

Coeliac Disease Management during SARS-CoV-2 Pandemic: Patient's and Families Experience from Southeast England

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Review Article

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Abstract

Aim: The health care system had to evolve rapidly to adapt to the multiple challenges posed by SARS-CoV-2 pandemic. At the Maidstone and Turnbridge Wells NHS trust we provide tertiary paediatric gastroenterology services to paediatric patients from Kent and East Sussex, including new patients with suspected Coeliac disease (CD) and long-term follow-up. This study looked at the patient and their family's experience of CD with regards to their disease management during the government-imposed lockdown from March 2020 to November 2021.

Methods: A retrospective study was done, using a telephone questionnaire to assess patient's and family's experience of the management of their coeliac disease. It included identifying symptoms during lockdown, access to gluten free (GF) products, and emotional wellbeing. 50 interviews were completed with patients (3 to 16 years of age) and their families.

Results: Our standard follow-up practice for patients with a confirmed diagnosis of CD is an annual review with specialist gastroenterology nurse and dietician and this target was met for 72% (36/50) of patients (both virtual and face to face clinic reviews). 98% (49/50) of patients denied development or worsening of any GI symptoms and 96% (48/50) of patients reported normal development in growth and height since the lockdown. 96% of patients (48/50) were able to procure GF product during the lockdown. During the initial 3-4 weeks of lockdown, some families reported limited options of GF products but were still able to procure some products. Patients and their families reported being emotionally well and with no significant changes in the weight and height of patients.

Conclusion: During the SARS-CoV-2 pandemic, patients with CD managed well despite the lockdown. We managed to see the majority of our patients (virtual/face to face clinics). There was no significant impact on procuring GF products and emotional well-being, despite multiple challenges.

Keywords: Coeliac Disease, SARS-CoV-2 Pandemic

Introduction

The health care system had to evolve rapidly to adapt to the multiple challenges posed by SARS-CoV-2 pandemic. During the UK government imposed lockdown and various restrictions from March 2020 to November 2021, health care providers had to rapidly modify the delivery of care to minimize the spread of SARS-CoV-2 to patients and staff [10]. As the disease burden of the pandemic increased and gastroenterology outpatient clinic

capacity decreased, health care providers shifted towards using telephone clinics to manage patients with Coeliac disease (CD).

The BSPGHAN and Coeliac UK guidelines advise annual or bi-annual (if stable long-term) clinic review by a paediatric dietician and paediatric gastroenterologist for CD [4]. The Maidstone and Tunbridge Wells NHS trust provides tertiary level care through a paediatric CD clinic led by a gastroenterology nurse and dietician. Globally one-to-one clinics, group sessions, telephone clinics and

online interfaces [3] have all been used for CD follow up. There is a consensus that long term follow up is beneficial but there is a lack of agreement on the most effective review method. Recent work supports the idea that patients prefer nurse or dietician led clinics to consultant led clinics [5]. And that telehealth clinics have also shown an increase in gluten free (GF) product dietary knowledge and increased gluten free diet (GFD) adherence [3,8]. Our study will help evaluate the efficacy of telehealth clinics being used for the long term management of patients with CD as there is limited research on the impact of lockdown on patients' management with CD.

CD is an immune mediated systemic disorder affecting every 1 in 100 persons in the UK [4]. It is characterized by a combination of gluten-dependant manifestations, including CD-specific antibodies, and enteropathy [4]. Patients can present as symptomatic or asymptomatic [4]. Symptoms include, abdominal pain, diarrhea, vomiting, faltering growth, constipation, skin rashes, joint pain/swellings [4]. The long-term management is adherence to a strict GFD [9]. We hypothesized that the lockdown would impact the procurement of GF product and thus affect CD management. The pandemic has been shown to affect the mental health of the population [9]. Hence, we assessed symptom control and the emotional well-being of patients. We wanted to understand if this group of people were more vulnerable than the rest of the population to the effects of the lockdown due to the pandemic. The overall purpose of this study was to determine if paediatric CD clinics could be managed safely over the telephone and to determine how this population responded to the multiple challenges of the SARS-CoV-2 pandemic.

Methods

A retrospective study using a telephone questionnaire was used to assess the impact of lockdown on CD management by patients with histologically confirmed CD. 50 semi-structured qualitative interviews were completed with paediatric patients and family members. The interviews were conducted by a medical student who was not involved in providing clinical care to the patients. Participants were recruited from the MTW trust CD clinic database. Inclusion criteria required patients to 16 years of age or less and with a confirmed diagnosis of CD, either via biopsy or non-biopsy pathway. 50 responses were collected from a pool of eligible persons (n=195). Patients were contacted up to a maximum of three times before being noted as unavailable. Each call attempt was noted, and calls were carried out until 50 responses were collected. The interview time ranged from 5-7 minutes and involved both the patient and the primary caregivers (most often the parents). The exclusion criteria were patients with inconclusive diagnoses of CD (borderline elevated tTG IgA) or awaiting endoscopy and biopsy confirmation and patients who were not compliant with GFD.

