Solid Organ Transplant Recipients' Opinions of Pre- and Post-Transplant Supervised Exercise Programmes: A Brief Report

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ABSTRACT

Purpose: Access to pre- and post-transplant supervised exercise programmes in Canada is not consistent across organ types. The opinions of solid organ transplant (SOT) recipients can contribute to the discussion among stakeholders regarding increasing the availability of supervised exercise programmes. The objective of the study was to determine Canadian SOT recipients' opinions of pre- and post-transplant supervised exercise programmes and the factors that influenced their participation. **Method:** An Internet-based questionnaire was distributed to members of the Canadian Transplant Association. It was part of a larger survey and examined seven items related to accessibility to, and opinion of, supervised exercise programmes. **Results:** A total of 35% ($n = 39$) of respondents had attended a pre-transplant exercise programme, and 54% ($n = 61$) had attended a post-transplant exercise programme. The majority of participants believed that a supervised exercise programme was beneficial to health and well-being. Perception of benefits, a physician's recommendation, and health status and symptoms were key influencing factors in the decision of whether to attend a pre- or post-transplant exercise programme. **Conclusion:** SOT recipients had positive opinions of supervised exercise programmes despite unequal access among organ groups. Some key influencing factors (e.g., a physician's recommendation) are modifiable and should be taken into consideration to encourage participation in such programmes.

Key Words: availability of health services; exercise; rehabilitation; organ transplantation; survey.

RÉSUMÉ

Objectif: L'accès à un programme d'exercice supervisé avant et après une greffe au Canada est inégal selon le type d'organe. L'opinion des personnes ayant reçu une greffe d'organe plein (GOP) peut enrichir les discussions des intervenants concernant l'augmentation de l'offre de tels programmes. Cette étude vise à déterminer l'opinion des greffés sur les programmes d'exercice supervisés avant et après la greffe et les facteurs qui ont influencé leur participation. **Méthodes:** un questionnaire en ligne a été envoyé aux membres de l'Association canadienne des greffés. Ce questionnaire faisait partie d'un sondage plus vaste et portait sur sept aspects liés à l'accessibilité des programmes d'exercice supervisés et à l'opinion à leur égard. **Résultats:** au total, 35 % ($n = 39$) des répondants avaient participé à un programme d'exercice avant leur greffe, et 54 % ($n = 61$) avaient participé à un programme après leur greffe. La majorité des participants était d'avis qu'un programme d'exercice supervisé avait des bienfaits sur la santé et le bien-être. La décision de participer ou non à un programme d'exercice avant ou après la greffe était influencée par les facteurs suivants : la perception des bienfaits, la recommandation d'un médecin ainsi que l'état de santé et les symptômes. **Conclusion:** les personnes ayant reçu une GOP ont une opinion favorable des programmes d'exercice supervisés malgré l'inégalité de l'accès selon les groupes d'organes. Certains facteurs (p. ex., la recommandation d'un médecin) sont modifiables et devraient être pris en considération afin de favoriser la participation à ces programmes.

Although the exercise programmes for solid organ transplant (SOT) recipients described in the literature vary in type and intensity of training, researchers have

observed several benefits, such as improvements in exercise capacity, muscle strength, cardiovascular variables, physical activity (PA) levels, and quality of life.¹

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Despite evidence of the benefits of exercise for SOT recipients, access to pre- and post-transplant supervised exercise programmes is not uniform across organ types. A 2011 Canadian survey on the availability of rehabilitation programmes for SOT candidates and recipients revealed that programmes were available for lung and heart patients, but only one Canadian transplant programme offered a supervised exercise programme for liver transplant recipients, and no such programmes were available for kidney recipients.² As such, discussion among key stakeholders about increasing the availability of supervised exercise programmes for SOT recipients, or establishing comparable alternatives, is necessary and should also consider the opinions of SOT recipients.

In addition to the fact that access to pre- and post-exercise programmes in Canada is limited, several factors related to transplant patients and their health may influence their participation in such programmes. These factors may be fear of movement, low physical self-efficacy,³ and symptom distress.⁴ To date, no study has investigated the factors that might influence the participation of SOT recipients in pre- and post-transplant exercise programmes in Canada. Therefore, the objective of this study was to determine Canadian SOT recipients' opinions of pre- and post-transplant supervised exercise programmes and the factors that influenced their participation.

METHODS

Study design

We conducted a cross-sectional, Internet-based questionnaire using LimeSurvey, an open-source online survey application (LimeSurvey, Hamburg, Germany). This article reports on the data from 7 items of a larger, 32-item survey that was designed to collect information on the SOT recipients' level of PA.⁵ The 7 items reported on in this article were not described in the main article⁵ and included questions about Canadian SOT recipients' access to, and opinions of, pre- and post-transplant supervised exercise programmes. We selected the qualitative survey method because it was the most appropriate method for meeting the objectives of the larger study (SOT recipients' levels of PA). However, the questionnaire did provide an "Other" response option, with a comment box in which participants could share any additional opinions on supervised exercise programmes.

