

Diet and physical activity after liver transplant: a study of barriers and facilitators to following advice

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Research report

Background

Immediately after liver transplant, patients are advised to follow a diet that is high in calories and protein and start gentle physical activity, such as walking, to aid recovery. After this, a healthy diet and more intense physical activity are recommended to help reduce the risk of health problems such as heart disease, cancer and osteoporosis.

Previous research suggests more support is needed to help recipients with their diet and physical activity.

Aims of the research

We wanted to understand liver transplant recipients' experiences with receiving and following diet and physical activity advice.

We also wanted to identify factors that helped or got in the way of following advice, so the healthcare team can support patients better.

Method

We interviewed thirteen people who had undergone liver transplant at Addenbrooke's Hospital. The participants had their transplant between 6 weeks and 14 years before the interview.

We asked them about their experiences of receiving and following diet and physical activity advice after their transplant. The interviews were audio-recorded and written up as transcripts.

Transcripts were read carefully and chunks of text were coded. For example, where support from friends and family was discussed, this was coded as 'family and friend support' and everything said about this by all participants was gathered in the same place, under a single heading. This sorting of data continued until themes and sub-themes that described the data were developed.

Results

Ten themes were identified as influencing diet and physical activity after liver transplant. Experiences varied between participants and over time after transplant.

The themes were:

1. Self-confidence
2. Healthcare professional support and advice
3. Social support and influence
4. Symptoms and side effects
5. The influence of the physical environment
6. Returning to 'normal'
7. Coping strategies
8. The format and consistency of advice
9. Other conditions
10. Beliefs and values

On pages 4-17, a summary of each finding is shown in a blue box, followed by a more detailed description.

1. Self-confidence

Participants experienced a loss of confidence with being physically active and eating after transplant.

Immediately after transplant some participants lost their confidence with walking and eating but this returned with support from healthcare professionals, for example through setting and achieving goals.

After discharge home a lack of confidence with physical activity returned for some. They felt afraid and unable to increase their activity and did not receive enough support from healthcare professionals. On the other hand, some participants felt capable and confident of progressing their activity without support.

2. Healthcare professional support and advice

Some participants felt well supported with diet and physical activity by the healthcare team but others did not.

In hospital, some participants felt well-supported by dietitians, physiotherapists and ward staff which helped them to follow advice, however, some felt more support was needed.

Advice that was brief and individually tailored was easier to follow and it helped when dietitians and physiotherapists visited participants regularly to adapt advice as their needs changed.

After being discharged from hospital, some participants described receiving enough advice and support or not needing advice. However, for others diet and physical activity advice for the home setting was lacking, described as “vague” and not sufficiently tailored to them as individuals. Specifically, a lack of support to be more physically active after discharge from hospital and prevent unwanted weight gain was described.

There was a desire for a benchmark to know how much physical activity they should be able to do and by when.

In the long-term after transplant, getting advice about a healthy diet and adequate physical activity at the right time when needed was important. For example, participants

described how excessive weight gain was not mentioned to them at clinic appointments.

Some participants described not receiving enough advice about a healthy diet, adequate physical activity and how to safely reintroduce previously restricted foods, for example those restricted due to risk of food poisoning.

3. Social support and influence

Family and friends were needed to help participants to follow diet and physical activity advice in hospital and at home. Participants' social network, including other liver transplant recipients, could have both a positive and negative influence on behaviours.

When healthcare professionals provided advice to participants' family and friends, as well as to participants, this enabled them to revisit the advice independently of healthcare professionals, which helped participants to feel more confident.

Participants' family and friends improved access to nourishing food during their hospital admission and this was particularly important for those who disliked the hospital food. Support to shop for and prepare food was needed at home as participants were not physically capable of this when first discharged from hospital.

Physical support from relatives or friends with regaining mobility helped participants to rebuild confidence. Some described their partners' encouragement as the main reason their physical activity and diet changed or described changing these behaviours together with their partner. Some needed permission not to do too much physical activity, and social support helped them to achieve a balance. When advice and

support was lacking from healthcare professionals, the expertise of family and friends was sought.

The dietary behaviour of others influenced participants in both positive and negative ways, for example the pressure to eat unhealthy meals prepared by others and the positive influence of health and wellbeing amongst friends and social media.

Participants had confidence in advice received from other patients who had experience of living with a liver transplant. Seeing other transplant patients following diet and physical activity advice or hearing about how they do this helped participants to implement advice.

4. Symptoms and side effects

For some, the symptoms and side effects of liver disease, medication and the transplant made it difficult to follow advice. For others, symptoms gave them motivation to implement advice as a way of getting better. Symptoms were the most severe in hospital and for some continued for years after transplant.

Participants described barriers to implementing advice which they felt were outside their control. These included symptoms related to medication, the transplant surgery and liver disease, for example, loss of appetite, taste changes, pain, fatigue, diarrhoea, nausea and vomiting. Dietary restrictions due to transplant side effects, such as a leaking fat-transporting system (chyle leak) and high blood sugars, caused it to be challenging to find suitable foods and meet nutritional recommendations. In hospital some people had trouble concentrating and remembering advice.

Being physically incapable of being active and eating, due to loss of strength and stamina, was a barrier to following physical activity and dietary advice and caused low self-confidence and negative emotions in some. However, being malnourished and not being capable of physical activity could also motivate a desire to make changes to improve.

For some, symptoms improved once they were at home, whereas for others these symptoms continued to be a barrier. New side-effects after being discharged home, such as anaemia, also became barriers to physical activity.

A change in food preference was experienced, for example, some participants gained a 'sweet tooth', compared to only desiring savoury food before transplant. Once recovery had started, a large appetite that required a lot of food to satisfy was also described by some participants. Some attempted to limit their food intake to prevent excessive weight gain, whereas others did not.

