

Supporting Quality of Life in Adults on Home Parenteral Support

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Home parenteral support (HPS) is life-sustaining for patients with chronic intestinal failure (CIF). Quality of life (QoL) can be affected by physical, psychological and social well-being. Patients/family and caregivers have highlighted QoL as a top future research priority and this document shows many of the difficulties experienced by them. It aims to reflect best practice and help healthcare professionals assess and optimise QoL. We recommend the use of a structured QoL assessment tool on a regular basis as a means to guide open-ended dialogue to explore personalised needs. Multi-centre studies to improve services are encouraged.

Key points

1. QoL is multidimensional encompassing not only the underlying illness but also emotional well-being, social integration, environmental stability and personal independence.
2. The social determinants of QoL include housing stability, income, education, and access to support networks.
3. Realistic expectations about adapting to HPS should be set.
4. Independence is encouraged and decision-making is shared.
5. When safe, eating and drinking is encouraged.
6. Healthcare professionals need to understand the family and caregiver's difficulties.
7. When possible, the number and duration of HPS infusions should be minimised.
8. The impact of the underlying gastro-intestinal disease, and associated symptoms must be appreciated.
9. Psychological issues (e.g. anxiety and depression) should be managed proactively, ideally with the support of a psychologist with expertise in CIF.
10. Peer support from patients and caregivers is beneficial.
11. QoL assessment tools (e.g. HPN-QoL, PNIQ, SF-36 and EQ-5D) may be used.
12. QoL assessment should be routine practice and the results reviewed by the multidisciplinary team.
13. Choose QoL tools with patient input and share the results; an HPN-specific tool may be preferred.
14. Use QoL tools as conversation starters.
15. Prioritise continuity and coordination of care.

Explanations

1. QoL is not limited to physical health. It encompasses emotional well-being, social integration, environmental stability and personal independence. Patients may experience reduced QoL due to disruptions in their social lives, roles within the family or workforce, and the emotional toll of living with chronic illness. A comprehensive assessment of QoL should consider these diverse domains.
2. Social factors such as housing stability, income, education and access to support networks significantly influence QoL. Patients who are socially isolated or experiencing financial hardship often report lower QoL and higher psychological distress. Holistic care planning should integrate social work support, benefits advice and community-based resources.
3. Adjusting to HPS is challenging, particularly for those transitioning from an acute illness. Patients newly initiated on HPS frequently report feelings of loss and reduced independence. It is important to prepare patients for the adaptation period, offering psychological support and peer mentorship to ease the transition.
4. Patients who are actively involved in their care decisions tend to feel more in control and report higher QoL. Encouraging autonomy in managing HPS routines, selecting equipment and adjusting schedules (where clinically appropriate) foster engagement and empowerment.
5. The ability to eat and drink, even if only minimally, can have a profound psychosocial benefit. It reinforces a sense of normality and supports social interaction during meals. Clinicians should work with patients to maintain safe oral intake wherever possible and provide tailored dietary advice. Where this is not possible, focused psychological support should be offered where needed.

6. HPS affects not only the patient but also their household. Caregivers may face significant physical, emotional and financial stress, especially when managing complex regimens or caring for patients with complex needs. Offer caregiver assessments and consider involving family members in education and planning sessions. Respite options should also be explored.

7. The infusion burden should be minimised if safe. The number and duration of HPS infusions are strongly linked to QoL outcomes. Patients receiving more nights of infusions per week usually report greater disruption to sleep, work and social activities. Where clinically appropriate, reducing frequency or volume of infusions can significantly enhance QoL.

8. The multimorbidity of patients receiving HPS includes the underlying gastro-intestinal condition (symptoms, duration and progression). This may have a large impact on QoL and may be helped by appropriately tailored psychological support.

A shorter remnant bowel length is associated with more severe symptoms such as high stoma output and dehydration, which negatively affect QoL.

Understanding this relationship can help guide discussions around expectations, symptom control strategies, and treatment options including hydration management and loperamide use.

9 & 10.

Mental health issues such as anxiety and depression are common and often under-recognised in HPS patients. Early identification through screening, referral to psychological support, and

encouragement of peer interaction can all help mitigate distress and support emotional resilience.

11. QoL assessment tools like HPN-QoL, PNIQ, SF-36 and EQ-5D provide structured ways to identify concerns that might not emerge in clinical reviews. Regular use helps track progress over time, informs care planning and supports evaluation of interventions.

12. Despite broad agreement on its importance, QoL is rarely measured consistently in practice. Multidisciplinary teams should incorporate QoL tools into routine reviews, allocate time for discussion of results and ensure that all members are trained in interpreting and responding to findings.

13. Patient-reported outcome measures are designed to elevate the patient voice. Yet, they are often selected without patient consultation and the results are seldom discussed. Engaging patients in choosing tools and sharing outcomes enhances transparency and supports shared care.

14. QoL tools are most valuable when used to guide meaningful, open-ended dialogue. They can help clinicians identify issues that may not be openly expressed and facilitate a more personalised approach. Particularly for less experienced staff, they offer a structured entry point for deeper discussion.

15. Fragmented care pathways can lead to miscommunication, missed issues, and reduced patient satisfaction. Establish clear channels for communication among all relevant services, including nutrition support teams, stoma nurses, relevant medical specialities and mental health services, to provide seamless, integrated care.

Suggested reading

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