

**Preliminary Oxford data on Quality of life related to Intestinal transplantation and HPN**

| <b>Patient</b>   | <b>Pre Tx Score<br/>EQ5D</b> | <b>Post Tx Score<br/>EQ5D</b> |
|------------------|------------------------------|-------------------------------|
| D.C.             | 30                           |                               |
| J.F.             |                              | 75 - 1 mo post                |
| J.F.             |                              | 85 - 1 yr post                |
| M.G.             | 10                           |                               |
| A.G.             | 25                           | 79.5 -1 yr post               |
| J.H.             | 10                           | 80 - 1 yr post                |
| J.H.             |                              | 80 - 2 yrs post               |
| K.K.             |                              | 90 - 3 yrs post               |
| D.L.             | 40                           |                               |
| B.M.             |                              | 80 - 5 yrs post               |
| I.M.             |                              | 40 (following explant)        |
| O.J.             |                              | 90 - 1 yr post                |
| C.P.             | 50                           |                               |
| M.S.             |                              | 65 - 3 yrs post               |
|                  |                              | 55 - 4 yrs post               |
| H.W              | 30                           | 85 - 6 mo post                |
|                  |                              | 65 - 1 yr post                |
|                  |                              |                               |
| <b>median</b>    | 30                           | 80                            |
| <b>max</b>       | 10                           | 55*                           |
| <b>min</b>       | 50                           | 90                            |
| <b>n records</b> | 7                            | 12                            |
| <b>Patients</b>  | 15                           | 15                            |
|                  |                              | *excl. explant                |

| <b>Home<br/>Parenteral<br/>Nutrition</b>    | <b><i>EQ5D 1st<br/>completion</i></b> | <b><i>EQ5D 2nd<br/>completion<br/>(interval 4-6 m)</i></b> |
|---|---------------------------------------|--|
|   | 80                                    |  |
|   | 70                                    | 30   |
|   | 45                                    |  |
|   | 70                                    |  |
|   | 30                                    |  |
|   | 90                                    | 70   |
|   | 60                                    | 50   |
|   | 25                                    |  |
|   | 80                                    |  |
|   | 40                                    | 50   |
|   | 75                                    | 75   |
|   | 80                                    | 90   |
|   | 60                                    |  |
|   | 75                                    |  |
|   | 35                                    | 45   |
|   | 60                                    |  |
|   | 75                                    |  |
|   | 35                                    |  |
|   | 75                                    |  |
|   | 45                                    |  |
|   | 50                                    |  |
|   | 95                                    |  |
| 7/29 declined to complete/did not return Qs |                                       |  |
| <b>median</b>                               | 65                                    | 50   |
| <b>min</b>                                  | 25                                    | 30   |
| <b>max</b>                                  | 95                                    | 90   |
| <b>n all records</b>                        | 22                                    | 7  |
| <b>Patients</b>                             | 29                                    | 29   |

These preliminary data show

1. There are practical difficulties in data collection from patients on HPN, often owing to illness behaviour/disinclination to complete questionnaires
2. There is a marked improvement in QoL after transplant which is may be maintained for up to 5y
3. The QoL on HPN was broadly stable when collected at two intervals 4-6m, apart from one patient admitted for an exit-site infection (decline in EQ5D from 70 to 30)
4. Post-transplant QoL is generally good (median EQ5D 80 post Tx). Median EQ5D on HPN, including one patient pending transplant, is 50-65.
5. There is a very wide range in quality of life for patients on HPN (25-95 measured by EQ5D)
6. HPNQoL data is currently too complex to synthesise

### **Conclusions**

Collecting such data should continue with more attention to formalising the intervals for data collection. Data from Cambridge would be welcome. It may yet provide a useful snapshot on the value and impact of intestinal transplantation. HPN patients differ and are not matched to the transplant population.

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