

ORIGINAL ARTICLE

Palliative care for patients with advanced fibrotic lung disease: a randomised controlled phase II and feasibility trial of a community case conference intervention

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ABSTRACT

Background Those affected by advanced fibrotic interstitial lung diseases (ILDs) have considerable unmet symptom and psychological needs. Case conferencing has been proposed to address these issues, but requires evaluation.

Aim To obtain preliminary information on the impact of a case conference intervention delivered in the home (Hospital2Home) on palliative care concerns of patients and their carers, and to evaluate feasibility and acceptability.

Methods Hospital2Home was trialled at a specialist centre using a Phase II fast-track randomised controlled trial with qualitative interviews. The primary outcome for effect was mean change from baseline of Palliative Care Outcome Scale (POS) (a measure of symptoms and concerns) at 4 weeks. Secondary outcomes included symptom control, quality of life, consent and recruitment rates and percentage of patients in the fast-track group receiving case conferences within 14 days.

Results 53 patients were recruited (26 fast-track, 27 controls). Mean (SD) POS scores at 4 weeks were -5.7 (7.5) fast-track vs -0.4 (8.0) control, (mean change difference between the two arms was -5.3 (95% CI -9.8 to -0.7) independent t test p=0.02); effect size (95% CI) -0.7 (-1.2 to -0.1). The secondary outcomes of quality of life, anxiety and depression were superior in the fast-track arm, and none were worse. Qualitative findings corroborate these data. Recruitment was successful and 53/67 (79%) of eligible patients consented. 6/25 (24%) had case conferences within 14 days.

Conclusions Community case conferences improve palliative symptoms and quality of life after 4 weeks. Hospital2Home for the most part is both feasible and acceptable. It now requires further testing in multicentre trials.

Trial registration number NCT01450644

Key messages

What is the key question?

- Could a palliative case conference intervention improve palliative care concerns and be feasible in advanced fibrotic interstitial lung disease (ILD)?

What is the bottom line?

- The case conference intervention may improve patients' and carers' palliative care concerns while being feasible and acceptable.

Why read on?

- People living with advanced fibrotic ILD experience high levels of unmet palliative care concerns and this work shows that evidence based palliative interventions such as the case conference can be developed and robustly evaluated to improve and direct care.

and carers' lives.^{2–4} In addition, poor communication and coordination of care, with little or no discussion surrounding important end-of-life preferences has been reported.⁴

Recent UK Government legislation promotes better integration of care to improve patient experience and outcomes, providing better continuity of individualised care at the end of life.^{5,6} Targeted organisation of care, improved communication and cooperation between disciplines across multiple healthcare settings is required to enable appropriate delivery of palliative care.⁷ Case conferencing at the interface between primary and specialist care may deliver individualised holistic care while addressing important unmet palliative care concerns.^{8–10} Research into case conferences in the non-malignant respiratory setting or centred on the patients' and carers' concerns are absent. In addition, there is a paucity of research developing complex interventions among those with fibrotic lung disease aimed at improving their symptoms and quality of life.¹¹

We conducted a phase II feasibility trial of a case conference intervention (Hospital2Home) to obtain

INTRODUCTION

Patients with idiopathic fibrotic lung diseases include a large patient subgroup with idiopathic pulmonary fibrosis (IPF), or with alternative diagnoses but an IPF-like outcome.¹ These patients experience substantial unmet symptom and psychosocial concerns that profoundly impact on patients'

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preliminary information in what ways Hospital2Home influences the palliative care concerns of patients with advanced fibrotic interstitial lung disease (ILD) and their carers, and to evaluate the feasibility and acceptability of the intervention in this group.

METHODS

Study design

A fast-track (wait list) randomised controlled trial with embedded qualitative interviews were conducted as part of a larger project developing and evaluating Hospital2Home using the Medical Research Council's guidance for developing and evaluating complex interventions.¹² After consent and baseline interview, patients were randomised to fast-track or waiting list groups. For fast-track patients, a Hospital2Home nurse organised a case conference as soon as possible. Waiting list patients were referred for the case conference 4 weeks after randomisation. During the course of the trial, it became apparent that it was extremely difficult to get the case conference for those patients who were randomised to the fast-track group organised within 1 week and sometimes the waiting list group's case conference at exactly 4 weeks. An amendment allowed flexibility in the time points of the case conferences and the assessments. Treatment allocation (fast-track/waiting list group) was by computer generated random permuted blocks (by the Institute of Cancer Research) with stratification dependent on severity of patient Palliative Care Outcome Scale (POS) at baseline (patients with a POS score ≥ 28 were classed as severe).

