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# Patient experiences of a physiotherapy-led multidisciplinary rehabilitative intervention after successful treatment for oesophago-gastric cancer

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## Abstract

**Purpose** To qualitatively explore the perceived impact of a 12-week rehabilitative intervention for oesophago-gastric cancer survivors on their physical, mental and social wellbeing.

**Methods** Of the 21 participants who completed the intervention, 19 took part in a semi-structured focus group interview. Four audio-taped focus groups were held, ranging in size from two to eight participants. Focus groups were transcribed and analysed using a descriptive qualitative approach.

**Results** At recruitment, participants were  $23.5 \pm 15.2$  months post-surgery and all had suboptimal fitness levels. Participants reported improvements in their physical capacity and ability to carry out activities of daily living during the intervention. These improvements led to increased confidence and social connectivity. Other participants were a valuable source of information and reassurance, while support from family members was variable. Future interventions should educate participants on how to maintain gains achieved during the intervention.

**Conclusions** Participating in an exercise-based multidisciplinary rehabilitative intervention reduces isolation and helps oesophago-gastric cancer survivors to safely negotiate their physical, emotional and social needs as they move further down the path of recovery.

**Keywords** Rehabilitation · Exercise · Physiotherapy · Oesophageal cancer · Gastric cancer · Confidence

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## Background

Curative treatment for oesophago-gastric cancer is invasive [1] and often poses challenges in the wake of surgery, such as reduced physical function [1–5], digestive problems [4, 6], fatigue [7], isolation [4, 8, 9] and a compromised quality of life [2, 4, 10]. Such challenges can persist for years [4], forcing patients to simultaneously manage physical and psychosocial complications related to their treatment.

Since treatment complications span multiple domains of wellbeing, efforts to address them must be multidisciplinary in nature. It is well-acknowledged [4, 5, 11, 12] that there is a need to develop rehabilitation interventions which address the manifold needs of oesophago-gastric cancer survivors. However, rehabilitative research in this area has largely been limited to periods shortly before and after treatment [1]. In recognition of this, a 12-week exercise-based multidisciplinary rehabilitative intervention was designed for survivors who

had completed treatment for oesophago-gastric cancer at least 6 months previously [5, 13].

Several studies have reported the benefits of participating in group exercise after completing cancer treatment [12, 14–19]. Quantitative data provide valuable insights into what constitutes safe exercise for different groups of cancer survivors. However, to optimise the design, implementation and uptake of rehabilitative interventions, participant experiences must be considered [18]. Therefore, qualitative data should be amassed to ensure that an intervention is tailored to the needs of participants.

This study aimed to qualitatively explore participant experiences of a 12-week multidisciplinary rehabilitative intervention for oesophago-gastric cancer survivors. Of particular interest was the perceived impact of the intervention on physical, mental and social wellbeing.

## Methods

This study was part of a convergent parallel mixed methods study design [20]. It was designed to complement the findings of the RESTORE randomised controlled trial (RCT), and as such, a qualitative descriptive (QD) approach was taken [21, 22]. This approach describes individuals' perceptions of phenomena and is appropriate for informing the delivery of interventions [23].

## Recruitment

Participants in the intervention arm of the RESTORE (Rehabilitation Strategies following Oesophago-Gastric Cancer) RCT were invited to take part in a focus group. This 12-week intervention was run on four occasions, facilitating 21 participants. There were no withdrawals or drop-outs. In week 10 of the intervention, participants were invited to provide feedback through a focus group. Participants were given 2 weeks to consider the invitation and to provide informed written consent to participate in a focus group on the last day of the intervention. Participants were eligible to participate if they had completed the intervention and had no evidence of cancer recurrence; all participants met these criteria.

## Rehabilitative intervention

The target population was individuals who had undergone an oesophagectomy or gastrectomy with curative intent in the previous 5 years. Individuals from this population who had medical approval to complete exercise testing and to participate in prescribed exercise were eligible to take part.

The intervention aimed to improve physical function and quality of life, with particular emphasis on increasing participant capacity to achieve recommended physical activity levels [5, 24]. The 12-week intervention consisted of 14 exercise sessions with a physiotherapist, individually prescribed exercise for home, sessions with a dietitian and education talks on recovery.