Development of the questionnaire

The multidisciplinary team at MTW developed the telephone questionnaire. The team consisted of a paediatric consultant, specialist gastroenterology nurse, dietician and a medical student. Ethical approval was granted by the MTW clinical audit assessment trust service. Following multiple discussions, a 11-item questionnaire was developed, which evaluated 5 areas of CD management. The areas included (a) Frequency of CD review before the pandemic, (b) symptom control, (c) GF product availability, (d) emotional well-being and (e) CD education

resources. Asking about the frequency of CD review established if the recommended guidelines [4] for annual clinic review were being met by the MTW trust. The symptom control domain used 4 questions to assess pre and post lockdown symptom control and the development of any new symptoms during the lockdown period. Of note, growth was monitored by asking about any negative changes in weight or height. GF product availability was assessed and any reasons for reduced procurement were explored during the interview. The final domains of emotional well-being and support groups used by the patient and family members were also explored. Table 1 includes the questionnaire used.

Table-1: CD management telephone questionnaire.

1	When was the last time you were reviewed?
2	What is the normal frequency/pattern for child's review? i.e., every 4 months, 6 months, 1 year
3	How has your CD been recently?
4	Have you developed any new GI symptoms or had any worsening of pre-existing symptoms during the lockdown period? i.e., abdominal pain, nausea, diarrhea, vomiting, constipation
5	Have there been any worrisome changes in height or weight?
6	Was your coeliac disease well controlled prior to lockdown?
7	Has there been a change in your diet during the lockdown?
8	During the lockdown were your choices for gluten free food limited/impacted? If so, why?
9	How have you been doing emotionally during lockdown? If not well, why?
10	Have you contacted the MTW nursing clinic for advice during this time?
11	Did you use any other resources when stuck? I.e., Coeliac UK, Facebook groups?

Ethical approval

The study was approved by the Maidstone and Tunbridge Wells clinical audit assessment service and was registered with the clinical audit department. All personal details of patients and family members who participated have not been disclosed in the public forum. All participants provided informed consent prior to completing the telephone questionnaire.

Results

For the study, 157 patients were contacted by telephone and 58 responses were recorded (response rate: 36.9%). Among the 58 telephone interviews conducted, 8 responses were rejected because they did not meet the criteria for the study. The exclusion criteria were patients with inconclusive diagnoses of CD (borderline elevated tTG IgA) or awaiting endoscopy and biopsy confirmation and patients who were not compliant with GFD. 99 patients did not attend the phone when contacted (max of three call attempts) or declined to participate in the study when contacted. Therefore, the total number of patients included in this study was 50 (n=50).

Frequency of review

The standard follow-up practice of annual review with a specialist gastroenterology nurse and dietician target was met for 72% (n = 36) of patients through both virtual and face-to-face clinics.

Symptom Management

Overall, 90% (n = 45) of patients reported to be asymptomatic and that their CD management had been good (Table 2). 88% (n = 44) of the group also described their CD as being well controlled prior to lockdown. Of the 12% (n = 6) who described poor control prior to lockdown, 8% (n = 4) attributed it to being undiagnosed at the time and consuming food with gluten. 96% (n = 48) of patients reported normal development in growth and height since the lockdown. 2 (4%) patients reported faltering growth, these patients continued to be under active surveillance. 98% of patients did not develop any new GI symptoms during the lockdown or experience worsening of pre-existing symptoms.

Table-2: Coeliac symptom scores for patient management since the end of lockdown and restrictions.

Coeliac symptom score of patients since lockdown			
Total (n = 50)	Good (n = 45)	Fair (n=2)	Poor (n=3)
Gender wise distribution			
Males (n=13)	12	0	1
Females (n = 37)	33	2	2

Effect of lockdown on emotional well-being

There was no negative impact on emotional well-being due to the pandemic and most patients reported to be doing well. Two families reported that the transition out of lockdown was emotionally difficult for their children and two families reported mild difficulty with adjusting to a GFD during the lockdown. Interestingly 1 patient reported developing a habit of eating in secret during lockdown.

