

پرسشنامه ارزیابی کیفیت زندگی بیماران بعد از پیوند کبد

دریافت کننده محترم پیوند کبد.... سلام!

این پرسشنامه جهت پی بردن به اینکه شما در طی چهار هفته پیش چه احساسی داشته اید، طراحی شده است. از شما بعنوان یک دریافت کننده کبد درباره علایم و روحیه شما سوال می شود. علاوه بر این، از شما درباره اینکه پیوند کبد چه اثراتی بر فعالیت های روزانه، سطح انرژی داشته و اینکه مراقبت های بعد از پیوند کبد چقدر روی زندگی شما اثر گذاشته است، پرسیده می شود. لطفا همه سوالات را تکمیل کرده و برای هر سوال فقط یک پاسخ انتخاب کنید.

راهنمای پرسشنامه:

تمام اوقات = هر روز
اکثر اوقات = حدودا ۵ بار در هفته
زمان قابل توجهی = ۲ تا ۴ مرتبه در هر هفته
گاهی اوقات = یک بار در هفته
زمان کمی = نزدیک به یک بار در هر دو هفته یا دو بار در هر چهار هفته
به ندرت = یک بار در هر چهار هفته

هیچ زمانی	به ندرت	زمان کمی	گاهی اوقات	زمان قابل توجهی	اکثر اوقات	تمام اوقات	سوال
							۱- در چهار هفته گذشته، چند بار درباره از دست دادن حافظه کوتاه مدت یا بلند مدت خود نگران شده اید؟
							۲- در چهار هفته گذشته، چند بار احساس افسردگی کرده اید؟
							۳- در چهار هفته گذشته، چند بار زودتر از حد معمول ناراحت شده اید؟

							۴- در چهار هفته گذشته، چند بار بیش از اندازه درباره سلامتی خود نگران شده اید؟
هیچ زمانی	به ندرت	زمان کمی	گاهی اوقات	زمان قابل توجهی	اکثر اوقات	تمام اوقات	سوال
							۵- در چهار هفته گذشته، چند بار احساس نگرانی داشته اید؟
							۶- در چهار هفته گذشته، چند بار درباره نحوه مصرف داروهای پیوند مشکل داشته اید؟
							۷- در چهار هفته گذشته، چند بار به دلیل مراجعات مکرر به پزشک در تنظیم برنامه های روزانه خود دچار مشکل شده اید؟
							۸- در چهار هفته گذشته، چند بار درباره نیاز به خون گیری های متعدد برای آزمایش احساس نگران شده اید؟
							۹- در چهار هفته گذشته، چند بار احساس کرده اید که باید همه چیز را برای پزشک یا هماهنگ کننده پیوند توضیح دهید؟
							۱۰- در چهار هفته گذشته، چند بار به دلیل مصرف تعداد زیاد داروها اذیت شده اید؟
							۱۱- در چهار هفته گذشته، چند بار درباره توانایی انجام فعالیت های روزمره (مانند کارهای خانه، بهداشت شخصی- و غیره) احساس محدودیت کرده اید؟
							۱۲- در چهار هفته گذشته، چند بار نگران کاهش قدرت عضلات خود شده اید؟
							۱۳- در چهار هفته گذشته، چند بار به دلیل تغییر وضعیت خواب اذیت شده اید؟

							۱۴- در چهار هفته گذشته، چند بار به خاطر طول دوره بهبودی پس از جراحی پیوند نگران شده اید؟
هیچ زمانی	به ندرت	زمان کمی	گاهی اوقات	زمان قابل توجهی	اکثر اوقات	تمام اوقات	سوال
							۱۵- در چهار هفته گذشته، چند بار به دلیل ترس از برگشت بیماری مشکل پیدا کرده اید؟
							۱۶- در چهار هفته گذشته، چند بار به دلیل کاهش احتمالی طول عمر نگران شده اید؟
							۱۷- در چهار هفته گذشته، چند بار به خاطر هزینه داروهای پیوند نگران شده اید؟
							۱۸- در چهار هفته گذشته، چند بار در پرداخت صورتحساب هزینه های پزشکی پیوند (شامل هزینه های دارو، آزمایشگاه و تصویربرداری) دچار مشکل شده اید؟
							۱۹- در چهار هفته گذشته، چند بار دچار درد مفاصل یا کمردرد شده اید؟
							۲۰- در چهار هفته گذشته، چند بار نگران راه افتادن بعد از جراحی شده اید؟
							۲۱- در چهار هفته گذشته، چند بار نگران توانایی خود در رانندگی کردن شده اید؟
							۲۲- در چهار هفته گذشته، چند بار برای دلواپسی خانواده در مورد بیماری یا وضعیت سلامتی نگران شده اید؟
							۲۳- در چهار هفته گذشته، چندبار درباره اینکه سربار اعضای خانواده باشید، نگران شده اید؟
							۲۴- در چهار هفته گذشته، چند بار درباره اینکه باید بیشتر از سلامت خود مراقبت کنید، نگران شده اید؟