Supervised exercise sessions included a warm-up, a 20–35 min of aerobic exercise prescribed at 30–60% of heart rate reserve, a low/moderate intensity (< 75% 1-repetition max) resistance training programme [25] and a cool-down. Supervised aerobic exercise increased in intensity and duration as the intervention progressed and was completed on a treadmill, stationary bike or cross-trainer. Home exercise was monitored with a Polar Heart Rate Monitor (PolarFT7, China). A dietitian assessed patients to ensure they remained weight stable. Education talks were delivered by a surgeon, physiotherapist, dietitian, occupational therapist, cancer nurse and cancer support centre representative.

## Data collection

Four focus groups were held between July 2016 and February 2017. Focus groups were solely facilitated by an occupational therapist (DC or LB) who had delivered one educational talk and who had experience of conducting focus groups with oncology patients [26].

A semi-structured QD approach was taken [27]. The discussion topics were pre-determined, but as each topic was explored, questions were asked for more detail. The discussion focused on: the impact of the intervention on daily living, facilitators and barriers to exercise and group exercise and education. Discussions were audio-recorded and were, on average, 46 (range 36–55) minutes long.

## Data analysis

Interviews were transcribed verbatim. Braun and Clarke's 6-stage approach to thematic analysis [20] was used to analyse transcripts. Four authors (AEB, LON, DC and EG) individually analysed all transcripts. Each author followed the same process for analysis using nVivo 11 (QSR International, Australia), where codes were systematically generated across the full data set and arranged into potential themes, coded extracts were re-checked to ensure they were congruent with the theme to which they had been assigned and themes were reviewed to ensure that they were clearly defined. A high level of agreement was apparent when the coded transcripts were compared and consensus was reached on final themes and interpretations.

## Results

Nineteen participants (Table 1) took part, with focus groups ranging in size from two to eight participants. Four main themes and 10 subthemes were identified following data analysis (Table 2).

### Impact on the individual

All participants had suboptimal fitness levels upon commencing the intervention, and many reported noticing positive changes in their fitness and endurance as the intervention progressed:

“And, over the weeks I’ve found that for the 30 minutes I’m going a lot further than when I started, and you’re saying, ‘Didn’t get this far the first time.’” [RESTORE11]

Participants reported others noticing, and responding positively to, their increased fitness. One participant described how his sons’ attitudes changed in light of his participation in the intervention:

“The thing I noticed is my two sons – who are into sport – you know, if there was anything going on, I wouldn’t get the phone call, but now I’m getting the calls, ‘We’re going to this game or that game or the other game.’ So, kind of their expectations have raised.” [RESTORE02]

While undoubtedly pleased with these physical changes, many participants were taken aback by the gains experienced, having underestimated the capacity of their body to recover:

“I suppose I was pleasantly surprised that I was able to do more, you know? I don’t know whether it’s part-exercise or what the last few years has thrown at us, that I kind of maybe had convinced myself that I wasn’t able to do a lot.” [RESTORE01]

Overcoming physical challenges previously believed to be insurmountable contributed to a more positive outlook on wellbeing. Participants discussed having fewer self-deprecating thoughts and more confidence being physically active:

“It gave you an idea that there is a good living, you can live good now after it [treatment]. The negativity is gone in me – I can’t say ‘I’m not able’ or ‘That’s wrong if you do that, you’re lifting too much or you’re doing too much’. You can do it.” [RESTORE09]

They also reported feeling more confident and motivated to carry out general activities of daily living:

“It gave you more confidence in getting you doing stuff, you know? You’re not saying, ‘Oh, I’ll leave it, I’ll do it

**Table 1** Characteristics of 19 oesophago-gastric cancer survivors participating in focus groups

Study ID	Gender	Age (years)	Cancer type	Time since surgery (months)	Employment status
RESTORE01	Female	54	Oesophageal	62	Employed full-time
RESTORE02	Male	74	Oesophageal	30	Retired
RESTORE04	Male	74	Oesophageal	23	Retired
RESTORE07	Male	81	Oesophageal	44	Retired
RESTORE08	Male	65	Oesophageal	10	Employed part-time
RESTORE09	Male	74	Oesophageal	35	Retired
RESTORE11	Male	61	Oesophageal	23	Retired
RESTORE13	Female	63	Oesophageal	37	Retired
RESTORE16	Male	57	Oesophageal	12	Employed part-time
RESTORE23	Male	71	Oesophageal	17	Retired
RESTORE26	Male	58	Oesophageal	8	Employed full-time
RESTORE29	Male	64	Gastric	16	Retired
RESTORE30	Male	63	Oesophageal	10	Employed full-time
RESTORE31	Male	74	Oesophageal	36	Retired
RESTORE33	Female	68	Oesophageal	42	Retired
RESTORE36	Male	63	Oesophageal	8	Retired
RESTORE39	Male	74	Oesophageal	9	Employed part-time
RESTORE40	Male	80	Oesophageal	16	Semi-retired
RESTORE41	Female	67	Oesophageal	7	Retired