Subjects

Patients with a clinical diagnosis of advanced idiopathic fibrotic lung disease (IPF by American Thoracic Society/European Respiratory Society criteria¹³ or fibrotic non-specific interstitial pneumonia) were recruited from the inpatient and outpatient settings in a specialist ILD centre (Royal Brompton Hospital, London). Patients included were considered to have end stage disease as judged by either high resolution CT or composite physiologic index scores. Total disease on CT was categorised as limited (<40%), extensive (>60%) or indeterminate (40–60%). The proportion of honeycombing was recorded as limited (<15%), extensive (>35%) or indeterminate (15–35%). Disease was classed as extensive if (1) Extensive disease (>60%) or honeycombing (>35%) on CT or (2) Composite Physiological Index >50 . Previous work done by Wells *et al*¹⁴ has shown a separation in survival between limited ($n=36$) and extensive ($n=100$) disease using this classification (HR=5.2 (CI 3.3 to 8.1) $p<0.0005$); the latter group (extensive disease) had a 10% survival at 2 years. A subsequent amendment allowed recruitment of patients considered to have end-stage disease clinically (based on clinical status, oxygen requirements and, in some cases, the presence of severe pulmonary hypertension) who were too unwell to complete pulmonary function tests.

To be included patients and carers had to be >18 years old, possess sufficient mental capacity and be able to complete questionnaires in English. Where possible, patient and carer dyads were recruited.

Intervention

All patients received best standard care throughout the study: Patients remained under ILD specialist care for the full duration of the study. This included receiving input from ILD physicians, ILD clinical nurse specialist, occupational therapist, physiotherapist and oxygen assessment and treatment services. In addition, all patients were able to access inpatient ILD treatment as needed. Referrals to community health professionals (as deemed

necessary by the ILD team) continued throughout the study. These could include referrals to community nursing (such as community matron or district nurses), respiratory services and community palliative care teams. The Hospital2Home intervention was delivered alongside best standard care (box 1). The fast-track group received the intervention after 1 week, the waiting list group after 4 weeks.

Primary outcome

The primary outcome was POS.¹⁵ POS was developed for patients with advanced cancer and includes aspects about pain and symptom control, patient and family psychosocial needs, and communication and information needs.¹⁵ The POS contains eight questions on anxiety, patient and informal caregiver concerns, and practical needs, each rated 0–4. The overall profile score is the sum of the scores from each of the 10 questions and can range from 0 to 40. Symptoms identified in preliminary work were added to question 2- 'Over the past 3 days, have other symptoms eg. having a cough, shortness of breath, fatigue or insomnia been affecting how you feel?'. This adapted POS was used to provide an assessment of change in palliative care needs (including symptom control).

Secondary outcomes

Secondary outcomes included changes in symptom control and quality of life measures (table 1). Details of each secondary measure can be located online in online supplementary appendix 1

Primary and secondary outcome data were collected by postal questionnaire at baseline in both groups. Subsequent time points were 4 weeks and 8 weeks after receiving the intervention in the fast-track group and just before receiving the intervention and 4 weeks after receiving the intervention in the waiting list group. Demographic information was also recorded. Qualitative interviews were conducted after completion of the trial. The topic guide used is depicted in figure 1.

Feasibility and acceptability

A priori criteria for trial feasibility were:

- Consent rate of at least 25%;
- Recruitment of 52 patients;
- 80% of patients in the fast-track group received their case conference within 14 days of randomisation.

The qualitative interviews were used in the post-trial evaluation to assess acceptability.

Sample size, randomisation and data analysis

Fifty-two patients were needed to enable estimation of change in POS between baseline and 4 weeks with accurate precision (assuming a SD of 2, a 95% CI for the difference between the fast-track and waiting list groups would be 2.2 units wide, ie, mean difference ± 1.1 units). Anticipated recruitment for qualitative work was 15 (5 patients, 5 carers and 5 health professionals).

We planned an intention-to-treat analysis. The differences in the change in POS scores (baseline to 4 weeks) between the fast-track and waiting list groups were compared using an Independent sample t test. For all secondary outcome measures descriptive methods were used to report the results in the groups using mean change scores with SD from baseline to week 4 and effect size at week 4. Only patients with week 4 data were included in change analysis. All quantitative data were analysed using Statistical Package for the Social Sciences (Version 21, IBM, Chicago, Illinois, USA).

Box 1 Hospital2Home intervention**Aims and rationale**

The intervention aimed to provide a quality comprehensive palliative care assessment and streamlining of transfer of data between specialist and community settings improving coordination of care and communication while codifying responsibility for the patient, carer and health professionals. In the UK, a case conference model of care (Hospital2Home) has been used in patients with cancer in the acute oncology setting. The Hospital2Home model of care is unique as it has the advantages of a case conference (multiprofessional and holistic) and a care plan (care individualised to each patient and carer). The fibrotic interstitial lung disease Hospital2Home model was developed using Medical Research Council guidance and informed through a systematic review¹¹ and qualitative interviews.^{3 4}

Personnel

Provider: A palliative care specialist nurse delivered the intervention. The nurse had received training on delivery of the intervention from specialist nurses delivering the cancer Hospital2Home intervention.

