Workshop 14 – Innovative nursing and psychosocial treatment delivery developed during COVID-19 restrictions

WS14.1
The effect of the COVID-19 pandemic on quality of life of adults with cystic fibrosis

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Objectives: The effect of the COVID-19 pandemic on the quality of life (QOL) of people with cystic fibrosis (pwcf) remains unclear. This study investigated the change in QOL, measured by the CFQ-R, in adult pwcf prior to and during the COVID-19 pandemic.
Methods: The CFQ-R scores of 88 adult pwcf completed at two routine clinic appointments (one prior to first COVID-19 case in Wales 28/2/20 and one post) were retrospectively reviewed. Any change in CFTR modulator therapy between these dates was recorded along with demographics, FEV_1% and BMI.
Results: 88 (52 male, 36 female) with mean age, FEV_1% and BMI of 32.2 years, 61.6% and 22.7 kg/m^2 respectively had two consecutive CFQ-R results in the above time frame. Overall, mean social domain scores significantly declined (60.4 to 54.2 $p < 0.001$) and mean emotion scores fell from 69.3 to 65.9 ($p = 0.07$). Results did not vary between males and females.
59/88 had a change in modulator status during this period, mainly commencing Symkevi® or triple modulator therapy, and this group experienced a significant increase in FEV_1% ($p < 0.01$) and BMI ($p = 0.02$) and a statistically significant improvement in every domain of the CFQ-R except emotion, eating, digestion and social. Their mean social score dropped significantly 59.5 to 54.2 ($p = 0.018$).
Of the 29 pwcf with no change in modulator status, there was no significant change in FEV_1% or BMI. Mean emotion domain scores, which assesses feelings of being sad, useless, lonely and difficulty making future plans, significantly worsened from 78.1 to 70.6 ($p = 0.018$). Mean social scores decreased from 62.1 to 54.2 ($p = 0.037$).
Conclusion: This is the first study looking at QOL during COVID-19 in pwcf. During the COVID-19 pandemic there have been developments in access to highly effective modulators, but despite improvements in FEV_1%, BMI and many CFQ-R domains suggesting improved health, emotion and social domain scores fell. This is likely to reflect the effect of the COVID-19 pandemic.

WS14.2
Potential factors influencing reduced requirements for intravenous antibiotics during the COVID-19 pandemic

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Objective: The use of intravenous antibiotics (IVAB) is a central part of the management of pulmonary infections in cystic fibrosis (CF). Adult patients with CF in England were advised to "shield" by the government (23.03.2020–01.08.2020) during the COVID-19 pandemic. Shielding was described as the requirement to not leave home and minimise all face-to-face contact. At our adult CF centre in London, there was a 50% reduction in requirement for IVAB, compared to the same period in 2019.
We aimed to identify potential factors contributing to the reduced requirement of IVAB during shielding.
Method: An 8-point patient questionnaire was given to 27 patients who had required ≥3 courses of IVAB in the year 2019. These were designed to identify: percentage of patients shielding, percentage of patients starting a modulator, variation in adherence to regular medications, chest physiotherapy, and requirement to IVAB.
Results: 70% response rate (n = 19).

FULLY SHIELDED	89%
PARTIAL SHIELDED	11%
DID NTO SHIELD	0%
REQUIRED ADDITIONAL ANTIBIOTICS	74%
REQUIREMENT FOR IVAB REDUCED	26%
REQUIREMENT FOR IVAB STAYED THE SAME	68%
REQUIREMENT FOR IVAB INCREASED	5%
DURING SHIELDING HEALTH STATUS REDUCED	21%
DURING SHIELDING HEALTH STATUS STAYED THE SAME	37%
DURING SHIELDING HEALTH STATUS INCREASED	42%
DURING SHIELDING ADHERENCE TO REGULAR MEDICATIONS STAYED THE SAME	79%
DURING SHIELDING ADHERENCE TO REGULAR MEDICATIONS INCREASED	21%
DURING SHIELDING ADHERENCE TO REGULAR CHEST PHYSIOTHERAPY REDUCED	11%
DURING SHIELDING ADHERENCE TO REGULAR CHEST PHYSIOTHERAPY STAYED THE SAME	68%
DURING SHIELDING ADHERENCE TO REGULAR CHEST PHYSIOTHERAPY INCREASED	21%
DURING SHIELDING PATIENT FELT THEY COULD ACCESS CF TEAM IF REQUIRED	95%
STARTED MODULATOR THERAPY IN THE PRECEDING 12 MONTHS	84%