**Table 2** Themes and subthemes developed from focus groups on participating in a rehabilitative intervention

Themes	Subthemes	Codes
Impact on the individual	Physical condition	Improved fitness
		Improved sleep quality
		Others noticing positive physical change
	Positive psychosocial effect	Physical capacity better than expected
		Increased confidence and positivity
		Less defeatist thinking
		Losing the ‘patient label’
		Providing proof of recovery to family
		Becoming more sociable
	Experience of fatigue	Sense of achievement
		Acquiring an understanding of fatigue
		Reduction in fatigue
Dietary intake	Adopting strategies to manage fatigue	
	Acquiring new knowledge on diet	
	Improved dietary intake	
	Less anxiety around diet	
Participating in an intervention	Facilitators of participation	Intervention tailored to individual capacity
	Challenges during participation	Encouragement from staff
		Difficulty of increasing exercises
		Resistance to exercise
Supportive relationships	Relationships with other participants	Family anxiety over increasing exercise
	Relationships with staff	Sharing experiences and information
		Feeling encouraged by peers
		Helpful guidance from staff
Intervention recommendations	Intervention structure and delivery	Encouraged, but not pushed
		Help sustain exercise after intervention
		Value of assigned exercise for home
		Duration and number of sessions
		More time for information exchange

tomorrow.’ You know now it’s important to keep going, get on with it.” [RESTORE36]

Participants also credited their increased activity levels with reduced fatigue. They adopted exercise-based strategies to attenuate fatigue, with one participant highlighting the value of short walks:

“I just go out, maybe I go to the shop – I don’t buy anything but I just get out of the house – and I come back fresh as a daisy!” [RESTORE23]

Alleviating fatigue increased some participants’ motivation to participate in the intervention:

“They said the exercise would help and it was hard to believe, because you think it’ll make you more tired, but it didn’t. It actually worked and the fatigue really lifted.

So I was looking forward to coming here every time it was on – I was counting the time when it was on again!” [RESTORE08]

Participants also discussed how their involvement in the intervention defied the ‘patient label’, and provided proof of recovery which encouraged others to include them once again in social activities:

“You’re sick, the person is ‘sick’ if you’re recovering from an operation. Like, they leave you recovering for 20 years or something! But they’ll say now, ‘Sure he climbed that thing [participant climbed a mountain during the intervention]. Bring him up, he’s no problem’. So eventually they get it and you re-join, you’re no longer an invalid or a patient for the rest of your life.” [RESTORE08]

One participant who had worked in a physically demanding job prior to his diagnosis reported that the physical and mental benefits experienced during the intervention catalysed his return to work:

“With me personally, it’s actually got me back to work. I had been thinking about it and thinking about it and thinking about it! But that was as far I got, you know? The impetus from this project and just feeling that wee bit better, I just thought, ‘Yeah, let’s take that jump.’” [RESTORE16]

### Participating in an intervention

While participants reported having to exert themselves to complete their exercises, they observed that the physiotherapist prescribed exercises which suited their capacity:

“The girls were tough but fair. There’s no point in being a wimp – they have to push you, but they knew your limits.” [RESTORE11]

However, some reported struggling with the week-on-week increases in exercise targets:

“The targets that are being set for you every week, you know, there, there’s no downward slope, it’s an upward slope all the time. You don’t seem to reach a steady point, and if you can stay there, you’re happy. It, it’s ever upwards, you know? I found it pretty hard to, to achieve.” [RESTORE16]

Despite this, many participants recognised the value of exercising beyond their ‘comfort zone’:

“Even though sometimes they were very tiring, at the same time I think it gave us a fresh look to say, ‘Well, look at the positive side rather than the negative side.’ There’s so many people that tell you, ‘Sit down and don’t do anything,’ ‘Take it easy, you’re after being through a lot.’ And now we have the confidence, to say, ‘Go and do it.’” [RESTORE09]