Procurement of GF food

40% (n = 20) of patient's families reported limited variety of GF products during the initial 3-4 weeks of lockdown. 96% (n = 48) were still able to procure GF product during the lockdown, though the choice was limited. Patients reported that staple items such as pasta, bread and flour were the most difficult to get. Patients received help from friends and family members to substitute these items in the early period of lockdown. Despite limited variety of GF product at times, 96% (n = 48) of patients did not change their diet during lockdown in comparison to the pre-lockdown period.

Support by supplementary resources

50% (n = 25) of families reported being members of Coeliac UK. As many patients had a family history for CD, multiple parents remarked using their own experience to support their child's management. 14% (n = 7) of patients reported being members of Facebook groups for CD. They commented that these groups were helpful for dietary knowledge and providing emotional support.

Discussion

This study focused on the impact of the SARS-CoV-2 related lockdown of March 2020 to November 2021 on the management of CD in paediatric patients. The BSPGHAN recommended guideline of annual or biannual review [4] for CD was met by 72% of our patient population. MTW patient population engaged well with the service despite the rapid transition to a telephone clinic. 96% of patients did not contact the clinic besides from their appointment time, as they felt adequately supported by the health care team. Recent work has also shown that patients enjoy

telephone clinics due to their flexibility, not having to travel and the virtual continuity of care [2]. Many parents remarked that the CD clinic consultations were sufficient for dietary guidance.

96% of our patient population was still able to procure some GF product throughout the lockdown though the choice and variety of GF products was limited. Two-thirds of them relied on friends and family to provide alternative GF options, 96% of patients maintained the same diet as prior to lockdown. Patients developed well during the lockdown with only 2 families reporting a delay in growth. Another indicator for good CD management was that 98% of patients did not develop any new or worsening of pre-existing GI symptoms. Patients also coped well psychologically as there was minimal reporting of emotional instability throughout lockdown. At the beginning of the pandemic there was concern regarding the potential vulnerability of patients with CD to the virus and the effects of lockdown [11]. However, our study has shown that patients with CD managed well despite the challenges. Recent work has also shown that for some patients with CD, their GI symptoms and illness perceptions improved during the lockdown [12]. Our study supports this point as many families reported stricter control of their GF diet and reduced cross contamination during lockdown.

Virtual clinics are already established as an effective way to manage long term chronic conditions such as IBD, diabetes and rheumatology [7]. A clinical audit of a dietician led virtual clinic (telephone and postal) established that more than 80% of patients reported preference for alternating between virtual review with face-to-face review in comparison to only attending an in person annual review [7]. There is limited work on comparing the efficacy of CD clinics run by different teams of health care professionals. However, some work has shown that people prefer meeting with a dietician or nurse in comparison with a doctor [5]. Our study supports this as well, because the MTW CD clinic is nurse and dietician led and was shown to provide an easier point of reassurance in comparison to consultant led clinics [2].

An added benefit of telephone clinics is that the quality of care is not compromised. Furthermore, work by Muhammad and colleagues has shown that GF dietary adherence can be increased via telephone consultations at 3 and 6 months post telephone clinic [3]. So, telephone clinics can improve dietary knowledge, and this was measured as a positive change in GF dietary adherence [3]. As the only long term management of CD is a GF diet, this work suggests that telephone clinics can reduce patient morbidity for CD [5].

Strengths and Limitations

The major strength of this study was the use of a standardized questionnaire with open ended questions. The open ended nature of the questions did not influence the patients answers and was suited to explore the opinions and perceptions of the respondents [13]. Furthermore, as the interviews were semi-structured, they allowed for clarification of the patient's responses, and this increases the validity of the study [13].

One of the major limitations of the study is the sample size. Only 50 responses were collected, and this group may not be representative of the population. Additionally, the questionnaire was not validated by a clinical psychologist or an external validation tool. Moreover, despite the many advantages of telephone interviews, there are limitations as well. Of the 157 patients contacted, only 50 responded and this non-response

rate may not be a random process and there may have been introduction of bias [13]. It has also been recognised that the personal characteristics of the interviewer can influence the responses [13]. Lastly, as the patient group was a paediatric population, the interviewer often spoke with the parents of the child rather than the child. Perhaps this impacted the detail of the response and the accuracy.

Conclusion

In conclusion our study provides evidence that paediatric CD clinics can be managed safely over the telephone. Patients with established or new diagnoses of CD both coped well despite the multiple challenges posed by the pandemic. There was no significant impact on procuring GF product, symptom control and emotional well-being for patients. Patients also reported feeling supported by health care providers via telephone clinic. Lastly this study supports the idea that dietician and nurse led clinics are effective for the management of CD.

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