved. All exercise sessions were performed under the supervision of a qualified physiotherapist in the gym of the hospice. The first session involved an in-depth initial assessment, including history of fatigue, co-morbidities, and current disease burden for each patient. Exercise counselling informed by the application of the transtheoretical model¹² (used to assess the patient's general 'readiness' for physical exercise) was delivered at this initial session. Following this consultation, an individualized exercise programme was devised and agreed with each participant, taking into account pre-diagnosis fitness, co-morbidities, fatigue, contraindications, or precautions to aerobic or strengthening exercises. The gym-based programme included a warm-up, followed by a mixture of cardiovascular exercises, balance exercises, and strengthening exercises targeting the upper limbs, lower limbs, and trunk, followed by a cool-down and stretching period. The programme was designed as a moderate-intensity aerobic and strengthening programme. This was managed by introducing the patient to the Borg Perceived Rate of Exertion (PRE) scale¹³ and encouraging the patient to report how heavy and strenuous they perceived the exercise to be. Having the benefit

of one physiotherapist to one patient for the duration of the session allowed the exercise programme to be immediately responsive to patient needs, as the intensity of each exercise could be adjusted to ensure the patient continued to work at moderate intensity (aiming for 12–14 on the Borg PRE scale). Dependent on the patient's comfort and ability, the warm-up and cardiovascular exercises included a selection from the recumbent cycle, treadmill, motomed cycle, and cross trainer. Duration, level, resistance, and incline (for treadmill) were increased over the 10 weeks as the patient progressed. Strength training also progressed, with weights being introduced if and when the patient was comfortable with the exercises. Strength training exercises included sit-to-stand, squats, lateral arm raises, side leg raises, bicep curls, and arm wall presses. Again, depending on the patient's ability, comfort, and wishes, simple abdominal exercises (to improve core strength), and balance exercises (to improve balance and coordination), adapted from the Otago Exercise Programme¹⁴ were introduced. The gym-based programme was additionally supported by a home-based exercise prescription that reflected the exercises carried out in the gym in addition to walking. The home-based programme focused on promoting maintenance of physical activity in line with current guidelines recommending at least 150 minutes of moderate-intensity aerobic physical activity a week, and muscle strengthening targeting all the major muscle groups on two or more days of the week.^{15–17} Information was provided to support the home-based programme, and patients were encouraged to complete a weekly exercise diary.

Measures of physical functioning, fatigue, and quality of life were administered at the initial session and on discharge from the exercise programme. Scores on the physical functioning and fatigue assessments were discussed with the patient – acknowledging and affirming their current abilities and discussing how these assessments would be used to design their individualized exercise programme. On discharge, changes in outcome assessments were discussed with the patient, and advice was given on maintaining changes. This was also an opportunity to collect informal patient feedback about the exercise programme.

Participants

Referrals to the programme were accepted from July 2011. Patients were accepted to the programme if they met the following inclusion criteria: the patient had a palliative diagnosis; was willing to participate in an exercise programme; and the referral had been approved by either the patient's general practitioner (GP) or consultant. Referrals to the programme were accepted from any healthcare professional involved

in the patient's care, provided that the patient's GP or consultant approved the referral.

Evaluation design

Pre- and post-intervention assessments were performed at the initial appointment and immediately after completion of the exercise programme. The following tests were employed to assess physical performance: (i) timed repetitive sit-to-stand, and (ii) 6 minute walk test. Patient reported outcomes included an assessment of: (iii) fatigue using the FACIT fatigue scale and (iv) quality of life using the McGill Quality of Life instrument (MQOL). Qualitative feedback from participants following completion of the programme was also recorded. Demographic and medical data were collected via patient self-report and extraction of relevant data from medical notes.

- (i) Timed repetitive sit-to-stand^{7,18,19} – this is an indirect measure of strength in the lower limbs. The patient is directed to sit on the plinth at its lowest setting and to raise themselves to a standing position without using their arms. The number of full repetitions completed in 1 minute is recorded.
- (ii) Six minute walk test²⁰ – this is a functional walk test that is easy to administer, and has been reported to be better tolerated, and more reflective of activities of daily living than other walk tests.²¹ The patient is directed to walk as far as possible back and forth along a 30 m corridor. The patient can use their existing walking aids where necessary and can stop and rest against a wall if needed. The distance in metres walked in 6 minutes is recorded.
- (iii) FACIT fatigue scale²² – this is a 13-item questionnaire that assesses self-reported tiredness, weakness, and difficulty conducting usual activities due to fatigue. The range of possible scores is 0–52, with 0 representing the most fatigue and 52 representing the least fatigue.
- (iv) MQOL instrument²³ – this is a 16-item multidimensional assessment instrument measuring self-reported overall quality of life, and subscale scores for psychological symptoms, existential well-being, support, and physical symptoms. The MQOL has been validated for use with palliative care populations, and has been found to have superior measurement properties to all other instruments used to assess the quality of life of palliative care patients identified in a recent review.²⁴

Analysis

Measures of central tendency and distribution were calculated for all the outcome measures, both pre- and post-intervention. Shapiro–Wilk tests were used to assess the normality of all outcome variables. *T*-tests (for normally distributed data) and Wilcoxon signed-rank tests (for non-normally distributed data) were conducted to compare scores on the tests of physical function, fatigue, and quality of life before and

after completion of the exercise programme. In all cases, a statistically significant finding was considered to be $P < 0.05$. Analysis was conducted by the second author using SPSS statistics software package.