Survey development

An in-depth literature review and consultation with clinical experts informed the development of the questionnaire. This article reports on the demographic data and the data resulting from the items regarding accessibility and opinion of supervised exercise programmes.

We used a 5-point Likert scale on which 1 = *not at all influential*, 2 = *slightly influential*, 3 = *somewhat influential*, 4 = *very influential*, and 5 = *extremely influential*

to evaluate how influential certain factors were in SOT recipients' decision to attend a supervised exercise programme as well as their opinions regarding such programmes. An additional "don't know" option was available. Pilot testing of the questionnaire by three transplant recipients and one expert clinician resulted in modifications to address clarity, language, and ease of use.

The University of Toronto Health Sciences Research Ethics board granted ethical approval for this study.

Study participants

To be included in the study, participants had to be adult (aged 18 years or older) SOT recipients (heart, lung, liver, kidney, pancreas) who had received their transplant in Canada and were able to read and understand English.

We recruited participants through the Canadian Transplant Association (CTA), a registered non-profit organization dedicated to raising awareness about organ donation and supporting donors and recipients throughout their transplant journey. Members of the CTA are transplant candidates or recipients, family and friends of transplant patients, and health care professionals. In January 2015, our CTA liaison sent an email invitation to participate in the survey, along with a link to the survey, to those CTA members who had provided the organization with their email address (approximately 378 members). This information was also posted on CTA's Facebook page. Eligible individuals had from January through March 2015 to complete the questionnaire. At 1, 3, and 5 weeks after the initial invitation, a thank-you/reminder email was sent out and a Facebook message was posted by the CTA liaison to increase the response rate.

Statistical analysis

We described data regarding demographics, accessibility, and participants' opinions of their supervised exercise programmes as frequencies and percentages using IBM SPSS Statistics, version 21 (IBM Corporation, Armonk, NY). We describe the data for each option on the Likert scale as a frequency and associated percentage.

RESULTS

A total of 137 CTA members opened the survey. Of those, 6 were ineligible, and 18 others did not complete the questionnaire. Thus, the final sample was 113 transplant recipients (65 men, 47 women, 1 other). The participants included liver ($n = 38$; 34%), heart ($n = 27$; 24%), lung ($n = 22$; 20%), kidney ($n = 22$; 20%), pancreas ($n = 2$; 2%) and multi-organ ($n = 2$; 2%) recipients (percentages total more than 100% because of rounding); the majority were between 41 and 70 years old (73%; $n = 83$) and had received their transplant more than 5 years ago (63%; $n = 71$; see Table 1). Of the respondents, 16% ($n = 18$) identified themselves as having a comorbidity that affected their ability to be physically active (Table 1).

Table 1 Characteristics of Study Participants ($n = 113$)

Characteristic	No. (%) of Respondents
Gender	
Male	65 (57.5)
Female	47 (41.6)
Other	1 (0.9)
Age	
18–30	8 (7.1)
31–40	14 (12.4)
41–50	24 (21.2)
51–60	34 (30.1)
61–70	25 (22.1)
71+	8 (7.1)
Type of transplant	
Single transplantation	104 (92.0)
Multi-organ transplantation	3 (2.7)
Re-transplantation	6 (5.3)
Date of transplant	
Within 1 year	7 (6.2)
1–2 years ago	12 (10.6)
2–3 years ago	8 (7.1)
3–4 years ago	7 (6.2)
4–5 years ago	8 (7.1)
5+ years ago	71 (62.8)
Organ	
Heart	27 (23.9)
Lung	22 (19.5)
Liver	38 (33.6)
Kidney	22 (19.5)
Pancreas	2 (1.8)
Multi-organ	2 (1.8)
Location of transplant*	
Alberta	23 (20.4)
British Columbia	16 (14.2)
Manitoba	1 (0.9)
New Brunswick	1 (0.9)
Nova Scotia	3 (2.7)
Ontario	54 (47.8)
Quebec	12 (10.6)
Saskatchewan	3 (2.7)
Comorbidity affecting ability to be physically active	
Yes	18 (15.9)
No	93 (82.3)
Don't know	1 (0.9)
Prefer not to answer	1 (0.9)

Note: These are the same respondents as those in a larger study about physical activity levels in solid organ transplant recipients; those results will be published in a separate article. Percentages may total more than 100 because of rounding.

*There were no respondents from Newfoundland and Labrador, Northwest Territories, Nunavut, Prince Edward Island, or Yukon.