Despite a 50% reduction in IVAB compared to the previous year, the majority of patients reported their requirement for IVAB remained the same (68%).
There was no self-reported increase in adherence to regular medications or chest physiotherapy. The majority of patients felt their overall health status remained stable or improved (78%). During this period the majority of patients fully shielded (84%) and started Symkevi®/Kalydeco or Kaftrio®/Kalydeco (as part of a trial or compassionate use program) (84%).
Conclusion: Increased adherence to regular medication and physiotherapy did not appear to be a factor in reducing the requirement for IVAB observed during the UK COVID-19 pandemic lockdown. Adherence to government shielding may have reduced exposure to community acquired infections and associated requirement for IVAB. Commencement of a modulator therapy was likely to have a positive impact on overall health and associated of reduction in requirement of IVAB.

WS14.3
Virtual consultation in cystic fibrosis: an Italian experience

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Objectives: Telehealth is growing rapidly and has the potential to transform the delivery of healthcare for patients with respiratory diseases. The aim of this prospective observational study was to determine acceptability of, and patient satisfaction with, the NuvoAir Home platform in patients with cystic fibrosis (CF) who had been enrolled in a virtual consultation (VC) service for more than six months.
Methods: The NuvoAir Home platform consists of a smartphone application, Bluetooth spirometer and a clinician portal. Patients were trained to use the NuvoAir Home platform in hospital by a member of the CF team and asked to do home spirometry, at least, once per month. After each VC, a survey was emailed to patients to evaluate their experience when using the technology.
Results: 42 consecutive CF patients managed at the adult CF centre, Federico II Hospital, Naples, Italy (18 males, 24 females, mean age 31.5 ± 6.8 SD yrs; 15 homozygous for F508del; FEV_1 52.3 ± 16.3 SD % predicted, BMI 22.3 ± 2.8 SD) were studied. A total of 22 (52.0%) survey responses over six months were received from patient consultations. All patients reported the NuvoAir Home platform easy to use and a good tool

to monitor lung function at home. The vast majority of patients (91.0%) reported that using the NuvoAir platform to share results with their CF team improved consultations and that they understood their CF better (81.8%) since starting the VC service; the remaining 18.2% of patients reported no change. All patients reported being likely to recommend the NuvoAir Home platform to other CF patients.
Conclusions: These data demonstrate that the NuvoAir Home platform was well accepted by CF patients, improved the quality of their consultations by allowing them to share data with their CF team and improved their understanding of their medical condition. A further investigation to determine whether its use improves clinical outcomes and healthcare utilisation is underway.

WS14.4
Exploring cystic fibrosis patient and staff perceptions of the Virtual Healthcare Hub during the COVID-19 pandemic at the All Wales Adult Cystic Fibrosis Service

