P129 NARRATING SICKLE CELL DISEASE: THE EXPERIENCES OF PATIENTS AND CARGIVERS

De Franceschi, L[1]; Galvani, C[1]; Ruffo, G[2]; Colombatti, R[3]; Graziadei, G[4]; Palazzi, G[5]; Venturelli, D[6]; Forni, G[7]; Quota, A[8]; Scopinaro, A[9]; Vindigni, R[10]; Zini, M[11]; Chesi, P[12]; Reale, L[12]

[1]Department of Medicine, Section of Internal Medicine, University of Verona, Policlinico GB Rossi, AOUI, Verona, ITALY; [2]U.O. Ematologia con Talassemia ARNAS Civico Di Cristina Benfratelli, Palermo, ITALY; [3]Clinic of Pediatric Hematology Oncology, Department of Child and Maternal Health, Azienda Ospedaliera - University of Padova, Padova, ITALY; [4]Department of Internal Medicine, Rare Disease Center, Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico, Milano, ITALY; [5]Dipartimento Integrato Materno Infantile U. O. Complessa di Pediatria Università degli Studi di Modena e Reggio Emilia, Modena, ITALY; [6]Transfusion Medicine Department University Hospital Modena, Modena, ITALY; [7]Centro della Microcitemia e Anemie Congenite e del Dismetabolismo del Ferro, Ospedale Galliera, Genova, ITALY; [8]U.O.S talassemia PO Vittorio Emanuele, Gela, ITALY; [9]UNIAMO Federazione Italiana Malattie Rare APS ETS, Roma, ITALY; [10]UNITED – Federazione Nazionale delle Associazioni Talassemia, Drepanocitosi e Anemia Rare, Ferrara, ITALY; [11]Novartis Pharma, Origgio, ITALY; [12]Istud, healthcare area, Milano, ITALY

Aims: SCAN (Sickle Cell Anemia Narrations) is a project aimed to collect narratives of patients with sickle cell disease (SCD) and their family members, to gain insight on living with SCD. Italian SCD population is multicultural, melting endemic patients of Caucasian descent and subjects of African descent as first or second-generation Italian citizen.
Methods: The research was carried in Italy between January-September 2021 and involved two patients' associations and seven comprehensive sickle cell centers. Illness plots for patients with SCD and family members, together with a sociodemographic survey, were collected online through the project's website. In-depth interviews were also conducted. Narratives were analyzed through narrative-based medicine classifications, NVivo software, and interpretative coding.
Results: Twenty-two patients with SCD (53% Caucasian, 33% African, 14% other) and ten family members participated in the survey. The patient's care pathway in 44% of the cases was described as difficult at the beginning but in the present was considered satisfactory. Misdiagnose of SCD was reported in 33% of patients' narratives, and their caregivers remarked the overall lack of empathy in communication of the diagnosis. Transitional care was described as positive in 17% of the cases. Although in 41% of the cases family members were described by patients as supportive, in the other cases difficult family situations were reported. Caregivers confirmed the difficulties encountered in managing the care pathway and the lack of coordination between comprehensive SCD centers and general practitioners. Lack of knowledge about SCD, even among health professionals, was remarked by 56% of the respondents. Weakness (53%), and pain in the limbs and hips (41%) impact patients' quality of life. Acceptance of SCD was the main coping element (79%). Patients' absence from job showed an average of 39 days per year due to the illness related to SCD. When stimulated about future expectations, patients indicated less pain (30%) and more efficient cures (20%) as still unmet needs.
Conclusion: SCAN is the first project on narratives from patients with SCD. Our findings highlight the SCD disease burden for both patients and caregivers. We also identify the need to increase disease awareness and to activate/improve services such as psychological/anthropologic support and transitional care.