Access to and opinion of supervised exercise programmes

Pre-transplant supervised exercise programmes

Among all transplant types, 35% ($n = 39$) of participants had attended a pre-transplant supervised exercise programme (see Table 2), and all believed that it had been beneficial to their health and well-being. Of those who had not participated in a pre-transplant supervised

exercise programme, 84% ($n = 62$) had not been given an opportunity to attend (see Table 3). Most notably, 85% ($n = 29$) of liver recipients and 90% ($n = 18$) of kidney recipients who had not participated in a pre-transplant supervised exercise programme had not been given the option to attend (Table 3).

Regardless of whether participants had attended a pre-transplant supervised exercise programme, they identified the factors that would affect their decision to attend. The main influencing factors were the perceived benefits (68%; $n = 77$), the participant's pre-transplant health status and symptoms (65%; $n = 74$), and a physician's recommendation (62%; $n = 70$; see Figure 1).

Post-transplant supervised exercise programmes

Across all organ types, 54% ($n = 61$) of participants had attended a supervised exercise programme post-transplant (Table 2), and 95% ($n = 58$) of attendees reported that they had found it beneficial to their health and well-being. Heart and lung transplant recipients had the highest participation rates, at 82% ($n = 22$) and 73% ($n = 16$), respectively. Of those who had not taken part in a supervised exercise programme post-transplant, 87% ($n = 45$) reported not being given the option of attending (Table 3). Of those who had not attended a post-transplant programme, 64% ($n = 33$) indicated that participating would have been beneficial to their health and well-being. Liver ($n = 18$) and kidney ($n = 19$) transplant recipients received the fewest opportunities to participate in post-transplant rehabilitation.

Regardless of whether they had attended a post-transplant exercise programme, participants were asked to identify the factors that would have affected their decision to attend such a programme. The primary factors were the perceived benefits (62%; $n = 70$), a recommendation from a physician (62%; $n = 70$), and their health status and symptoms (59%; $n = 67$; see Figure 2).

DISCUSSION

The study findings indicate that the majority of the SOT recipients considered pre- and post-transplant supervised exercise programmes to be beneficial for health and well-being, despite unequal access among organ groups. In making the decision whether to attend a pre- or post-transplant supervised exercise programme, participants identified the main influencing factors to be the perceived benefits, their health status and symptoms, and a recommendation from a physician.

The results revealed that a very low proportion of liver and kidney transplant recipients had the opportunity to participate in a pre- or post-transplant supervised exercise programme. These results are consistent with the findings of Trojetto and colleagues,² who reported that, across Canada, there was only one transplant exercise programme for liver recipients and none for kidney recipients. This is a concern, considering that kidney and

Table 2 Supervised Exercise Program Attendance or Non-Attendance, by Organ Type (N = 113)

Organ type	No. (%) of respondents			
	Pre-transplant		Post-transplant	
	Attended	Did not attend	Attended	Did not attend
Heart (<i>n</i> = 27)	13 (48.1)	14 (51.9)	22 (81.5)	5 (18.5)
Lung (<i>n</i> = 22)	18 (81.8)	4 (18.2)	16 (72.7)	6 (27.3)
Liver (<i>n</i> = 38)	4 (10.5)	34 (89.5)	18 (47.4)	20 (52.6)
Kidney (<i>n</i> = 22)	2 (9.1)	20 (90.9)	1 (4.5)	21 (95.5)
Pancreas (<i>n</i> = 2)	2 (100.0)	0 (0.0)	2 (100.0)	0 (0.0)
Multi-organ (<i>n</i> = 2)	0 (0.0)	2 (100.0)	2 (100.0)	0 (0.0)

Table 3 Invitations to Participate in a Supervised Exercise Program for Those Who Did not Attend such Programmes, by Organ Type

Organ type	No. (%) of respondents							
	Pre-transplant				Post-transplant			
	No.	Invited	Not invited	Unsure whether invited	No.	Invited	Not invited	Unsure whether invited
Heart	14	0 (0.0)	9 (64.3)	5 (35.7)	5	1 (20.0)	3 (60.0)	1 (20.0)
Lung	4	0 (0.0)	4 (100.0)	0 (0.0)	6	1 (16.7)	5 (83.3)	0 (0.0)
Liver	34	2 (5.9)	29 (85.3)	3 (8.8)	20	1 (5.0)	18 (90.0)	1 (5.0)
Kidney	20	0 (0.0)	18 (90.0)	2 (10.0)	21	1 (4.8)	19 (90.5)	1 (4.8)
Pancreas	0	0 (0.0)	0 (0.0)	0 (0.0)	0	0 (0.0)	0 (0.0)	0 (0.0)
Multi-organ	2	0 (0.0)	2 (100.0)	0 (0.0)	0	0 (0.0)	0 (0.0)	0 (0.0)

Note: Percentages may total more than 100 because of rounding.

Figure 1 Factors affecting participants' decision to attend a pre-transplant supervised exercise programme.