Results

During the period between 1 July 2011 and October 2013, 73 referrals to the service were received, with 42 patients (57.5%) going on to complete the initial assessment and start the exercise programme. Of those patients who completed the initial assessment: 15 were unable (due to death, changing or deteriorating condition) or chose not to complete the programme, 4 completed the programme but were discharged with no final assessment data collected, and 9 are currently participating in the programme. Hence, baseline and follow-up assessments have currently been completed with 14 patients. Table 1 presents the demographic and medical characteristics of the sample ($n = 14$). The mean age of the sample was 61 years 2 months (range 37–77 years).

Changes in physical function, self-reported fatigue, and quality-of-life scores are reported in Table 2. All outcome data were normally distributed with the exception of 'physical functioning' subscale scores. A Wilcoxon signed-rank test was conducted to examine changes in this variable. All participants ($n = 14$) maintained or improved their physical functioning (sit-to-stand and 6 minute walk test) and overall quality of life. An improvement in fatigue was demonstrated by 85.8% of participants ($n = 12$), with 2 participants demonstrating a deterioration in fatigue over time. There were statistically significant

Table 1 Demographic and medical characteristics of the sample

	<i>n</i>	%
Gender		
Male	12	85.7
Female	2	14.3
Primary diagnosis		
Cancer*	7	50.0
Myeloma	3	14.3
Lymphoma	2	21.4
Multiple sclerosis	1	7.1
Motor neuron disease	1	7.1
Marital status		
Married	13	92.9
Single	0	0
Widowed	0	0
Unknown	1	7.1
Source of referral to exercise programme		
Physiotherapist	8	57.1
Palliative care consultant	4	28.6
Occupational therapist	2	14.3
General practitioner	0	0

*Oesophageal (1), kidney (1), breast (1), colon (1), brain (2), head and neck (1).

Table 2 Comparison of outcome measurements pre- and post-participation in exercise programme

	Pre Mean (SD)	Post	T	P value
Physical performance				
Sit-to-stand (repetitions)	16.9 (7.96)	23.5 (8.2)	-4.45	0.001
6 MWT (m)	335.8 (145.7)	400.5 (159.1)	-4.76	<0.001
Fatigue	22.3 (11.6)	29.3 (8.9)	-2.84	0.015
Quality of life				
Total score	6.1 (1.7)	7.2 (1.4)	-3.38	0.005
Physical symptoms*	3.7 (4.1)*	6.8 (4.0)*	-1.70*	0.008*
Psychological symptoms	6.8 (3.1)	7.7 (2.2)	-1.85	0.097
Support	7.5 (1.9)	8.6 (1.4)	-3.60	0.006
Existential wellbeing	5.9 (2.6)	6.6 (2.3)	-0.99	0.351

*Median, interquartile range, and Z score are reported for 'physical symptoms'.

improvements on physical function measures (sit-to-stand and 6 minute walk test), fatigue scores, and McGill total quality-of-life scores. While there were improvements on all McGill subscale scores, the only statistically significant improvements were in 'physical symptoms' and 'support' subscales.

No patients suffered any serious adverse effects during exercise participation.

Brief informal feedback collected on discharge (from patients who had completed the programme) was positive and raised issues around the timing of referrals, and the perceived benefits of the programme on self-esteem and confidence.

I learnt that I needed to control my fatigue and not let it control me

I gained in confidence and self-esteem

I would highly recommend this programme to others with cancer and hope that it is a big success

I feel I have got my life back... Thank you

I only wish I'd known about this (service) earlier

I can't believe how much I am able to do now

Discussion

The rationale and design of our exercise programme was informed by research literature, which has demonstrated the positive impact of exercise participation on physical functioning, fatigue, and quality of life for patients receiving palliative care. A review in 2009⁴ identified six studies investigating the impact of physical exercise in palliative care patients. We have reported the preliminary findings of an evaluation of an exercise programme implemented in a clinical setting for a small sample of patients with incurable disease receiving palliative care, including patients with a non-cancer diagnosis. We have found statistically significant improvements in physical performance, fatigue, 'physical symptoms' and 'support' subscales of quality of life, and overall quality-of-life scores. Given the focus of the exercise programme,

improvement in physical symptoms is directly explicable. However, the mechanisms by which an exercise programme may improve perceived support are less clear. This may be a direct result of participation in a one-to-one programme, or as an indirect consequence of improved physical function, leading to improved independence and opportunities for social interaction. Future research should explore the mechanisms by which participation in exercise and rehabilitation programmes might contribute to improved quality of life among palliative care patients. Although the patients' weekly exercise was discussed at the start of each session, we did not formally measure adherence to the home-based component of the exercise programme. Therefore, we cannot assess the extent to which participation in the home-based exercises contributed to the observed improvements in physical functioning, fatigue, and quality of life, relative to the gym-based component. Future research might determine the relative impact of home- and gym-based exercise programmes on outcomes for palliative care patients. Several eligible patients who declined participation in our exercise programme cited that they were uncomfortable with the hospice environment. Future research might also explore the acceptability of home- and gym-based exercise programmes for patients with different medical and demographic characteristics. The application of health behaviour change models, such as the Theory of Planned Behaviour²⁶ or the Health Action Process Approach,²⁷ and behavioural counselling methods such as motivational interviewing can be utilized to increase uptake and adherence to such programmes.

