

# Therapeutic perceptions in management of transplant athletes at transplant games

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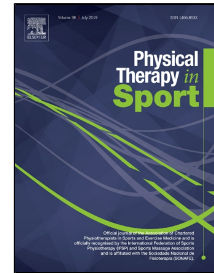
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Therapeutic perceptions in management of Transplant Athletes at Transplant Games

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## 'Therapeutic management of the transplant athlete'

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TITLE

"Therapeutic perceptions in management of Transplant Athletes at Transplant Games"

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ABSTRACT

Objective: To investigate manual therapist's knowledge and beliefs of working with Transplant Athletes (TxA) at Transplant Games.

Design: On-line questionnaire

Participants: Thirty present and previous members of Transplant Sport 'therapy team' (age; 35 ±14 years, 24 female).

Main outcome measures: Questions concerned demographics and general information on the background of the therapists. Closed questions with rating statements concerning beliefs when treating TxA and open questions asking for advice the participants would give to colleagues and further information they would like to have available to them.

Results: TxA were thought to be a vulnerable group of athletes requiring special precautions and considerations. Two areas of information evolved: "general advice for TxA management" and "specific advice for therapists". General advice was to understand TxAs and be vigilant with hygiene. Specific therapy advice was to avoid grade V manipulations and care with taping and massage, because of complications resulting from side effects of long-term medication.

Conclusion: There appears to be a lack of research-based evidence to guide practitioners in their management of TxAs. Generic, good advice is now available from experienced practitioners however there is a paucity of research evidence to support this. Thus, there is a potential danger of being overcautious in approaches to treatment which ultimately may impact on athletic performance.

KEYWORDS:

Transplant Recipients; Sport; Rehabilitation

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## INTRODUCTION

Life-saving organ transplant surgery is becoming more prevalent with 130,000 solid organ transplants being undertaken worldwide every year (Observatory on Donation and Transplantation 2016). Numbers are likely to increase as this figure only represents 10% of the global need for organ transplantation (Bezinover et al 2019) and life-saving transplant surgery is one of the most successful advances in modern medicine becoming a routine medical treatment for organ failure. As such, the post-operative management of transplant surgery is starting to be addressed for therapists through description of best practice for physiotherapists working post-operatively with lung transplants (Shkurka & Oulton 2017, Polastri 2019), kidney (Campanati-Palhares et al 2018) and a single case study following heart transplant (Polastri et al 2017). The paucity of post-hospital discharge guidelines for healthcare workers, combined with a lack of knowledge for exercise prescription in the transplant population, has become a significant barrier for transplantees engagement in exercise (Mathur et al 2018). The Canadian Network for Rehabilitation and Exercise for Solid Organ Transplant Optimal Recovery (CAN-RESTORE) are taking steps to combat this barrier by providing on line information (CAN-RESTORE, 2014) and education for transplantees and therapists. However, the question remains as to how this information translates into the sporting arena?

Organised sporting events for transplantees were the brainchild of leading transplant surgeon, Maurice Slapack (Griffin 1990). At the first Transplant Games in 1978 there were 99 competitors from 5 countries (Neale et al 2017) with the World Transplant Games Federation subsequently being founded 1987 (WTGF, 2017). Since then the world has witnessed a growth in competitive transplantee athletes (TxA) with 69 countries competing with a total of 1500 TxA in 14 disciplines in

Malaga (WTGF 2017). Competitive TxA's range from 4-80 years as exercise is as important for transplantee children, as adults (Vandekerckhove 2016). All organised transplant sporting events enable Tx to compete in an environment that is empathetic to their life changing event and lifestyle journey. Although Transplant Sport celebrated its 40<sup>th</sup> anniversary in 2018; scientific research regarding the management of TxA is still in its infancy.

