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Opinion Paper

Experiences of the COVID-19 pandemic: A survey of patients on home parenteral nutrition

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SUMMARY

Patients on home parenteral nutrition (HPN) have had to endure sweeping changes to their personal lives and medical care during the COVID-19 pandemic. We evaluated the patients' perspectives of these changes at our Intestinal Failure/Rehabilitation centre in order to initiate a debate on improving HPN care. The findings point to high levels of anxiety and depression amongst the 35 patients surveyed with many reporting frustration at conflicting information from different sources. Telephone consultations were well received and most were keen for these to continue. In light of these results, we outline recommendations to enhance our patients' experiences in the coming phases of the pandemic.

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1. Introduction

In the United Kingdom (UK), patients with Intestinal Failure (IF) receiving home parenteral nutrition (HPN) number just over 2300 or 40 per 1 million population [1]. As with all patients with chronic diseases, the sweeping changes necessitated by the COVID-19 pandemic have significantly disrupted the personal lives and medical care of patients on HPN. During government enforced lockdowns in March 2020, November 2020 and January 2021, the UK government advised 'shielding' measures for the most vulnerable people living with chronic illness including HPN patients. Shielding meant that patients followed enhanced self-isolation where they were asked to remain at home and minimise any social interaction. The infrastructure surrounding the care of HPN patients was also severely disrupted with a reduced service for delivery of PN, fluids and ancillaries and shortage of HPN nurses due to redeployment [2]. All HPN patients received letters from their HPN centre explaining the rationale for shielding and recommendation for vaccination provided once strategies were developed nationally. HPN patients also saw widespread implementation of virtual consultations and a subsequent reduction in biochemical monitoring and radiological procedures [2].

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There have been surprisingly few studies evaluating HPN patients' experiences of the COVID-19 pandemic and the effects of changes to HPN care instituted during the height of the global crisis. As we now enter a new phase of the pandemic, review and reflection of previous measures is essential to improve HPN care going forward. Therefore, we aimed to present the results of a small survey of patients at our centre to initiate a debate on the topic and draft recommendations for ongoing HPN care.

2. Method

An electronic survey was prepared on the Alchemer online interface (www.alchemer.com). Links for the survey were disseminated via email and post to all HPN patients registered at our centre. The survey link was open between 1 December 2020 and 31 March 2021. The survey consisted of 39 multiple choice or free text questions and was prepared by a multidisciplinary group based at our centre including specialist nutrition nurses, gastroenterologists and dietitians. The survey questions did not undergo a validation process as there were few validated COVID questionnaires available at the time and a validation process would have missed the first waves of the pandemic. The survey was registered locally as a clinical audit and a transcript is available in [Appendix I](#).

The results were analysed using Microsoft Excel 2019 and Alchemer's custom filters. Chi-squared testing was used to assess associations between variables. A two-sided analysis was used and a p-value <0.05 was considered statistically significant.

3. Results

3.1. Survey sample

Of the 98 patients registered at our centre and contacted to complete the survey, 35 completed the questionnaire giving a response rate of 35%: 22 females and 13 males. Mean age of respondents was 54.4 years (range: 19–84). 15 patients received PN 7 days a week, 3 received PN 6 days a week, 4 received PN 5 days a week, 9 received PN 4 days a week, 4 received PN 3 days a week. 19 patients were on PN for >5 years, 11 patients were on PN for 1–5 years, 5 patients were on PN for <1 year. 5 patients were on concomitant immunosuppression.

3.2. Sources of COVID-19 related health information

Most patients received official letters with advice on shielding during the lockdown phases of the pandemic, 31 (89%) from the government and 33 (94%) from the HPN centre. In addition, patients accessed a range of other information sources for advice on protecting themselves (Fig. 1). The most commonly accessed sources were UK government or NHS websites (74%), the HPN centre (34%) and the GP practice (17%).

Most patients reported high levels of satisfaction with the information provided with an average score of 8.7 out of 10 (range 2–10) and 29 (83%) reported that information accessed alleviated their anxiety. However, 8 patients expressed frustration at conflicting information from various sources (23%) and 7 were frustrated at inadequate information received (20%).

Patients accessing social media platforms and online sites other than the NHS website were more likely to complain of inadequate and conflicting information than those that accessed official sources only ($p = 0.02$).

3.3. Shielding

The vast majority followed guidance to shield during both the 1st and 2nd lockdowns in the UK, 94% and 91% respectively. Patients were equivocal about their anxieties on easing of the shielding restrictions with an average score of 5.8 out of 10 (range 1–10, with 10 being “extremely anxious”).

3.4. Quality of life

Patients rated their quality of life prior to the pandemic at an average score of 6.1 out of 10, with scores of 10 being “fantastic”.

Average quality of life scores during the pandemic were significantly worse at 4.6 out of 10 ($p = 0.006$), see Fig. 2. Patients rated their anxiety & depression during the pandemic at an average of 5.4 out of 10, with scores of 10 being “extreme anxiety and depression”. 8 patients (23%) reported scores of 8 and above. Most felt adequately supported by family and friends (88%). 8 patients (22%) reported financial worries and 17 patients (49%) reported sleeping difficulties.