The small sample of patients represented by the evaluation, combined with the delivery and evaluation of the programme at a single site by a small staff team, limits the generalizability of our findings. In addition, the interpretation of our findings is limited by the evaluation design, most significantly by the lack of a control group. We cannot be sure that the improvements seen in physical functioning and wellbeing are

a result of participation in the exercise programme, and would not be seen as a result of usual care or other interventions available to these patients. We do however believe this to be unlikely, given that physical performance is likely to deteriorate as the patient's disease progresses, and other interventions available to our patients do not focus specifically on the improvement or maintenance of physical performance. Our numbers are also too small for subgroup analysis. Given the complexity observed among palliative care patients in relation to symptoms, treatment, and co-morbidities, we acknowledge that some patient groups may be more or less responsive to the benefits of physical exercise than others, particularly in relation to fatigue outcomes. Some patients' (such as those with a diagnosis of motor neuron disease or multiple sclerosis) ability to complete the tests of physical performance may have been compromised by neurological factors.

As this evaluation was conducted in the context of routine care, there was no attempt to blind the assessor collecting the outcome data. We did however attempt to limit bias during assessment by utilizing standardized outcome measures. In order to make our service as responsive as possible to individual patient need, there was no time limit set for completion of the programme and as a patient's condition changed or deteriorated, there were occasional gaps of weeks between sessions. This could have impacted on the results as the period of support received could have been prolonged.

We continue to develop our service. One area that requires attention is the high proportion of patients who completed the baseline assessments but were lost to follow-up. Similar levels of attrition have been reported in research studies investigating the impact of physical exercise among cancer patients.^{3,25}

A higher level of attrition is inevitable in this population, and is most often a result of death, worsening condition, or abrupt alterations in disease manifestations. However, patients may benefit from earlier referral to the service, to allow realization of maximum benefit from the effects of physical exercise. The potential benefits of earlier referral also emerged in our patient feedback. Our inclusion criteria required that the referral had to be approved by the patient's consultant or GP, and referrals may have been withheld for patients who might have benefitted from the programme, despite the burden of a palliative diagnosis and associated co-morbidities. Hence, continued education is necessary to raise awareness among healthcare professionals and potential referrers of the benefits of exercise for palliative care patients and to promote earlier referral. Future research should explore the perceptions of exercise and rehabilitation in palliative care settings among healthcare providers

and patients, and the factors influencing uptake of such services.

We are currently planning to re-launch the service with a combined education and marketing campaign, targeting potential referrers. We plan to explore patients' perceptions of the effective components of the intervention, and to systematically assess methods of improving the service, including uptake and referral. We also plan to collect further information on patients' 'readiness for exercise', and to examine more systematically the reasons for patient attrition and drop-out. As referrals and uptake improve, we may be able to examine the impact of the exercise programme on subgroups of patients with different demographic and medical characteristics, such as disease type, gender, age, previous experience of exercise, and baseline physical performance.

Through our experience of delivering the service, and feedback received from both patients and health professionals, we have identified several salient factors which we believe are key to the successful implementation and delivery of a physical exercise programme in a hospice setting. We have not engaged in a systematic assessment of these factors but offer them as advice for other service providers:

1. On-going marketing and promotion is necessary to raise and maintain awareness of such a service, and should include an educational component targeted at patients and healthcare staff, which clearly describes the benefits and appropriateness of physical exercise for palliative care patients. We believe it is particularly important that marketing and education promotes early referral to the service, to optimize the potential benefits for patients.
2. Outcome data should be used to demonstrate and promote the benefits of the exercise programme among patients and healthcare professionals, including potential referrers. In practice, the completion of outcome assessments needs to be balanced against the burden of administration for patients and staff.
3. A staff member who champions the service can be a key contributor to its successful implementation. Careful consideration should be given to staffing levels and capacity issues.

Conclusion

The results of this evaluation, albeit with a small number of palliative care patients, are encouraging and contribute to existing evidence that structured exercise programmes can improve physical functioning and wellbeing, and reduce fatigue among patients in palliative care settings. Further research is necessary to identify the mechanisms by which participation in exercise programmes contributes to improvements in patient outcomes, and to identify methods of improving uptake of such services. Future research should

also explore the impact of exercise participation for patients with differing diagnoses.

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Disclaimer statements

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Conflicts of interest None.

Ethics approval The project described is not research requiring ethics approval, but falls within the definition of service evaluation.

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