The majority of literature pertaining to transplantees concerns those with kidney transplants, as this is the most commonly transplanted organ and the first organ to be successfully transplanted. However, solid organ transplantees, no matter which organ, are observed to have reduced exercise tolerance, muscle weakness, decreased aerobic capacity and weight gain which results in muscle deconditioning (Didsbury, 2013). The general benefits of physical activity are well established for the general population (Fuezeki et al 2017) however, in transplantees it is yet an unproven intervention (Didsbury, 2013) with caution and monitoring being necessary in exercise prescription to avoid harm (Hernández-Sánchez 2016). For example, kidney transplant recipients are able to improve their performance capacities and eventually recover to their pre-transplant levels of performance, as evidenced in the elite sporting world with individual examples freely available in the public domain (e.g. Aries Merritt, Jona Lomu). Although research is developing within the field of TxA there is a paucity of research available to guide therapists working with TxA in the sporting environment. In this instance, information for therapists can generally only be gleaned from small scale trials along with anecdotal information.

An initial question for therapists working with TxA's is: how do TxA's differ from any other athlete? All are competing to win, train hard and are proud to represent their countries whereas they are all acutely aware that were it not for their



transplant they would not be alive today; their 'second chance at life' being a key part of their motivation to compete and maximise on their potential (Anderson, 2017). A further question relates to: what is the current medical support for British and World Transplant Games and what can be learnt from them? The World Transplant Games generally have medical teams to support the TxA, however, provision is dependent on what the host country can provide and is variable (Khan, 2013). Each team frequently provides their own transplant doctor and, in addition, like a small number of other countries (New Zealand, South Africa, Holland, Hungary, Hong Kong and France) the British Team, also provides physiotherapy or similar therapy support. In 2019 the World Transplant Games are to be held in Newcastle Gateshead in August where a team of therapy volunteers are supporting this event. In an attempt to understand the therapeutic management of TxA and aid development of the Transplant Games therapy support team this research aimed to determine the knowledge and beliefs from therapy personnel (including physiotherapists, sports therapists, osteopaths, chiropractors and sports rehabilitators) who have worked with TxA at Transplant Games. These results will contribute to the development of an appropriate resource for those wishing to work with TxA in the future and identify therapists training requirements.

#### METHOD

This was a cross-sectional survey with a questionnaire deemed the most suitable tool. This method ensures anonymity and minimises expense for resource information gathering from the diverse population, in terms of working and living areas of the Transplant Sport UK therapy team. Questions were developed through consultation with the Lead Therapist for Transplant Sport UK along with an active researcher within Transplant Sport.

Following ethical approval, a Bristol on Line survey link was emailed by the lead researcher to the pool of members of Transplant Sport UK therapy team who had worked at previous Transplant Games. A follow up second email was sent to all as a second request after a month. The questionnaire notated informed consent prior to 17 questions. Questions 1 to 8 concerned demographics and general information on the background of the therapists. Questions 9 to 11 were closed questions with rating statements from strongly agree, agree, disagree and strongly disagree and don't know. These were designed to encourage reflection for participants on their experiences with TxA before the next section. Questions 12 to 17 were therefore open questions asking for advice the participants would give to colleagues and further information they would like to have following their personal experience of working with TxA at Transplant Games.

Following closure of the survey the results were downloaded and transferred into Excel for descriptive and frequency analysis. The responses were read several times for familiarisation and immersion into the data before final analysis. All responses were checked by a colleague blind to the specific area to reduce bias. Data are presented as absolute frequency of response and percentage of responders (i.e. n [%]) unless otherwise indicated.

## RESULTS

Thirty present and previous members of the Transplant Sport UK 'therapy team' (41% return rate from a pool of 71) who had volunteered for previous games over the last 10 years completed the survey (mean age and SD 35 ±14 years, 24 female) Participants consisted of physiotherapists (15), student physiotherapists (2), and sports therapists (11); who were 12 ±15 years post qualification, with 10 ± 12 years' experience of working in sport and 4 ± 4 years working with TxA.