Although many participants’ confidence in their physical abilities increased, family members did not always share this confidence. One participant adopted measures to hide the fact that he had been doing household chores from his partner, who he described as caring for him like he was ‘ten babies’:

“As soon as she’s [his partner] gone into town, the brush is out and I’m in the garden, and I’m snipping the little

bits and putting them in a bag in the bottom of the bin so she won’t see them!” [RESTORE40]

Conversely, others reported receiving encouragement from family throughout their participation, which increased their motivation to reach their exercise targets:

“She [daughter] would be a good motivator. She’d say ‘The bike,’ ‘Are you going out?’ or ‘Get a half hour in before the match’ or something like that. So it has been a double sort of thing.” [RESTORE01]

### Supportive relationships

The support of fellow participants was deemed invaluable. Many participants spoke of the isolation they felt, with some never having met another person with the same diagnosis prior to the intervention:

“I had never met anybody with oesophagus cancer. People would say to me, ‘Where the hell is your oesophagus?!’” [RESTORE33]

In light of this, participants discussed the support they received through having access to others with relatable symptoms:

“You know, you’re having something going on that wouldn’t happen before the operation, and you’re thinking, ‘Is this back now? Is this something?’ Then you’ll hear someone here say, ‘Yeah, I get that as well,’ and you’re saying, ‘Oh. That’s alright, then.’ It’s reassuring.” [RESTORE11]

It was also acknowledged that a ‘very good atmosphere’ with ‘a good bit of banter’ had evolved, making it easy to exchange information and interact with those leading the intervention.

### Intervention recommendations

When asked for suggestions for improvement, participants often focused on measures to help them sustain the gains achieved. They emphasised the value of exercise prescribed for home, recognising its importance for seeing advances in fitness levels:

“God yeah, I think if you hadn’t the homework, you’d do nothing until the next session.” [RESTORE23]

Given the identified value of ‘homework’, participants queried the possibility of occasional visits back to the centre or of

remote monitoring of physical activity after the intervention, to sustain motivation:

“I know that once I don’t have the ‘Big Brother is watching me,’ to, you know, if I could convince myself that if I kept running that monitor, somebody is checking the data, you know?” [RESTORE01]

“If you had these monitors at home and you were, say, by 11 o’clock, you have to have your readings in and they [physiotherapists] were able to read these from you at home. Even though it’s at a distance, you can send it in over the net or something, and she can see that you did it.” [RESTORE08]

Most participants felt that the number and duration of sessions were appropriate; a small minority would have liked more than 14 sessions, but no one wanted fewer sessions. Given the emphasis placed upon peer support, some participants recommended more time for discussion during the education talks:

“You could certainly do with a little bit more time for asking questions and kind of sharing, just generally – sharing the information.” [RESTORE13]

Participants remarked that they have a wealth of knowledge specific to oesophago-gastric cancer to offer. They believed that when the opportunity arises to share this knowledge, every effort should be made to take advantage of the value of exchanging information:

“We actually have a lot of knowledge. Sometimes I’d go to my GP, but because I’d know so much about this now, I can tell him things! So I think we shouldn’t underestimate the knowledge that we’ve gained. So, just having the opportunity to share information around is crucial.” [RESTORE01]

## Discussion

This is the first study to explore the experiences of oesophago-gastric cancer survivors who participated in a multidisciplinary rehabilitative intervention. The findings indicate that participating in such an intervention had important physical, mental and social benefits for those involved.

One of the principal benefits experienced—and from which many other benefits stemmed—was improved physical function. Treatment for oesophago-gastric cancer may induce weight loss, muscle loss and sarcopenia [3, 28], all of which compromise physical function [1, 5, 28]. Furthermore,

oesophago-gastric cancer survivors often experience long-term complications such as fatigue, pain and diarrhoea [3, 8, 29], complications which undoubtedly make it difficult to restore physical function without professional guidance [4, 11, 30]. It has been reported [31] that less than 25% of cancer survivors meet physical activity guidelines [24], and with the fitness levels of all participants in this study classed as suboptimal, the potential for improvement in physical function was significant. The positive changes in function reported here are similar to those described in other studies [12, 17, 18, 31], with participants reporting increased fitness, a higher capacity to carry out activities of daily living and reduced fatigue.

