

results were compared against one another using a paired t-test. Total of 46 sets of data collected.

Results Patients felt they were given more information about their diagnosis (mean 5.15 – >9.08, p value < 0.0001), prognosis (mean 4.76 – >9.04, p value < 0.0001) and treatment options (mean 4.63 – >9.28, p value < 0.0001). Patients felt they had more control over their disease (mean 3.67 – >6.66, p value < 0.001) and more confidence they were being managed correctly (mean 4.39 – >8.52, p value < 0.001). Patients felt more satisfied with their care after being seen at an ILD specialist clinic (mean 6.04 – >9.44, p value < 0.0001). More patients strongly agreed information given met their expectations (7/45 – >37/46) and was delivered in a way that was clear and easy to understand (11/45 – >36/45). 87% (40/46) of patients strongly agreed there is more benefit in being seen at a specialist centre.

Conclusion Evidence supports the utilisation of specialist centres to manage patients with ILD. Results show there is a significant improvement in patient understanding, experiences and satisfaction.

P276 DEVELOPMENT OF PATIENT REPORTED EXPERIENCE MEASURE (PREM) FOR IDIOPATHIC PULMONARY FIBROSIS (IPF)

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Background Research into patient experiences of living with IPF has increased. A key challenge is how to use this data intelligently to enable commissioners and providers to improve the quality of services delivered to this group of patients. This project aims to develop an IPF-PREM informed by patients’ perceptions of their healthcare experiences. The IPF-PREM is underpinned by the NHS Patient Experience Framework (NPEF);¹ National Institute for Health and Care Excellence (NICE) Quality Standards (QS15 and 79) and aligned to national initiatives integrating Patient Reported Outcome Measures (PROMs) and PREMs into NHS care.

Methods A scoping exercise was undertaken with patients diagnosed with IPF on their journey through the healthcare system covering eight areas corresponding to the NPEF.¹ Twenty patients representing all stages of the disease trajectory participated in one of three focus groups. Transcripts underwent content and thematic analysis. Patient preferences were also sought on questionnaire design.

Results A number of key themes emerged. See Table 1. Of particular importance were issues concerning access: to specialist centres, medication and primary care services; consistency of care to prevent confusion; coordination of care especially for patients with multi-morbidities and getting the right information at the right time in the right way. Information enabling practical self-management was highly valued. Overarching was the need for continuity of care close to home. Participants valued having a nurse to co-ordinate care and to talk to at *all* stages of the care pathway. The response categories patients were keen to avoid were visual images such as smiley faces.

Conclusions The IPF-PREM will provide a valuable quality indicator for IPF service delivery at all stages of the disease trajectory complementing IPF PROMs. Implementation of the PREM will enable commissioners and providers to improve the quality of the services and the patient experience of care delivered across the wider inter-disciplinary team.

REFERENCE

1 DH 2011 NHS Patient Experience Framework.

P277 MEASURING SEDENTARY BEHAVIOURS IN PATIENTS WITH IDIOPATHIC PULMONARY FIBROSIS USING WRIST-WORN ACCELEROMETERS

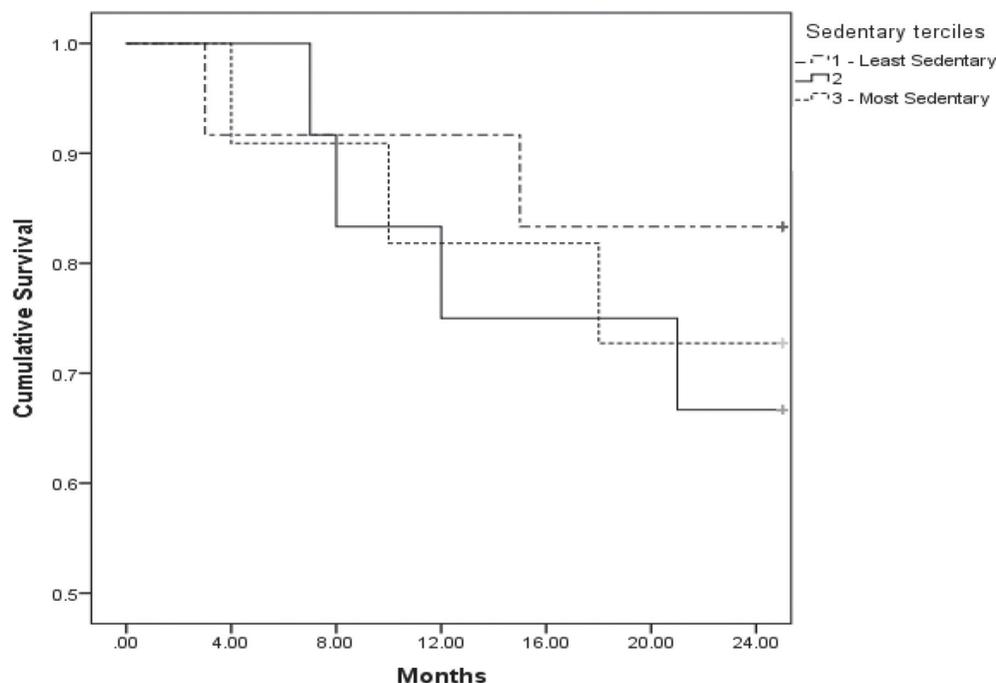
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Introduction Idiopathic pulmonary fibrosis (IPF) patients suffer increasing functional limitation as the disease progresses. Increasing sedentary behaviour (SB) time has been associated with poorer health-related quality of life. Determining thresholds for activity vigour in patients with respiratory disease is difficult due to variability in cardiorespiratory limitations between individuals.

