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FIGHTING AGAINST MALNUTRITION AND RAISING AWARENESS OF HOME PARENTERAL NUTRITION AND HEALTH RELATED PSYCHOSOCIAL FACTORS AFFECTING COMPLIANCE, HOSPITAL ADMISSIONS, CLINICAL OUTCOME AND COSTS: A TERTIARY REFERRAL UNIVERSITY HOSPITAL MULTIDISCIPLINARY MODEL TO TRANSLATE AT NATIONAL AND INTERNATIONAL LEVEL Simona Di Caro MD PhD, Farooq Rahaman MRCP PhD

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### Background

Patients on home parenteral nutrition (HPN) encounter a broad range of problems. The focus of Nutrition teams is mainly on the infective and metabolic complications of parenteral nutrition (PN); however these patients represent an even more complex challenge with multiple underlying medical conditions and consequent impaired quality of life, depression, anxiety and somatic physical complaints affecting their daily life and that of their family/carers (1). Indeed many of the issues arising from HPN are psychological or social in nature (2). All these factors have an impact on Quality of Life (QoL) and consequently on compliance, hospital admissions, polypharmacy condition (relating mainly to excess of analgesia and narcotic bowel syndrome) and ultimately clinical outcome and costs (3-6).

### Rationale

Specialist psychological support is often not available as part of the care either for inpatients and outpatients under the Nutrition Team, despite the crucial impact it can have on management and consequent malnutrition.

# Survey/Implementation

As a screening tool to identify patients with emotional and social difficulties arising from physical health who might benefit from psychological support, we administered to HPN patients a validated Quality of Life questionnaire (specific for HPN) and a Healthy Survey questionnaire (SF-36), while all those not on HPN but with complex nutritional needs completed only the SF-36, whilst on the ward or in the outpatients setting (7, 8).

Twenty patients (6 males, mean age 59.4 =/- 25 years) completed the questionnaires. Interestingly, all patients spontaneously expressed positive, comments that the Nutrition Team was interested in assessing their QoL.

## Results/Outcomes

55% (11/20) and 25% considered their general health as poor or fair, respectively. 90% reported limitations in moderate activities (such as pushing a vacuum cleaner, climbing one flight of stairs, carrying groceries, etc), 65% admitted emotional problems and 75% interference with social/family life related to health issues. 80% reported severe pain interfering with their activities and 60% of patients "expect their health to get worse", the remainder responding "not known" (35%) rather than not (5%).

Among the 10 patients on HPN, 7, 2 and 1 respectively reported that HPN made the feel "better", "worse" or "no change": all agreed that HPN has affected their abilities to do things including sleeping pattern for 9/10. Seven patients felt less attractive or that they had a distorted body image as a result of health problems and/or presence of a catheter or previous surgery. Eight patients answered they were "a bit" or "not at all" interested in sex.

All the 20 patients felt their underlying illness made them "very much for the worse" and scored their quality of life in a scale 0-1- on average 3.5: none of them scored above 5 and two patients scored 0.

#### Outcomes/actions to measure in a second step are:

Use of the questionnaires into routine practice as a screening tool to identify patients under the Nutrition Team for benign disease who would benefit from psychological support.

To introduce a dedicated Clinical Psychologist into the Nutrition Team at UCLH in order to offer support/treatment (Relaxation/Cognitive Behavior Therapy/Hypnosis/Stress Management)

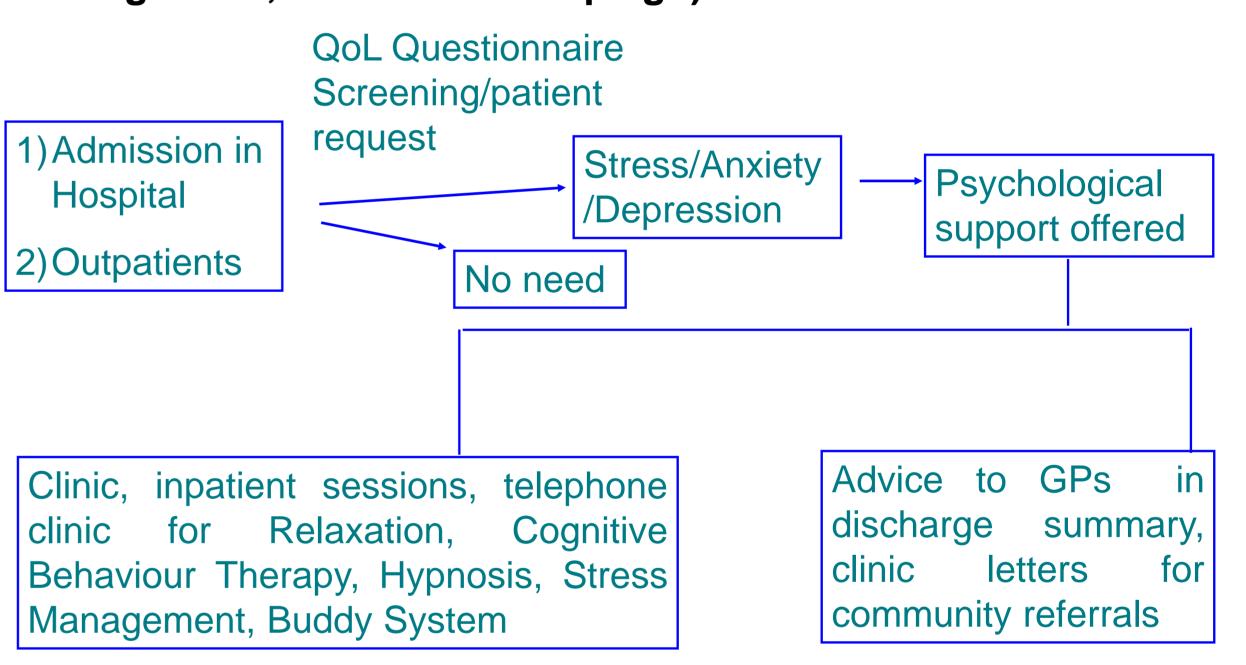
To introduce a "buddy system" which is effectively used in school setting, women health, bariatric surgery.

To assess the impact of offering long-term specialist psychological support to HPN patients in terms of compliance, improvement of QoL, hospital admissions, seeking medical advice/treatment, polypharmacy and ultimately costs

To interface with GPs and local Services for patients who are not local to the Trust area in need of psychological support in order to offer a stream less care.

#### **Finances**

Part of the grant will cover one study year of a clinical psychologist with an interest in complex nutrition patients' care, who will be fully dedicated to patients on the ward and in outpatients setting, allowing a mulltidisciplinary approach and offering effective and prompt support/therapy to patients, liaise with the community (GP, support groups, etc). The rest of the grant will cover the set up of the Buddy logistic expenses the study (data System and management, awareness campaign).



#### Conclusions

Our screening confirms the data present in literature and daily clinical experience that patients under the care of Nutrition Teams overall are in need of a specialist psychological support, that is expected to have a significant impact on clinical management, outcome and costs.

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