Participants considered the TxA population as vulnerable (6 strongly agree [20%], 21 agree [70%], 2 disagree and 1 don't know); requiring special consideration (10 strongly agree [33%], 19 agree [63%], 1 disagree) and requiring special precautions to be taken (11 strongly agree [33%], 19 agree [63%]) When asked what precautions should be taken (64 statements), these were: general medical (33, [52%] e.g. 'medications and the effect certain ones have such as anti-coagulants'), specific therapy advice (18, [28%] e.g. strapping (8, [14%]), specific massage process (4, [7%]) and to 'avoid manipulations' (5, [8%]), general therapy (12, [20%] e.g. Infection risk and washing hands) and concerns associated with being a TxA (8, [14%] e.g. 'depending on type of transplant', and 'fistulas'). There were 2 non responders. When asked what considerations should be made (58 statements) these were concerns associated with being a TA (25, [43%] e.g. the 'history of the transplant and the physiological response', 'if they are competing the affect their transplant has on the body', 'how they prepare or recover when competing'), general medical (15, [26%] e.g. medication and side effects), specific therapy interventions (10, [17%] e.g. massage interventions, skin state, 'avoid manips'), psychological considerations (5, [9%] e.g. 'managing expectations' 'mental state') and the holistic approach to the athlete (3, [5%]).

Information relating to treatment of TxA (49 statements) were resourced from: medical professionals (24, [50%]), the internet and journals (16, [33%]) and athletes themselves (5, [10%]) with 4 non-responders. Information that would be useful in aiding treatment (42 statements) were: physiological effects of transplant (15, [33%] e.g. 'how different organ transplants affect physiology'), medication (11, [24%] e.g. 'knowledge of drug impacts and different regimes'), specific therapy considerations for TA (9, [20%] e.g. 'research regarding manual therapy and exercise based

treatments') and specifics of history taking for TxA (4, [10%] e.g., 'specific subjective questions') with 3 who 'don't know'.

The advice the participants would give to colleagues working with TxA were (36 statements): special therapy considerations (9, [25%] e.g., 'being careful with taping'), gaining information from athletes (8, [22%] e.g., 'find as much information from the athlete' and 'listen to their story'), general advice (7, [19%] e.g., 'treat them the same as any other athlete but consider what the athlete has gone through' and 'aware of signs of fatigue') and advice to ask if unsure (5, [14%]). The final question on information they would like or feel would be useful for novice practitioners (39 statements) were for: precautions and cautions (11, [28%]), physical and psychological aspects of transplantation (10, [26%]), specific management for therapists working with TxA (5, [13%]), rules around competition (5, [13%]) and literature (3, [8%] for example case scenarios and journal recommendations). There were two non-responders. In all cases where no response was provided, these were from student participants.

## DISCUSSION

This study was the first to evaluate responses from the pool of Transplant Sport UK therapy personnel concerning their understanding and experiences of working with TxA. The results indicate that TxA were considered a group of vulnerable athletes requiring special considerations. Therapists obtained information pertaining to TxA predominantly from medical professionals with much fewer obtaining information anecdotally from the athletes themselves. Information therapists would value related to transplant history and medication particularly to understand their effects upon physiological function. The information considered

important for novice practitioners in the area related to both physiological and psychological aspects of transplantation.

The question relating to whether TxA athletes are vulnerable was designed to encourage participants to reflect on their behaviour and attitude towards TxA and whether they treat them any differently to other athletes, clients or patients. The findings suggest the majority of respondents agree that TxA are vulnerable and consider they require special considerations and need specific precautions to be taken. The vulnerability related to medication and side effects which could impact on TxA. For example side effects are frequently: osteopenia or osteoporosis which are considered an absolute contraindication for manipulation (Maitland et al 2001) and skin conditions which could influence the application strapping and taping. Skin cancers being the prime concern (Coghill et al 2016), alongside fungal infections as a result of immunosuppressant therapy (Ferrándiz-Pulido et al 2019) and fragile skin through prolonged use of corticosteroids (Jung et al,2016). The specific precautions identified generated the greatest number of responses which may support the proposal that TxA should be given additional considerations, as clarified by participant 21,

“Usual precautions as for any client like hand washing clean area before treatment. No grade V high velocity thrust. Care with taping.”

