The Newcastle upon Tyne Hospitals

# 'Patients' & Carers' Heart and Lung Transplant Café' Clinical Audit (2022)

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## 1. Background

- Pre and post-operative heart and lung transplant patients are affected by emotional, cognitive and social changes
- Social support provided by networks such as family, friends, community positively impacts upon coping and self-management (1)
- Online support groups, such as the Heart and Lung Transplant Café, allow patients to gain social support from peers with similar lived experiences through sharing, networking and communicating together (2)

# 2. Aims

- 1. Explore patients' and carers' positive and negative experiences of participation in the Heart and Lung Transplant Café
- 2. Evaluate and identify ways in which best practice and quality of service can be improved to ensure that patient feedback is implemented into the service

### 3. Methods

#### Design

Convergent parallel mixed-methods
 design

### Participants

13/70 respondents = 19% response rate
Males and females aged between 31-80 vears

#### Procedure

- · Approved by Trust communications
- Informed consent gained, anonymity and confidentiality maintained
- · Patients recruited via volunteer sampling
- Online questionnaire sent to patients via monthly emails - data collected over 3 months

#### **Data Analysis**

- Quantitative Descriptive statistics
- Qualitative Inductive approach to thematic analysis

Healthcare at its best

with people at our heart

2.



## 4. Results

### **Descriptive Statistics – 3 Most Common Experiences:**

- 1. Felt listened to when discussing and sharing their experiences (n=13, 100%)
- 2. Felt it was a safe space (n=12, 92.3%)
- 3. Would recommend the café to a family/friend (n=12, 12.3%)



Thematic analysis:



### 5. Discussion

- · Findings consistent with the limited existing literature
- Strengths For those whom attending in-person is psychologically/physically demanding, emotional support was greatest incentive, promoted sense of empowerment in living with chronic/long term condition
- Weaknesses Length of sessions, joint pre and postoperative heart and lung transplant sessions, greater involvement from medical consultants, online questionnaire prevented follow-up questions, patients from UK, English speaking country – lacks generalisability ≠ representative
- Recommendations Greater advertising, "Special" events, reduce session length, updated list of attendees, regular evaluation
- Goktas, S et al., (2019). Social Support Perceptions and Hope Levels of Patients Waiting for Organ Transplantation. *Transplantation Proceedings*, *51*(7), 2245-2249.

Perkins, V., Coulson, N., & Davies, E. (2020). Using Online Support Communities for Tourette Syndrome and Tic Disorders: Online Survey of Users' Experiences. *Journal Of Medical Internet Research*, 22(11), e18099