

Patient Quality of Life with Intestinal Failure



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This blog looks at the quality of life (QoL) for patients with high output enterostomies (HOPE) and enterocutaneous fistulas (ECF) and how adjustments to care can make a positive impact on their QoL.

A standard care pathway for HOPE and ECF patient involves a high level of contact points with multidisciplinary teams, therapies, and extended hospital stays. All are necessary to stabilise the patient however, the impact on a patient's day-to-day life and the effect on their QoL is high^{1,2,3,5}.

Patients subjected to long hospital stays and/or with therapy fatigue have a heightened risk of institutionalisation. The actual impact on a patient depends on their level of resilience and the support they require and receive. With this in mind, it is necessary to use as many options as available to reduce the impact of care intervention on a patient's mental health and QoL. This could be achieved by keeping clinical contacts to a minimum, only administering therapies that are clinically indicated and encouraging as much interaction as possible with family and friends^{1,2,3}. Examples of possible changes to the way care is implemented include; grouping visits made by different disciplines so there are not multiple appointments over a day; planning the administration of intravenous medication and fluid at times of low activity, such as bedtime; and planning frequent home and overnight stays.

The literature available on the QoL of patients with type two intestinal failure is mostly centered around the administration of home parenteral nutrition (HPN) and their assimilation back into their normal lives⁵. This is the primary area of research as this is the standard care pathway for intestinal failure patients. Other factors are not independently examined and are only seen in relation to HPN. Nevertheless, a patient's rehabilitation at home versus an extended inpatient stay is well studied, with home rehabilitation being the favourable option.

This is because patients are amongst their family, friends, and belongings so they are given a more realistic understanding of how their life will function, rather than the hospital's sterile environment⁵. The improved QoL from rehabilitating at home versus inpatient can be corroborated with other rehabilitation programmes for other diseases such as chronic obstructive pulmonary disease, cardiac rehab, and orthopaedic procedures^{1,2,3,4}.

Bluthner et al. (2020) identify factors that improve the QoL of intestinal failure patients and suggest focusing on addressing social factors, emotional factors in relation to oral eating, early stoma closure, educational interventions, and new targeted therapies⁵. The reduction of therapy and contact in the form of health care professional visits is viewed favourably by patients as a "step towards resolution" and moving on with their lives. This is where targeted therapies, such as The Insides™ System, can be utilised to improve QoL. The Insides™ System is a patient managed therapy that allows the reintroduction of oral food and freedom from the constraints of an intravenous administration giving setting.

References

1. Smith, K., Arthur, H., McKelvie, R. & Kodis, J. (2004) Differences in sustainability of exercise and health related quality of life outcomes following home or hospital-based cardiac rehabilitation. *Eur J Cardiovasc Prev Rehab*, 11(4), 313-319. 10.1097/01.hjr.0000136414.40017.10
2. Candemir, I., Ergun, P., Kaymaz, D., Demir, N. & McCurdy, S. Comparison of unsupervised versus supervised hospital outpatient rehabilitation in patients with chronic obstructive pulmonary disease. *Expert Rev Respi Med*. 13(12), 1195-1203. 10.1080/17476348.2019.1675516
3. Sindhupakorn, B., Numpaisal, P., Thienpratharn, S. & Jomkoh, D. (2019) A home visit program versus a non-home visit program in total knee replacement patients: a randomised controlled trial. *J Ortho Surg Res*, 14(1), 405. 10.1186/s13018-019-1412-6
4. Kim, J., Lee, M., Lee, D., Kang, D., Min, J., Lee, J., Chu, S., Su Cho, M., Kim, N. & Jeon, J. (2018). Effects of a 12-week home-based exercise program on quality of life, psychological health, and the level of physical activity in colorectal cancer survivors: a randomised controlled trial. *Supportive Care in Cancer*, 27, 2933-2940. 10.1007/s00520-018-4588-0
5. Bluthner, E., Bednarsch, J., Stockman, M., Karber, M., Pevny, S., Maasberg, S., Gerlach, U., Pascher, A., Wiedenmann, B., Pratscke, J. & Pape, U. (2020). Determinants of quality of life in patients with intestinal failure receiving long term parenteral nutrition using the SF-36 questionnaire: A German single-center prospective observational study. *JPEN*, 44(2), 291-300. 10.1002/jpen.1531