References

1. SLF Freitas et al, Quality of life in adults with sickle cell disease: an integrative review of the literature *Rev Bras Enferm*. 2018 Jan-Feb; 71(1):195–205
2. Pelandri F et al, Life for patients with myelofibrosis: the physical, emotional and financial impact, collected using narrative medicine-Results from the Italian 'Back to Life' project *Qual Life Res 2018; (6):1545–1554*
3. Kato GJ et al, Sickle Cell disease *Nat Rev dis Primers* 2018; Mar 15;4:18010
4. Ragusa L et al, Caring and living with Prader-Willi syndrome in Italy: integrating children, adults and parents' experiences through a multicentre narrative medicine research *Bmj Open* 2020; 10(8):e036502
5. Charon R, The patient-physician relationship. Narrative Medicine: a model for empathy, reflection, profession, and trust *JAMA* 2001; 286(15):1897–1902
6. Fioretti C et al, Research studies on patients' illness experience using the narrative medicine approach: a systematic review *BMJ Open* 2016; 6(7):e011220
7. Greenhalgh T et al, Narrative based medicine: why study narrative? *BMJ* 1999; 318(7175):48–50
8. Marini MG. Languages of Care in Narrative Medicine. Words, Space and Time in the Healthcare Ecosystem. *Springer International Publishing*; 2019.
9. Midena E et al, Real-life patient journey in neovascular age-related macular degeneration: a narrative medicine analysis in the Italian setting. *Eye* 2021 doi:10.1038/s41433-021-01470-9
10. Tonini MC et al, Narrative medicine to integrate patients', caregivers' and clinicians' migraine experiences: the DRONE multicentre project. *Neurol Sci*. 2021; 15:1–12.

P130 PROVIDING ADEQUATE HEALTHCARE TO PEOPLE WITH HEMOGLOBINOPATHIES DURING THE PANDEMIC (COVID-19)

Sophia Delicou, S[1]; Aikaterini Xydaki, A[1]; Konstantinos Manganas, K[1]; Lucia Evliati, L[2]; Chrysoula Kalkana, C[2]; Michael Diamantidis, M[3]; Achilles Manafas, A[3]; Marianna Katsatou, M[4]; Leonidas Roumpatis, L[4]; Theodoros Aforozis, T[1]

[1]Hippokratio General Hospital Athens, ATHENS, GREECE; [2]General Hospital Evaggelismos, ATHENS, GREECE; [3]General Hospital of Larissa, LARISSA, GREECE; [4]Corfu General Hospital, CORFU, GREECE

Background: Countries around the world were dealing with an increase in demand for COVID-19 healthcare, which was exacerbated by fear, confusion, and mobility restrictions, all of which impacted the provision of health care for all conditions. Patients with severe diseases, such as hemoglobinopathies, seem to pose additional challenges.
Aim-Methods: An anonymous questionnaire was developed and given to 130 patients from four Thalassemia and Sickle Cell Disease Units of the National Health System of Greece Hospitals using stratified random sampling technique. To perform statistical analysis on the questionnaires, the MedCalc 2018 application was used.
Results: There were 130 participants (51 % women, 49 % males) with transfusion-dependent thalassemia (84%), transfused sickle cell disease (15%), and other conditions (1%). During the pandemic, patients' main concern was a lack of blood for transfusions (64 percent). The consistency of scheduled transfusions was not impaired (72 %) during the lock-down, while they were occasionally delayed (21 %) or did not appear at all (7 %). Similarly, when it came to systemic iron chelation therapy, 82 % were consistent, whereas 6 % stopped taking the drug on a regular basis because of worry of not having enough. The pandemic and lockdown had an impact on the annual follow-up of basic disease comorbidities, with 42% postponing the standard cardiac evaluation, 30% postponing magnetic resonance imaging of the liver-heart, and 23% cancelling major assessments or treatments such as biopsies or in vitro fertilisation (IVF) therapeutic interventions. Finally, 6% of scheduled surgeries had to be rescheduled.
Conclusion: Patients with hemoglobinopathies received their scheduled transfusions without delay during the pandemic. A small percentage of patients modified their home medications because they were concerned about not being adequate during the pandemic.
The significant consequence of the pandemic on our patients was the postponement of scheduled assessments and medical procedures required for chronic complications of their underlying condition.

References

1. World Health Organization. (2020). COVID-19: Operational guidance for maintaining essential health services during an outbreak.