3.5. HPN deliveries

6 patients (17%) reported disruption to their PN deliveries. 11 patients (31%) did not receive extra IV fluids or multichamber emergency contingency PN bags. Out of 10 patients receiving regular home nursing attendance, 2 reported disruption in nurse visits.

3.6. Blood tests

30 (86%) patients had at least one blood test performed whilst shielding. The majority were performed in hospital (46%) followed by at home (42%) and at the GP surgery (12%). Patients reported average scores of 8.8 out of 10 for confidence that all protective measures to prevent the spread of COVID were taken during blood tests, scores of 10 being extreme confidence.

3.7. Appointments

17 patients (49%) reported that the pandemic had affected non-HPN medical care. The majority of patients (34, 97%) had undertaken an appointment with the HPN centre during the pandemic, with the vast majority being over the telephone (31, 91%). 8 patients (24%) reported that their appointment had been delayed as a result. Telephone clinics were well received on the whole (Fig. 3): 9 patients (29%) claimed these were as good as face to face, 1 (3%) claimed they were better than face to face, 19 (61%) felt they were helpful but no substitute for face to face and 2 (6%) felt they were a waste of time. 19 patients (53%) were keen to continue telephone clinics after the pandemic. No patients received video consultation but 21 patients (60%) were interested in undertaking these if offered.

3.8. Fears around contracting COVID-19

Average score for concerns of contracting COVID-19 was 4.3 out of 10, with a score of 1 denoting “extreme concern”. 16 patients