However, several statements relating to precautions and considerations demonstrated the words ‘precaution’ and ‘considerations’ may not have a universal understanding. Medically precautions are generally understood to mean those “meant to reduce the risk of transmission of blood borne and other pathogens from both recognized and unrecognized sources” (WHO 2007). This would mean effective

hand-washing and good general hygiene. As many TxA take lifelong immunosuppressive medication there is a high risk of co-morbidities (Roedder et al 2014), such as non-melanoma skin cancers (Wheless et al 2014) through compromised immune systems rendering them vulnerable to infections. In the general population there is an increased risk of infection with very prolonged bouts of exercise and intense training (Gleeson & Walsh, 2015), which frequently occurs to many TxA at Transplant Games. However, some infections in TxA do not always manifest clinical signs of infection. For example, 40% of infections do not result in fever, particularly in fungal infections with almost 22% of fevers being non-infectious (Fisherman 2017). Therefore, Fisherman (2017) recommends considering infection as a differential diagnosis with changes in the clinical state of transplantees, even when there is an absence of common signs or symptoms. Clearly medication is a complex area, however, the importance of hygiene and reducing infection is of paramount importance when working with TxA. This is especially important as older adults (over 50 years), of which there are a significant number competing within transplant sport, are at even greater risk of infections (Colvi et al 2017).

In contrast to precautions, considerations are 'careful thought' and occur frequently over a length time (Oxford English Dictionary, 2018). Overall the statements from precautions and considerations generated a vast amount of information from which two main areas were identified: "general advice for TxA management" and "specific advice for therapists". Cumulatively these form the basic foundation of knowledge and information required for personnel working with TxA. The general advice appears to be from their experiences and are summed up by two responses:

“The level of activity they are used to. The psychological aspects of transplant and competition - emotional state, motivation, survivor guilt, indebtedness to donor” (P1).

“If they are competing, the effect their transplant has on the body, such as deinnervation therefore how they prepare or recover when competing.” (P2).

These statements illustrate the holistic management of the TxA which other participants also mention. Specific therapeutic considerations can be summarised concisely by one respondent:

“Avoid Grade V manips. Care with any tape as often allergies. Mindful of medication and possible side effects. More conscious of skin problems” (P24)

There were several statements concerning massage and adaptation of techniques to “avoid compromising delicate tissues”. This could be argued should happen with any massage therapy and it could be that physiotherapists do not have as much massage and soft tissue skills in their education as sports therapists, yet touch is an integral part of any sports physiotherapist (Scott & Malcolm 2015).

There was a diversity of experience of participants in their daily therapy practice through years of experience and association with transplant sport. Just over half the participants were physiotherapists which is to be expected as the first healthcare practitioner to be associated with Transplant Sport UK was a physiotherapist. A third were sports therapists which may reflect the practical nature of this profession being involved in sport. Opportunities for specifically working within transplant sport as an organised sporting event are quite limited at present, with Transplant Sport UK events being held only 2-3 times a year. However, it is likely that with the increasing number of transplants undertaken and TxA competing

outside Transplant Sport UK events, that TxA will be increasingly seen within therapists' daily practices and during student work experiences.

Therapists are required to maintain their continued professional development (HCPC 2013, CSP 2011 & SST 2019) and as such may wish to develop their knowledge of Tx. However, where do they access information to aid this development? As expected, participants derived information and predominantly help from colleagues and less so from the athletes (Scurlock-Evans 2014). However, the specific information being searched for on web-based sources and the reason for the enquiry is unknown. In general, healthcare professionals tend to struggle with resourcing evidence-based practice and prefer to have resources from 'human' in preference to 'computer' sources (Scurlock-Evans 2014). There is existing evidence-based information regarding clinical considerations in the application of exercise for Tx (McKenzie 2015) although far less information specifically relating to transplant sport. It is plausible that a lack of knowledge may result in clinicians not using the best correct treatment (Jain et al 2015) and be cautious in their approach for fear of doing harm which could influence the outcome of the sporting transplantee performance. Therefore, what information would be useful to the practitioner? Included in the area of "general advice for TxA management" was medication and their effects, the physiological effects of transplantation and in the area "specific advice for therapists" were treatment considerations for: massage, manipulations and taping. Finally, what advice would participants share with a colleague? These statements similarly contained practice-based evidence statements, which although very valuable should be consolidated and supported with evidence-based research. Currently there is a paucity of information to guide therapists working with TxA however sports participation after solid organ transplantation is purported to be the



long term aim in rehabilitation to maximise their quality of life (Senduran Yıldırım & Yurdalan 2012). Transplantees are recommended to start with light activities, such as darts and bowling; progressing to medium intensity activities, such as table tennis and volleyball. Following adaptation to these sports' badminton, mini marathons and cycling are recommended. Contact sports: football and basketball are not recommended 'as they may cause a serious trauma and lead to organ damage' (Senduran Yıldırım & Yurdalan 2012: 451). However, these recommendations are only suggested for liver Tx.