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							۲۵- در چهار هفته گذشته، چند بار ترسیده اید که کبد پیوندی شما پس بزند؟
							۲۶- در چهار هفته گذشته، چند بار در مورد ایجاد عفونت ناشی از مهار ایمنی (کاهش توانایی بدن شما برای مبارزه با عفونت ها) به دلیل مصرف داروهای مهار کننده ایمنی دچار نگرانی شده اید؟
							۲۷- در چهار هفته گذشته، چند بار نگران ایجاد عوارض ناشی از مصرف اشتباه یا فراموش کردن مصرف داروها شده اید؟
							۲۸- در چهار هفته گذشته، چند بار نگران سختی بازگشت به کار شده اید؟
							۲۹- در چهار هفته گذشته، چند بار دردهای مربوط به عمل جراحی پیوند را داشته اید؟
							۳۰- در چهار هفته گذشته، چند بار به دلیل عوارض جانبی داروهای پیوند اذیت شده اید؟
							۳۱- در چهار هفته گذشته، چند بار به دلیل زمان طولانی برای گرفتن وقت ویزیت پزشک به دردمس افتاده اید؟
							۳۲- در چهار هفته گذشته، چند بار دچار احساس سوزن سوزن شدن یا بی حسی شده اید؟

- تمام امتیازات معنوی این پرسشنامه به مرکز تحقیقات پیوند کبد دانشگاه علوم پزشکی تهران تعلق دارد.
- پژوهشگران جهت اطلاع از دستورالعمل این پرسشنامه می توانند با آقای دکتر محمد جواهریان ارتباط داشته باشند.

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Supporting Information

- Post Liver Transplantation Quality of Life Instrument (pLTQ)

Post Liver Transplantation Quality of Life Instrument (pLTQ)

The Scale:

- 1: All of the time (daily)
- 2: Most of the time (about 5 times a week)
- 3: Good bit of the time (2 to 4 times a week)
- 4: Some of the time (once a week)
- 5: A little of the time (close to every other week or twice in a 4 week period)
- 6: Hardly any of the time (once in a 4 week period)
- 7: None of the time

1. In the past four weeks, how often have you felt concerned about having short and//or long term memory lost?
2. In the past four weeks, how often have you felt depressed?
3. In the past four weeks, how often have you been irritable?
4. In the past four weeks, how often have you been more worried than usual about your current health state?
5. In the past for weeks, how often have you felt anxious?
6. In the past four weeks, how often have you had a problem following instructions for taking your transplant medications?
7. In the past four weeks, how often have you felt troubled about needing to make special arrangements because of frequent doctor visits?
8. In the past four weeks, how often have you felt concerned about needing to have multiple blood draws?
9. In the past four weeks, how often have you felt the need to clarify everything with the doctor or transplant coordinator?
10. In the past four weeks, how often have you been bothered by having to take too many medications?
11. In the past four weeks, how often have you felt limited in your ability to carry out daily activities (housework, personal hygiene, etc)?
12. In the past four weeks, how often have you been concerned about having decreased muscle strength?
13. In the past four weeks, how often have you been bothered by changes in your sleep patterns?
14. In the past four weeks, how often have you been concerned about the length of recovery from your transplant surgery?
15. In the past four weeks, how often have you been troubled by the fear of having your disease recur?
16. In the past four weeks, how often have you been concerned about potentially having a shortened lifespan?

17. In the past four weeks, how often have you been concerned about the cost of your transplant medications?
18. In the past four weeks, how often have you had trouble with medical billing for transplant expenses?
19. In the past four weeks, how often have you had joint or back pain?
20. In the past four weeks, how often have you been concerned about learning to walk after your surgery?
21. In the past four weeks, how often have you been concerned about being able to drive?
22. In the past four weeks, how often have you been concerned about your family worrying about your illness or state of health?
23. In the past four weeks, how often have you been worried about being a burden on your family members?
24. In the past four weeks, how often have you been concerned about having to take better care of your health?
25. In the past four weeks, how often have you feared that your transplanted liver would be rejected?
26. In the past four weeks, how often have you been worried about developing an infection due to being immunosuppressed (decreased ability for your body to fight off infections) as a consequence of being on antirejection medication?
27. In the past four weeks, how often have you been concerned about developing complications from taking your medications incorrectly or forgetting to take them?
28. In the past four weeks, how often have you been worried about difficulty returning to work?
29. In the past four weeks, how often have you experienced pain related to your liver transplant surgery?
30. In the past four weeks, how often have you been bothered by side-effects from your transplant medications?
31. In the past four weeks, how often have you been bothered by having long waits for doctor appointments?
32. In the past four weeks, how often have you experienced numbness or tingling?