Abstract P276 Table 1

| NPEF domain | Focus group themes |
|--|---|
| Respect for patient-centred values | Recalibrating quality of life and wanting feedback on PROMs data; impact of breathlessness on independence; the need to talk and the need not to talk to be respected |
| Coordination and integration of care | Challenges of managing other health issues and lack of social/fiscal support – administrative processes often a barrier |
| Information, communication and education | The need to talk to others affected with IPF; more information at the beginning; to understand choices in healthcare; information customised to specific needs |
| Physical comfort | Impact on activities of daily life and how to physically manage these – support with transitions to oxygen therapy; need for effective symptom relief |
| Emotional support | Better access to psychological/counselling services for self and caregivers. Value having telephone support; healthcare professionals responding promptly to requests for advice. Wanting and not wanting to know prognosis |
| Involvement of family and friends | Family may have different information needs – respecting patient’s wishes – support for wives; husband’s; partners often lacking – guilt associated with burden of caring |
| Transition and continuity | Do not want to be abandoned at end of life – feel better supported by clinicians known at diagnosis. Value copies of correspondence. Value having a key contact – particularly specialist nurse |
| Access to care | Having a progressive condition makes waiting to be seen by a specialist centre or for transplant assessment stressful. Travel presents challenges: dichotomy of wanting care close to home but with specialist input; too many health care appointments |



Abstract P277 Figure 1 2-year survival analysis by tertile of sedentary behaviour

SB time is not confounded by this limitation and may be a more reliable measurement of activity in patients with severe exercise limitation such as IPF.

Methods Thirty-nine IPF patients wore a GENEActiv actiwatch continually for 7 days. Participants underwent measurement of forced vital capacity (FVC), diffusion capacity of carbon monoxide (DLCO), 6 minute walk distance (6MWD)

Results Valid data was downloaded from 35 of the 39 participants (89.7%). Mean acceleration intensity recorded in the most active 5 hours of each day (M5; in milli-g) were 43.8 milli-g and time spent in SB was 551.7 minutes per day, higher than estimates of time in SB in similar age demographics in previous studies. Daily SB time correlated moderately with M5 values (pearson correlation -0.366 , $p = 0.030$). Only M5 values predicted time in SB. No variability in SB time was seen by day of the week. There was a trend towards higher one and two year mortality with greater periods of time in SB.

Conclusions Wrist-worn accelerometers reliably collected data and were well tolerated. IPF patients spent long periods of time in sedentary behaviours. Of the standard clinical measures used, 6MWD predicted daily activity but not SB time; no clinical measures predicted SB time. Increased time in SB may be associated with poorer outcomes in IPF patients; replacing time in SB with light activity may be a more achievable goal than increasing moderate or vigorous activity levels in IPF patients and improve outcomes.

Over 4000 new cases of IPF are diagnosed each year with a poor prognosis and median survival time of 3 to 5 years. Assessments of exercise performance using the 6-minute walk test (6MWT) have been shown to be useful in predicting survival in a variety of pulmonary conditions.

Aim We wished to determine if indices of the six-minute walk test could predict survival in patients with IPF at one year and long-term survival.

Methods We undertook a retrospective data analysis of patients with a confirmed diagnosis of IPF over the last 4 years. Data was obtained on 86 patients, who were divided into Group 1 – survivors ($n = 56$) and Group 2 – non-survivors ($n = 30$).

Indices obtained from the 6MWT included SpO₂, min, median SpO₂ rest, BORG scores, HR_{rest} and HR_{max} and distance walked. Spirometry, static lung volumes, and date of death were also recorded. Data are presented as median (IQR) in the format (Group 1 vs Group 2). Kaplan-Meier analysis was used to compare various indices and between groups.

Results There was no significant differences between the two groups for FEV₁ (2.0 (0.58) vs 2.01 (0.55)), FVC (2.83 (1.16) vs 2.52 (0.88)) or TLC (4.19 (1.58) vs 4.09 (1.62)). From the 6 MWT, SpO_{2,rest} was not significantly different (95 (2) vs 94 (5.5)), nor were HR_{rest}, HR_{max} or BORG scores.

There was a significant difference for SpO₂, min (90 (8) vs 84 (13); $p < 0.01$) and distance walked (380 (140) vs 340 (180); $p < 0.05$). Kaplan-Meier analysis was used to assess outcomes for distance walked of $<$ or $>$ 250 m and 350 m and SpO₂, min $<$ or $>$ 85% and 88%.

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DOES THE SIX-MINUTE WALK TEST PREDICT SURVIVAL AT ONE YEAR AND IN THE LONGER TERM IN PATIENTS IDIOPATHIC PULMONARY FIBROSIS (IPF)?

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