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Objectives: The All Wales Adult Cystic Fibrosis Service (AWACFS) developed a Virtual Healthcare Hub (VHH) during the COVID-19 pandemic to minimise risk whilst continuing patient care. The VHH consists of virtual multidisciplinary team (MDT) clinics, leisure centre, individual physiotherapy reviews and group connects and Q+A sessions. This study explored patient and staff perceptions of the VHH and how this could be improved in the future.
Methods: Online patient and staff questionnaires evaluating the use of the VHH in the AWACFS during the COVID-19 pandemic were gathered between 23/12/2020 and 20/01/2021.
Results: 67 patient questionnaires were analysed. The most widely used service (92%) was virtual MDT clinics with 83% finding them "very" or "extremely helpful". 72% of participants would 'often' or "always" use virtual MDT clinics following the COVID-19 pandemic. Group connects and Q+A sessions run by the CF psychosocial team were particularly popular, with 85% of users finding these "very" or "extremely helpful". 77% of patients found the virtual leisure centre run by the physiotherapy team "very" or "extremely helpful".
20 staff questionnaires were analysed. 95% perceived the VHH to be either "very" or "extremely helpful" to deliver care and 100% of service providers would like to continue delivering the VHH in the future.
Both patients and staff considered "reduced risk of infection by COVID-19/other" as the highest ranked advantage of connecting virtually. The highest ranked disadvantage by patients was "preference to see professional in person" and by staff "ability to address physical concerns is limited". Staff ranked "technological difficulties" as the main barrier and "better technology" as the main way to improve CF virtual services in the future.
Conclusion: Both patients and staff considered the majority of virtual connections provided to be successful and helpful during the COVID-19 pandemic, with staff keen to support these VHH services and adapt based on patient feedback.

WS14.5
SARS-CoV-2 driving rapid change in cystic fibrosis services: the role of the clinical nurse specialist

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Objective: COVID-19 led to rapid changes in healthcare services across the globe. At this adult CF service, much of the CF multidisciplinary team (MDT) were re-deployed and the CF ward, ambulatory care and outpatients were closed. However, a small team remained, including the nurse specialists (CF-CNS). The CF-CNSs quickly adapted their role and as well as providing support and advice by phone and email, they implemented an emergency service in an area previously not used for this to ensure patients did not feel abandoned, provide treatment for exacerbation and prevent disease decline.
Methods: All patient contacts and reasons for contact were recorded. QI methodology was used (Plan, Do, Study, Act) alongside process mapping to design the emergency service. Success was measured by the reduction in number of contacts and the number of patients reviewed with or without intervention in the emergency service.
Results: In the first two weeks of the emergency service the CF-CNSs had assessed (by phone), reviewed (face-to-face) and consequently started two patients on home intravenous antibiotics. Twelve weeks later, 36 patients had been taken through the same process, medically reviewed ± intervention. There were 1,187 patient contacts in March (mostly related to COVID-19, unwell, medication), 904 in April and 870 in May (related to blood test results, unwell, medication).
Conclusion: The motivation of the CF-CNSs was pivotal to the success of this initiative. They were supported by the remaining CF MDT and CF consultants who provided phone advice.

WS14.6
Working together, apart: developing a new model for a cystic fibrosis psychology-led virtual support group

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Objectives: While challenging, the COVID-19 pandemic has increased opportunities for virtual working in cystic fibrosis (CF) services, including patient groups. It is an established necessity that psychological support groups are jointly facilitated, which poses a challenge for lone Psychologists. In the context of COVID-19 and pressures on services, MDT members are less available to collaborate. Psychology referrals have increased and people with CF (PWCF) are at increased risk of social isolation. A virtual group was developed incorporating two CF services; addressing both the psychotherapeutic needs of PWCF and the need for collaboration of the lone Psychologists.
Method: Two Psychologists from Glasgow and London adult CF centres connected online in June 2020. Similarities in therapeutic approach, experience of lone working, and need to increase outpatient contact were identified. Key themes to structure a series of groups were identified from Psychology referrals. The logistics of cross-NHS Trust working, GDPR, and IT issues were discussed and navigated. In January 2021 approval was given by stakeholders, including Information Governance. The group terms of reference and a pathway for patient recruitment and screening were developed.
Results: Working as lone CF Psychologists can be isolating, with less opportunity for creativity. Collaborating has reduced isolation and made it possible to develop a virtual patient group. Regular meetings helped us stay connected and committed in a time of uncertainty and change. Our experiences mirror the anticipated benefits of the support group for PWCF. We hope to model this as facilitators.
Conclusion: We present a way to overcome the barriers of isolation and lone-working to creatively collaborate on running virtual patient groups. This new service model presents opportunities for diversity and new ways of thinking. We hope that the group will help to reduce social isolation for PWCF in the same way it has done for two lone CF Psychologists.