P131 REAL-TIME VACCINATION IMPACTS IN SICKLE CELL DISEASE: A REAL-WORLD PATIENT CASE STUDY FOR INFLUENZA AND COVID-19 VACCINATION

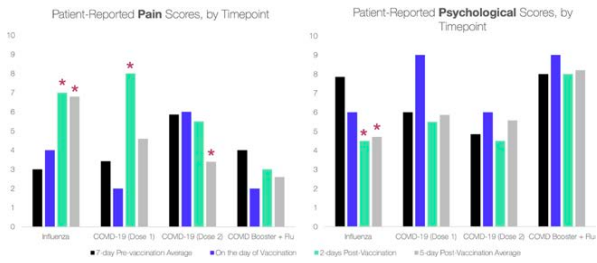
Agrippa, O[1]; Summers, K[1]; Anie, K[2]; Telfer, P[3]; James, J[4]; Low, E[5]

[1]Eleven Health, London, UNITED KINGDOM; [2]London North West University Healthcare NHS Trust, London, UNITED KINGDOM; [3]Barts Health NHS Trust, London, UNITED KINGDOM; [4]The Sickle Cell Society, London, UNITED KINGDOM; [5]Eric Low Consulting, Edinburgh, UNITED KINGDOM

Background: Sickle Cell Disease (SCD) comprises a group of red blood cell (RBC) disorders, with a diagnosed global population of ~20 million[1]. It is a chronic disease characterised by morphological RBC abnormalities in low oxygen due to β-globin mutation, causing vascular obstruction and complications including pain crisis and stroke[2-4].
The pandemic has seen patients with SCD face a higher risk of severe forms of COVID-19 infection and mortality[5]. Despite the approval of

COVID-19 vaccinations, there is limited understanding of their impact in SCD. Evidence suggests that this has led to poor vaccine uptake due to patients feeling uncertain of their safety, potentially putting patients with SCD at risk, in addition to negatively impacting quality of life.
Aims: To improve understanding of the real-world impacts of COVID-19 vaccination on both patient-reported outcomes and automatically recorded biometric datapoints in real-time, specifically in the context of Sickle Cell Disease, in order to support the improvement of patient confidence and vaccine uptake, thereby reducing COVID-19 risk.
Methods: An FDA approved, CE marked smartwatch was provided to a 37 year old male with diagnosed HbSC following informed consent. This device was worn day and night over a 15-month period, automatically recording key biometrics including sleep quality, heart rate, and activity levels. This was supplemented by manual patient self-recording of SpO_2 levels and ECG traces through the device, as well as self-reported pain scores (0–10, low-high), psychological scores (0–10, low-high), and symptoms entered via a patient-reported outcomes (PRO) portal. Metrics were compared as a 7-day pre-vaccination average, day of vaccination snapshot, and post-vaccination 2-day and 5-day average, in order to track any changes in patient wellbeing across the period following vaccination with reference to their baseline.
Results: Live monitoring of day-by-day indicators of patient health revealed that, following an initial spike post-COVID-19 vaccination, physiological and psychological wellbeing metrics, as well as real-time biometrics such as sleep quality and activity levels, returned to pre-vaccination levels within 5 days.

While pain scores remained statistically significantly high following influenza vaccination, this had returned to pre-vaccination levels over the 5-days following COVID-19 vaccine (Dose 1). Notably, while no significant difference was seen after 2-days of the second dose, pain scores had dropped significantly lower than even pre-vaccination levels post-Dose 2 in regards to the 5-day average. No significant changes were seen following the combined COVID-19 booster and flu vaccinations.



Summary – Conclusion: Our data identifies trends in the temporary impact of COVID-19 vaccination upon both PROs and real-time biometric datapoints. However, PROs highlighted a lesser impact in comparison with more traditional influenza vaccination.
Furthermore, these impacts were seen to resolve within 5 days following vaccination, with post-vaccination SpO_2, activity levels, sleep quality, and PRO averages returning to pre-vaccination levels following this initial spike. No ECG abnormalities were recorded pre- or post-vaccination.
In conclusion, this work indicates a visible but short-term impact of COVID-19 vaccination upon a patient with SCD, suggesting no heightened risk with COVID-19 vaccination in a previously poorly explored disease.