Many participants expressed surprise at their enhanced physical performance, having become habituated to doubting their physical capacity. Since oesophago-gastric surgery has traumatic consequences for physical health [1, 4, 32], a loss of faith in physical capacity is understandable [15, 33–35]. However, the potentially negative consequences on mental outlook emphasises the need to help patients reclaim losses in physical function as soon as possible after surgery [4, 32]. Exercise-based rehabilitation has been credited with returning a sense of ownership to cancer survivors over an area of their health which has, in many respects, been managed by other individuals [11, 14, 18, 19, 36, 37]. Similarly, several participants in this study viewed exercise as a way of reclaiming their body [12] and creating distance from the status of ‘cancer patient’ [37].

As their physical performance improved, participants observed that they felt less negative and more confident. Cancer survivors often hover between feeling hopeful for a cancer-free future and feeling dread in the face of recurrence [4]. They have been reported to try and resist negativity by adopting measures which help them to take control of daily living and pursue normality [38]. Participation in this intervention was a tangible effort to regain the means to live more productively and take charge of some pre-diagnosis responsibilities. Given the numerous references to improved confidence among this group, it is clear that regaining some of the physical losses experienced during treatment can have a profound effect on an individual’s confidence and perceived self-worth [35, 38].

Several participants reported experiencing positive changes in their social connectivity as their physical wellbeing and mental outlook improved. A cancer diagnosis often invokes some manner of disconnect within a person’s social network [4, 17], where treatment and complications can lead to more restricted living circumstances, potentially resulting in isolation and a reduced quality of life [4, 9]. Several participants used their physical and mental gains to shed the ‘patient label’ and to prove to their social network that they were capable of resuming pre-diagnosis activities. Social support independently predicts health-related quality of life [9, 39] and encourages adherence to rehabilitative measures [40], making access to

informed social support invaluable. Some participants emphasised the role of family in ensuring that they adhered to their prescribed exercises, whilst others highlighted the higher expectations of those around them in relation to their capacity to participate in everyday activities. Conversely, the family members of a small number of participants continued to doubt their physical capacity to the point of impeding their return to pre-diagnosis activities. Given the documented benefits of social support [14, 17, 19], it may be necessary to address the concerns and knowledge gaps of family members at the outset of interventions such as this one, so that participants can fully benefit from the rehabilitation provided.

Although challenges were sometimes experienced in amassing family support, the support of fellow participants was unanimously deemed helpful. The opportunity to exchange information with others in a similar situation fostered a shared identity and a sense of reciprocal concern among the groups [15]. This solidarity [17, 19] alleviated some of the isolation participants had felt, with several highlighting that the intervention was the first time they had met others with a similar diagnosis. Peer support is a recognised benefit of group exercise [12, 16, 41, 42] and is especially beneficial among small groups [17], as there were in this study.

When asked for suggestions to improve the intervention, participants focused on sustaining their improved fitness, making suggestions of remote monitoring of physical activity and of visits back to the research centre. Since their enhanced fitness originated within a supervised environment, their reluctance to forgo this environment is understandable [31]. An increased motivation to be active has been reported for up to 5 years after an exercise intervention ends [43]. Therefore, as part of its design, a future intervention could teach participants to identify and manage barriers to exercise once the intervention ends [33]. Feedback in this study highlighted the need to empower participants to identify supports which help them to sustain improvements beyond the intervention [16, 31].

Before concluding, a number of methodological considerations must be highlighted. The results highlight the perceived benefits of participation and provide insights into some psychosocial benefits of participation which can be difficult to quantify [35]. To encourage candid feedback, discussions were facilitated by individuals who had had only one interaction with participants prior to the focus groups. Transcripts were systematically analysed [20, 44] by four authors and a high level of agreement was reached on final themes and interpretations. Finally, the COREQ criteria [45] were used to ensure that the study was comprehensively presented.

## Conclusion

This study explored the experience of participating in a multidisciplinary rehabilitative intervention designed for

individuals who had been successfully treated for oesophago-gastric cancer. The recovery of this population is complex and addressing their myriad needs warrants a multidisciplinary approach which helps participants to safely negotiate their physical, emotional and social needs as they move further down the path of recovery.

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## Compliance with ethical standards

Ethical approval was granted by the St James's Hospital-Tallaght Hospital joint ethics committee.

**Conflict of interest** The authors declare that they have no conflict of interest.

**Informed consent** Informed consent was obtained from all participants included in the study.

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