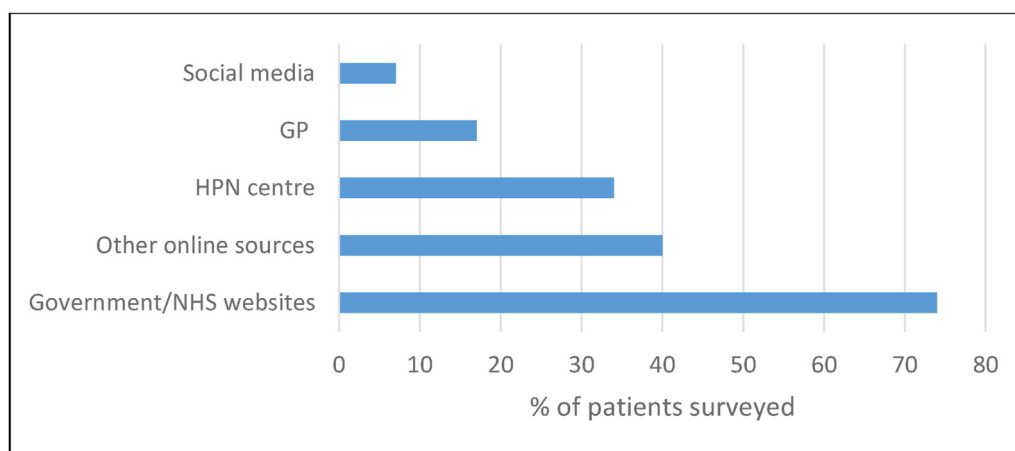


Fig. 1. Sources of patient information

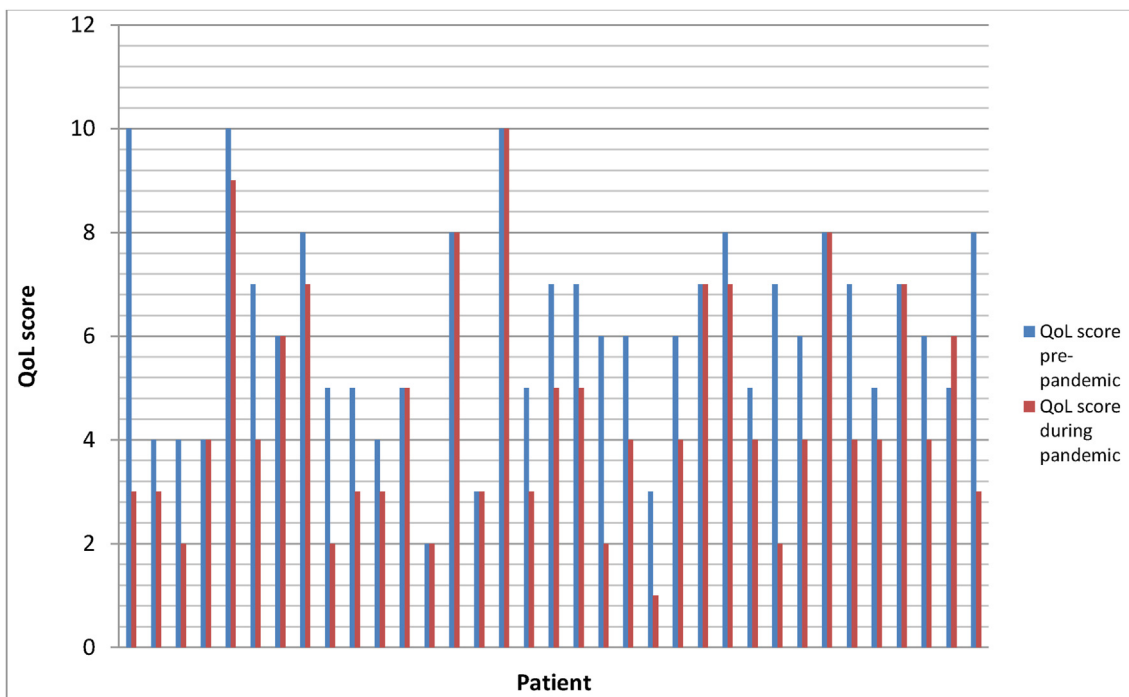


Fig. 2. Quality of life (QoL) scores pre- and during the pandemic for each of the patients surveyed, scores of 10 denoting “fantastic” QoL.

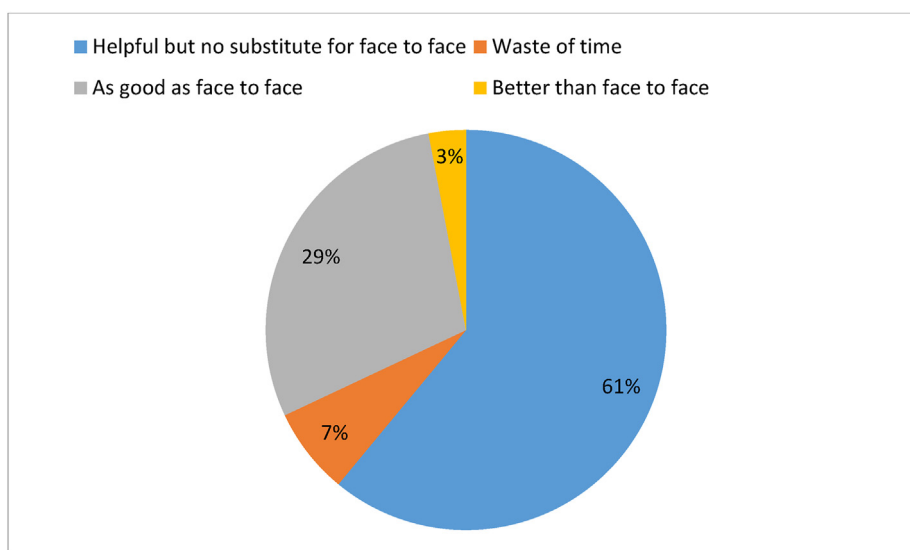


Fig. 3. Patient views on telephone clinics

(17%) gave scores of 3 and under. 5 patients (14%) reported contracting COVID-19.

4. Discussion

Few studies have evaluated the experiences of HPN patients during the COVID-19 pandemic and the effectiveness of measures introduced. This survey, although limited by small numbers and set in single centre, can serve as a starting point for reviewing HPN care going forward.

Firstly, many of the new measures to counter the pandemic's effects were well received. Telephone consultations, in particular, were popular and over half of patients surveyed were keen for

virtual clinics to continue post-pandemic. A pre-pandemic study had shown virtual clinics to be effective [4] and it is clear that these are here to stay in HPN care. There have been very few studies evaluating the utility of virtual consultations in improving HPN patient outcomes and cost effectiveness and further research is needed in this regard.

Secondly, this survey highlights the need to improve communication avenues between primary/secondary care and HPN patients. Although, the vast majority of patients received information letters from the government and our HPN centre on shielding and protecting themselves during the pandemic, many felt this was inadequate and some were left frustrated at conflicting information from various sources. A similar survey in patients with Inflammatory

Bowel Disease demonstrated the benefits of information from trusted sources as well as regular contact with the care provider in alleviating patient concerns during the pandemic [5]. Moreover, the pandemic has exposed the information sharing inadequacies between primary and secondary care. Unpublished survey data from PINNT, the leading artificial nutrition patient support group in the UK showed that 41% of patients who contacted their GP surgery found that their primary care givers had no knowledge of their advice to shield [6]. Measures to streamline the primary and secondary care interface are needed to enhance HPN patients' experiences and increase cost effectiveness.

Finally, increasing anxiety and depression amongst HPN patients point to the urgent need to bolster patchy psychological service provision in this vulnerable patient group. The increase in psychological and psychiatric comorbidity generally during the pandemic is well documented [7]. In HPN patients specifically, a recent international survey of clinicians involved in HPN care showed that over 70% of participants reported anxiety, worry and apprehension amongst their HPN patients [2]. The rise of psychological morbidity is especially worrying given the already high prevalence of mental health problems amongst HPN patients and the relative lack of specialised IF psychology services across the UK [8].

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authors critically reviewed the manuscript. AM finalised the submission. All authors thank the participants for taking time to complete the survey.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.clnesp.2022.05.021>.

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