Figure 2 Factors affecting participants' decision to attend a post-transplant supervised exercise programme.

liver transplant patients are generally frail and present with sarcopenia, two factors that affect post-transplant outcomes but that could be improved with exercise.^{6,7} Furthermore, in this study, almost all SOT recipients who had participated in pre- or post-transplant supervised exercise programme, or in both, stated that they had found these programmes to be beneficial to their health and well-being.

Participants identified the perceived benefits of supervised exercise programmes as being highly influential in deciding whether to attend. This finding contrasts with the results of a systematic review and meta-synthesis by Clark and colleagues,⁸ who identified only a small number of studies that had established that the perceived physical and psychological benefits of cardiac rehabilitation programmes were an influential factor in participation. This difference may be accounted for by the fact that exercise is a well-established component of cardiac management, and, as such, cardiac rehabilitation candidates do not question the likely benefits of exercise; this places more decision-making value on other factors.

Another factor affecting the decision to attend a supervised exercise programme was a physician's recommendation; this has also been shown to be a factor in cardiac rehabilitation.⁹ Given that participants identified the perceived benefits and a physician's recommendation as key factors influencing participation in a supervised exercise programme, PA counselling and referral to an exercise programme by a physician, when appropriate, should be essential components of SOT programming. Thus, future research should investigate physicians' level of knowledge about exercise and their level of confidence in PA counselling in SOT. Future studies should

also explore appropriate ways to disseminate the evidence in favour of exercise in SOT recipients to key health care professionals involved in transplant management. In addition, a larger survey of the same participants⁵ identified knowledge about exercise as an influential factor in being physically active and the absence of PA guidelines as a barrier to engaging in PA. All these results suggest that the development and dissemination of exercise guidelines would be appropriate for health care professionals because they would help them promote participation in, and realize the health and psychosocial benefits of, PA for transplant recipients.

Although only 16% of respondents ($n = 18$) reported having a comorbidity that affected their ability to be physically active, they identified their health status and symptoms as key influencing factors in whether they attended a supervised exercise programme. Regardless of the presence of comorbidities, SOT recipients may experience pre- and/or post-transplant deconditioning, side effects from immunosuppressants, organ rejection, and infection,¹⁰ and such complications can cause an episodic illness and have an impact on recipients' willingness to participate in rehabilitation programmes. Future research is required to determine an optimal exercise delivery method as well as setting, timing, and protocol for transplant candidates and recipients¹¹ to overcome health concerns and symptoms while exercising.

Our study has several limitations. Although the CTA had email addresses for the majority of CTA members (90%), a small subset of members was unable to receive the questionnaire. Participants were also recruited on Facebook, giving non-CTA members who met the eligibility criteria the opportunity to complete the survey;

however, this method also required Internet access. A second limitation is that the survey was available only in English, which may have been a barrier for patients who were not bilingual. Furthermore, because of study recruitment methods, we had to rely on a projected sample size and are thus unable to report a definitive response rate. In addition, recruitment was performed through the CTA, which may have affected the representativeness of the participant population. However, the CTA sample pool includes individuals across Canada of all ages and transplant types, and this was represented in the participant characteristics of this study.

Another limitation of the study is that we did not stipulate a restriction on time since transplant to be eligible for inclusion. Of the participants, 63% reported receiving their transplant more than 5 years ago, a fact that may have contributed to a possible recall bias when giving their opinions about exercise programmes and about whether they had been invited to participate in one. Programme availability may also have been different many years ago. A final limitation of this survey is that our sample may have had a survival bias, capturing the opinions of only those transplant recipients who had survived longer after transplantation. The survey may have missed relevant information from recipients who may have participated in pre- or post-transplant exercise programmes but were no longer alive at the time of the survey.

CONCLUSION

This study describes SOT recipients' positive opinions of supervised exercise programmes despite unequal access among organ groups. Some key influencing factors (e.g., a physician's recommendation) are modifiable and should be taken into consideration to encourage participation in such programmes.

KEY MESSAGES

What is already known on this topic

Solid organ transplant (SOT) candidates and recipients may experience reduced exercise capacity secondary to pre- and post-transplant factors. These factors would limit their ability to participate in work, family, and societal roles and would increase their risk for cardiovascular disease and mortality and reduce their quality of life. Evidence supports the benefits of exercise for SOT recipients, yet the availability of supervised exercise programmes across Canada is inequitable among organ groups. No previous studies have investigated SOT recipients' opinions of supervised exercise programmes or the factors that influenced their participation.

What this study adds

This is the first survey conducted across Canada that has investigated SOT recipients' opinions of supervised exercise programmes. The majority of the participants thought that pre- and post-transplant supervised exercise programmes were beneficial for their health and well-being. They also indicated that the perceived benefits, their pre-transplant health status and symptoms, and a physician's recommendation were the most important factors influencing their decision to participate in such programmes.

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