This current research suggests that TA are thought to be a vulnerable group of athletes requiring special precautions and considerations. The information available is largely practice-based evidence, but at present not organised, formulated or consolidated. The two areas "general advice for TxA management" and "specific advice for therapists" could be utilised as the basis for information for therapists working with TxA (table 1). However, it is vital to consider that all athletes are a rich source of information and essential information can be gleaned from them. This however can be time-consuming and in the pressured competing sporting arena there is a paucity of time for this process. Case studies, as suggested could be invaluable tool with the 'human' component which therapists prefer (Mckenzie et al 2015) however caution should be taken as the findings cannot be generalised. It should also be recognised the response rate of 42% may increase response bias however it should also be acknowledged this is currently a niche area of interest and comes from those interested, involved practitioners with good experiential knowledge. Similarly it should be acknowledged that the responses were from therapists who have been associated with Transplant Games in order to provide therapists working at future games with their recommendations and advice. The

survey did not specifically consider the training or management outside the transplant games environment which is an area for future research.

### CONCLUSION

In conclusion there appears to be a lack of research-based evidence to guide practitioners in their management of the TxA. Although generic, good advice is available from experienced practitioners, as with many specific populations, there could be a danger of being overcautious in their treatment with the resultant potential detrimental effect on athletic performance. However, reducing the risk of infection should be the first precaution. Future research should be undertaken regarding the physiological responses of various treatments in TxA to enable practitioners to be knowledgeable and appropriately cautious in their approach.

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## APPENDIX 1

### Questionnaire

Please tick YES below to confirm that by filling in this questionnaire you are confirming that: you give consent to use your questionnaire answers in this research study, you have read and understood the information above about the study, you understand that your participation is voluntary and that you are free to withdraw at any time without giving a reason. You understand that all the information you provide is anonymous. If you do not agree then please tick NO to exit the questionnaire

1. Yes or No

### **Demographics**

This section will ask you a range of personal and work information.

2. Age in years

3. What is your gender?

4. Which profession are you practicing?

5. How long ago in years did you qualify or graduate?

6. Which area do you principally work within?

Musculoskeletal, Sport, Neurology, Respiratory, Hospital environment, Outpatients, Private practice/clinic, Gym, Other (please specify)



7. How many years have you been working within sport?
8. How many years ago did you first work with transplantee athletes?

**Your beliefs concerning transplantees.**

Please read the following statements and respond to what you believe concerning transplantee athletes

9. Transplantees are a vulnerable group of athletes?

Strongly agree, Agree, Disagree, Strongly disagree, Don't know

10. Transplantees require special precautions?

Strongly agree, Agree, Disagree, Strongly disagree, Don't know

**Working with transplantees**

Transplantees are an under researched area and there is a paucity of information available on the management of this group of people who are competing in sport.

11. Therefore what precautions and considerations have you made or do you feel you should take if any?

12. What precautions do you take when working with transplantee athletes?

13. What considerations do you make when working with transplantee athletes?

14. Where do you currently resource information from concerning your management of transplantee athletes?

15. What information would be useful to you for working with transplant athletes?

16. What advice would you give to a colleague for working with transplantee athletes?

**Information you would feel would assist you when working with transplantees.**

17. What information would you like available or feel would be useful for novice practitioners working with transplantee athletes?

## Table 1: Summary of therapist's responses

### Precautions

#### General medical

Medications & side effects such as anti-coagulants'

#### Specific therapy advice

Strapping

Specific massage process

Avoid manipulations

#### General therapy

Infection risk & washing hands

### Considerations

#### Concerns associated with being a TxA

Type of transplant & fistulas.