Symptoms such as nausea, loose stools, weakness, pain and fatigue continued to be a barrier to physical activity and healthy eating for some participants years after the transplant.

5. The influence of the physical environment

The environment could be both a help and a barrier to implementing advice in hospital and at home.

In hospital, participants experienced barriers to implementing advice, including physical barriers such as being attached to drip-stands, poor access to supplement drinks and a lack of opportunity for upper body exercise. However, the environment was also used as an opportunity to aid physical activity via goal setting and tracking progress, for example walking laps of the transplant ward. While some participants described good quality hospital food with a wide selection of options, others reported their dislike of hospital food as a barrier to eating well.

After hospital discharge, more control over food and more opportunity for physical activity at home, compared to hospital, were also described as facilitators. Walking was talked about as an activity available to all and used to promote recovery. Daily tasks of living that required physical effort, such as housework, also encouraged activity.

In the long run, the convenience of having a gym at work, the availability of interesting and accessible walks, having a dog and good weather were all environmental factors that facilitated physical activity. Bad weather and not having access to safe or enjoyable walking routes were barriers.

6. Returning to 'normal'

There was a desire to return to normal and this influenced diet and physical activity behaviours. For example, participants were motivated to follow advice when it helped them to return to normal.

A desire to return to normal and the belief that diet and physical activity were important for this were facilitators to implementing advice. Advice was easier to follow when participants enjoyed the process of implementing it and when it was similar to their pre-illness behaviours.

For some participants, transitioning from the diet required for their liver disease to a "normal" way of eating was challenging as the special diet had become normal and an important part of their routine to manage their condition.

Coming to terms with a normal body weight after being underweight for a long time was challenging for some and they were slow to realise when weight may have increased too much, as weight gain was mainly viewed as positive and a sign of malnutrition improving.

7. Coping strategies

Participants' ways of coping with the transplant experience influenced their diet and physical activity behaviours. For example, achieving goals helped participants to cope, and adopting healthy behaviours helped them to regain control.

Achieving goals, such as walking a set distance on the ward, and experiencing benefits of implementing advice helped participants to cope better. Learning about other liver transplant recipients' experience with diet and physical activity also enabled some participants to cope better. For example, one participant said, "with the NG [feeding] tube, having someone else who hated it as much as I did was a god send because it made me feel like I wasn't so irrational".

Poor health after transplant threatened participants' ability to cope and was a barrier to implementing advice. Whereas making progress towards 'normal' helped participants to cope as a sign of recovery and the start of beginning to enjoy life again. Accepting that recovery is a difficult time, being persistent with implementing advice and having faith that the situation will improve were described as required to cope with the challenges of recovering and implementing advice.

Participants explained how they felt responsible to "make the most of the second chance given" at life, which gave them

purpose and motivation to follow a healthy diet and stay active.

For some participants, adopting healthy behaviours was described as a way of regaining control of health, reducing the risk of future ill-health and respecting the donor. However, others did not feel able to think about changing their behaviours as this meant they would have to face up to having had a liver transplant and this threatened their ability to cope.

8. The format and consistency of advice

Tailored and personalised advice and consistent messages about diet and physical activity was helpful. Advice was valued more when its importance was explained by the transplant doctors and surgeons.

Receiving tailored and personalised advice that fit with everyday life helped participants to put advice into practice. Participants paid attention to advice from healthcare professionals who were confident and knowledgeable and those who had an empathetic and encouraging approach. Participants valued diet and physical activity advice more when its importance was highlighted by doctors and surgeons.

Consistent messages about diet and physical activity across the healthcare team made participants feel more confident about accepting the advice. However, some participants described receiving advice that conflicted. Participants who experienced conflicting advice lost confidence in healthcare professionals and their advice.

9. Other conditions

Conditions, other than the liver disease, were barriers to following advice but could also motivate participants.

Participants described a range of health factors as barriers to following diet or physical activity advice across all time periods after transplant. Some participants, such as those with ulcerative colitis, needed to avoid certain foods to manage their health conditions. Some were not able to undertake the recommended levels of physical activity, for example due to joint problems. For others, conditions like diabetes encouraged healthy behaviours.

10. Beliefs and values

Participants' beliefs about the advice they were given influenced how much they valued it and their ability to follow it. 'Self-determination' was described as helping to follow the advice, whereas being 'lazy' did not.

Participants who expressed the belief that following diet and physical activity advice would be beneficial to them, or that their previous behaviour would have a negative impact on their health, described making changes to their behaviour. On the other hand, those who believed implementing the advice would be harmful, or not beneficial, described not changing their behaviour.

Other barriers to behaviour change were acknowledging but not valuing the potential impact of behaviour on health, and not being willing to accept the perceived costs they would experience if they changed their behaviour.

"Self-determination" was described as helpful, whereas others described themselves as "lazy", not "self-motivated" and "not particularly good at following people's advice".

Impact of the research

This research has led to changes in the way we support liver transplant recipients, for example:

- We have introduced a supplement drink fridge on the transplant ward to help patients access supplement drinks themselves, without asking a member of staff.
- We have developed an information sheet with advice about being active before liver surgery to reduce loss of strength whilst waiting for transplant.
- We have changed the advice we give after transplant to include better guidance about physical activity, healthy eating and preventing unwanted weight gain.
- The transplant team at Addenbrooke's Hospital is working towards a pre- and post-transplant rehabilitation service in collaboration with the six other transplant centres in the UK.

This research has also informed another research project, which has been funded to help develop a programme to better support liver transplant recipients with their diet and physical activity behaviours. More information about this project can be found here:

<http://www.mrc-epid.cam.ac.uk/research/studies/bolt/>

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