References
1. 'Cure Sickle Cell Initiative', *National Heart, Lung, and Blood Institute*
2. Ilesanmi et al, *Hematol Rep.* 2010; **2**:1
3. Steinberg et al, *TheScientificWorldJournal* 2008; 8
4. Brown et al, *European Hematology Association Congress* 2021
5. Panepinto et al, *Emerging Infectious Diseases* 2020; **26**:10

P132 REVIEW OF THE INTEGRATED PSYCHOLOGICAL INPUT AT ANNUAL REVIEW CLINICS FOR PEOPLE WITH SICKLE CELL

Tamblyn, W; Isabella Rahman, I

Guy's and St Thomas' NHS Foundation Trust, London, UNITED KINGDOM

Background: At Guy's and St Thomas' NHS Foundation Trust, the Haematology Health Psychology Service (HPS) is embedded within the Clinical Haematology Department. As a centre of excellence for the care of people with Sickle Cell, HPS has been forward-thinking in its endeavour to find ways to provide integrated person-centred care since it was founded in 1997. This includes working alongside other healthcare professionals as part of a multi-disciplinary team on ward rounds and specialist clinics. A twice-weekly annual review clinic is held at Guy's Hospital for people with Sickle Cell in line with national guidelines.
Aims: This poster presents the findings from a recent evaluation of the long-standing integrated psychology input at the Sickle Cell annual review clinic. The aim is to explore the outcomes of the annual review clinic for people with sickle cell and consider the benefits and limitations of this holistic model of care.
Methods: This evaluation explores whether a need for further support was identified during the annual review appointment and what kind of support was offered. This could include a referral for psychological therapy in the service, a briefer intervention offered during or post the review or being signposted or referred to alternative sources of support. Clinical risk is also examined.
Results: The analysis is currently still in progress.
Summary/Conclusion: Although the analysis is still ongoing, the benefits of an increased presence of psychology in traditionally medical-only clinics will be discussed and the implications of a 'catch-all' approach will be explored; that many patients may have been seen for appropriate psychological support who might otherwise have not known it was available, or may have been reluctant to reach out for support. This will highlight the importance of holistic care when striving for excellence in person-centred Sickle Cell provision.

P133 TEENAGE WELL-BEING -- A VIRTUAL SUPPORT GROUP

Lewis, A; McCarthy, L; McCubbin, I

Oxford University Hospitals, Oxford, UNITED KINGDOM

The pandemic in 2020 and measures to control the COVID-19 virus led to many teenagers and Young People(YP) isolated from their friends, through shielding and extended home schooling. It has affected their mental health and wellbeing, with an increasing demand upon mental health services (BMJ 2021,Miller et al 2020,Jeffery et al 2021).
In the Thames Valley we look after approx 200 YP with haemoglobinopathy disorders, a third between the ages of 13 & 18 years. A low prevalence area, a very wide geographical spread, making access to specialist services challenging. Access to technology and virtual connections, and a newly appointed psychologist led us to look at provision of an online wellbeing support group for teenagers.
Aims: To invite teenagers between 13–18 years to a weekly 'drop in' group, where they would be able to access strategies and resources to support with varying aspects of well-being, as well as the opportunity to ask questions, in a safe supportive environment.
Method: The group initially ran on a weekly basis for one hour at the end of the school day, led by 2 specialist nurses and a clinical psychologist. We covered subjects such as: stress, anxiety, low mood, fatigue, as well as more media related content like vaccinations and navigating social media.
We used the Zoom platform, but then moved to Microsoft Teams, as this was the Trust's preferred platform. Our YP and their parents were contacted and asked if they would like to join and then they would be sent an invite via email. A reminder was also sent the day before the next meeting. Parents would be included in any email communication and resources; however, they were not encouraged to join the meeting.
Meeting etiquette and ground rules were explained at the beginning of the meeting and with each new attendee, in order to establish trust and