History of transplant & physiological responses

Effect of transplant on the body: preparation and/or recovery

#### General medical

Medication & side effects

#### Specific therapy interventions

Massage interventions

Skin state

Avoid manipulations

#### Psychological considerations

Managing expectations

Mental state

#### The holistic approach to the athlete

### Advice to share

#### Special therapy considerations

Careful with taping

#### Gaining information from athletes

Find as much information from athlete

Listen to their story

#### General advice

Treat them the same as any other athlete

Consider what the TxA has gone through

Be aware of signs of fatigue

Ask if unsure

#### Information that would be useful for novice practitioners

Precautions and cautions for TxA

Physical and psychological aspects of transplantation

Specific management for therapists working with TxA

Rules around competition

Literature e.g. case scenarios and journal recommendations

### Information requested

#### Physiological effects of transplant

How different organ transplants affect physiology

Medications e.g. knowledge of drug impacts & different regimes

#### Specific therapy considerations for TxA

Research regarding manual therapy & exercise based treatments

#### Specifics of history taking for TxA

Specific subjective questions

(1) Conflict of Interest,

There are none

ACCEPTED MANUSCRIPT

(2) Ethical Approval

Ethical Approval: Coventry University provided ethical approval. The ethics protocol reference number is: P73007

(3) Funding

Funding: There was no funding provided for this research

## Highlights

- Athletes competing following a life-saving transplant are increasingly being seen by physical therapists.
- Transplant athletes are considered vulnerable.
- Awareness in the impact of transplant surgery is essential to avoid deleterious effects on performance
- Practitioners need to be knowledgeable and appropriately cautious in their approach

Table 1: Summary of therapist's responses

<b>Precautions</b>	General medical	<ul style="list-style-type: none"> <li>• Medications &amp; side effects such as anti-coagulants'</li> </ul>
	Specific therapy advice	<ul style="list-style-type: none"> <li>• Strapping</li> <li>• Specific massage process</li> <li>• Avoid manipulations</li> </ul>
	General therapy	<ul style="list-style-type: none"> <li>• Infection risk &amp; washing hands</li> </ul>
<b>Considerations</b>	Concerns associated with being a TxA	<ul style="list-style-type: none"> <li>• Type of transplant &amp; fistulas</li> <li>• History of transplant &amp; physiological responses</li> <li>• Effect of transplant on the body: preparation and/or recovery</li> </ul>
	General medical	<ul style="list-style-type: none"> <li>• Medication &amp; side effects</li> </ul>
	Specific therapy interventions	<ul style="list-style-type: none"> <li>• Massage interventions</li> <li>• Skin state</li> <li>• Avoid manipulations</li> </ul>
	Psychological considerations	<ul style="list-style-type: none"> <li>• Managing expectations</li> <li>• Mental state</li> </ul>
	The holistic approach to the athlete	
<b>Advice to share</b>	Special therapy considerations	<ul style="list-style-type: none"> <li>• Careful with taping</li> </ul>
	Gaining information from athletes	<ul style="list-style-type: none"> <li>• Find as much information from athlete</li> <li>• Listen to their story</li> </ul>
	General advice	<ul style="list-style-type: none"> <li>• Treat them the same as any other athlete</li> <li>• Consider what the TxA has gone through</li> <li>• Be aware of signs of fatigue</li> <li>• Ask if unsure</li> </ul>
	Information that would be useful for novice practitioners	<ul style="list-style-type: none"> <li>• Precautions and cautions for TxA</li> <li>• Physical and psychological aspects of transplantation</li> <li>• Specific management for therapists working with TxA</li> <li>• Rules around competition</li> <li>• Literature e.g. case scenarios and journal recommendations</li> </ul>
<b>Information requested</b>	Physiological effects of transplant	<ul style="list-style-type: none"> <li>• How different organ transplants affect physiology</li> <li>• Medications e.g. knowledge of drug impacts &amp; different regimes</li> </ul>
	Specific therapy considerations for TxA	<ul style="list-style-type: none"> <li>• Research regarding manual therapy &amp; exercise based treatments</li> </ul>
	Specifics of history taking for TxA	<ul style="list-style-type: none"> <li>• Specific subjective questions</li> </ul>