Global Indicator of Change

The Scale:

-3: Much worse

-2: Worse

-1: A little worse

0: No change

+1: A little better

+2: Better

+3: Much better

1. How would you rate the change in your pain related to your liver transplant over the last 6 months since you last filled this questionnaire?
2. How would you rate the change in your strength over the last 6 months since you last filled this questionnaire ?
3. How would you rate the change in your mood disturbances over the last 6 months since you last filled this questionnaire?
4. How would you rate the change in your concern over rejection in the last 6 months since you last filled this questionnaire?

ABBREVIATIONS

- pLTQ, Post Liver Transplantation Quality of Life Instrument
- HRQoL, Health related quality of life
- OLT, orthotopic liver transplantation

Appendix 2

Summary of differences between the original PLTQ and the Persian version (PV-PLTQ):

The original Post-Liver Transplant Quality of Life Instrument (PLTQ) developed by Saab et al. is a disease-specific, 32-item questionnaire with 8 domains. In developing the Persian version (PV-PLTQ), we strictly preserved the structure of the original instrument: all 32 items and all 8 domains were retained, no items were added, deleted, or merged, and the 1–7 response scale (higher scores indicating better health-related quality of life) was kept unchanged. Therefore, any differences between the English and Persian versions are limited to linguistic and cultural adaptation of wording, and not to the underlying constructs or scoring.

Linguistic and cultural adaptations

The translation and cross-cultural adaptation followed a forward–backward procedure, expert committee review, and production of a pre-final version. Most items were translated concept-by-concept using natural, everyday Persian expressions. In a few cases, minor adaptations were required to improve clarity and cultural relevance for Iranian liver transplant recipients, while keeping the original meaning intact. Typical modifications included:

- Using commonly understood Persian terms for emotional states (e.g., depression, anxiety, irritability, worry) instead of literal, technical phrasing;
- Clarifying certain healthcare-system concepts (e.g., frequent doctor visits, multiple blood tests, communication with the doctor or transplant coordinator) using wording that reflects post-transplant care in Iran;
- Adding short explanatory phrases for potentially unfamiliar concepts such as “immunosuppression” (explained as reduced ability of the body to fight infections);
- Providing examples of typical transplant-related expenses in Iran (e.g., medication, laboratory tests, imaging) when referring to medical bills, without changing the construct of financial burden;
- Choosing culturally resonant expressions for family-related items (e.g., feeling like a burden on family members) while preserving the original psychosocial meaning.

None of these adaptations altered the content of the items, their allocation to domains, or the scoring direction. The PV-PLTQ can therefore be considered conceptually equivalent to the original PLTQ.

Pretest (cognitive debriefing)

The pre-final PV-PLTQ was pretested in a group of liver transplant recipients to evaluate clarity, relevance, and acceptability. Participants reported that the instructions, items, and response options were easy to understand and applicable to their post-transplant experience. Only minor wording refinements (e.g., simplifying phrases and ensuring consistent time-frame wording such as “in the past four weeks”) were made based on patient feedback.

Importantly, no items were considered irrelevant or confusing, and no changes were made to the number of items, domains, or response scale after pretesting.

Table. Domains and examples of adaptations between the original PLTQ and PV-PLTQ

Domain	Examples of wording / cultural adaptation in PV-PLTQ	Effect on content
Emotional Function & Worry	Use of familiar Persian expressions for depression, anxiety, irritability and excessive worry; emphasis on health-related concerns in everyday language.	Constructs unchanged; items still assess emotional distress and health-related worry as in the original PLTQ.
Medications	Clarification of following medication instructions and concerns about side-effects using common clinical terms; cost item expressed as cost of transplant medications.	No change in meaning; still evaluates perceived burden of medication use and its financial impact.
Physical Function	Activities (housework, walking after surgery, driving) described with common verbs used in daily Persian speech.	Retains the same physical functioning construct; only wording made more natural.
Healthcare	Doctor and transplant coordinator mentioned together; phrases adapted to reflect typical clinic visits and repeated blood tests in Iran.	Healthcare interaction concepts preserved; no structural modification.
Graft Rejection Concern & Infection	Technical term “immunosuppression” supplemented with a brief explanation (reduced ability to fight infection).	Underlying concern about rejection and infection remains identical to the original.
Financial	Medical bills described with examples (medications, laboratory tests, imaging) relevant to Iranian patients.	Still measures financial burden; only contextual clarification added.
Pain and Physical Symptoms	Pain, numbness, and tingling expressed with common symptom terms used by patients.	No change in construct; items continue to capture symptom burden related to liver transplantation.

Appendix 3. The score of PV-PLTQ among participants with different demographis characteristics

Variable	Age		Sex		Level of education			
	< 50 y	≥ 50 y	Female	Male	Under diploma	Diploma	Undergraduate	Postgraduate
Mean ± SD	5 ±1.43	5.5 ± 1.55	5 ±1.4	5.27 ± 1.3	5.1 ± 1.7	5.2 ± 1.1	5.3 ± 0.9	5.2 ± 1
The statistical analysis showed insignificant differences between groups.								