Supervision: Clinical supervision was provided to assist in identifying and advising on strategies to address problems compromising effective management of the palliative care concerns of these patients and carers. The supervisors met with the nurse approximately weekly and provided additional telephone support as needed.

Attendees: The patient, their carer, Hospital2Home nurse, general practitioner, community matron/district nurse, respiratory nurse and community palliative care nurse (and any other health or social care professional involved in their care or identified as important by the patient) were invited to attend. All patients in the waiting list group who received the case conference had a carer who was present at the case conference. However only 19/25 patients in the fast-track group had carers and only 18 of these attended the case conference. There was consistent representation from community nursing and palliative care teams. However, less than 50% of general practitioners attended the case conferences.

Format

Setting: Case conferences were conducted in the community at a place chosen by the patient (all patients chose their home) Mean (SD) time in minutes taken to organise the case conference for fast-track group 204 (78) range 60–360 and for waiting list group 219 (86) range 60–390.

Schedule and duration: 25 patients in the fast-track group and 24 patients in the waiting list group received the case conference. The Hospital2Home nurse contacted patients after randomisation. For patients in the fast-track group where possible, the case conference was organised within 1 week (6/25 (24%) had case conference within 14 days, median 23 days, range 12–51). For patients in the waiting list group, this was organised for 4 weeks time (median 40 days, range 7–100). The median length of case conference was 90 min in both groups with a range of 60–120 min in the fast-track group and 60–150 min in the waiting list group. The Hospital2Home nurse followed up the case conferences in each group with the patient/carer via telephone at 2-week, 1 month and 2-month intervals. Patients and carers were also able to contact the nurse directly as needed for the length of the study. Contacts in addition to scheduled follow-up were mean (SD) 49 (78) min, range 0–300 min for the fast-track group and 35 (48) min, range 0–120 min for the waiting list group.

Content

Prior to the case conference, the Hospital2Home nurse telephoned the patient and carer to identify what their current palliative care concerns were and what they hoped to achieve from the case conference. This included identifying whether patients wished to discuss the sensitive matter of disease progression and planning for the future. During the case conference, which was led by the Hospital2Home nurse, current and anticipated care palliative care concerns were discussed. This included physical, psychological, social and spiritual concerns. In addition, where appropriate, end-of-life preferences were discussed. Preferred place of care—where the patient wished to be cared for in the last few weeks of life was discussed in 17 (68%) of fast-track and 23 (96%) of waiting list case conferences. For 13 (52%) of the fast-track group and 23 (96%) of the waiting list group this was home. Preferred place of death—where the patient wished to die was discussed at 11 (28%) of fast-track and 10 (42%) of waiting list case conferences. Reasons for non-discussion for preferred place of care and death were patient choice.

An action plan was agreed upon for each concern discussed at the case conference and a responsible healthcare professional allocated for each item. Following the case conference the Hospital2Home nurse, with contact details of each health professional, drafted an individualised care plan. The individualised care plan was then communicated to the patient and carer, the ILD specialist team, the general practitioner, all attendees at the case conference and any other health professional identified by the patient as involved in their care. The Hospital2Home nurse would check with the patient/carer at the follow-up phone calls that all action points on the care plan had been completed by the allocated health professional. The Hospital2Home nurse aimed to resolve any issues by liaising with the relevant community health professionals.

Delivery

Delivery methods: A collaborative problem solving approach was used whereby the patient and health professionals set agreed goals and jointly developed strategies to achieve them (with advice from the supervisors as needed).

Standardisation: Pro forma were used to standardise delivery and general content of the case conference and follow-up phone calls and to document issues arising from individual discussions, agreed goals, and difficulties and points for action or discussion at supervisory meetings. Symptom control management was guided by evidence based guidelines developed during preliminary work (available on request from corresponding author).

All qualitative interviews were digitally recorded and transferred verbatim onto a secure transcription database. Analysis was conducted using a constant comparison approach²³ within

Framework analysis as described by Ritchie and Spencer.²⁴ Qualitative analysis was facilitated by NVivo V9. Efforts to maximise analytical rigour included dual coding of a sample

Table 1 Outcome measures used

Baseline characteristic/ outcome	Instrument/measure
Patient	
Patient palliative care needs	Palliative Care Outcome Scale ¹⁵ with additional questions for breathlessness, cough, fatigue, insomnia (to be completed by patient and carer)
Patient breathlessness at best/worst	D12 scale ¹⁶
Patient quality of life	Kings Brief Interstitial Lung Disease questionnaire ¹⁷ and SGRQ ^{18*}
Patient functional ability	Medical Research Council breathlessness scale ¹⁹
Patient anxiety	Hospital Anxiety and Depression Scale ²⁰
Patient use of other services	Service use questions
Preferred place of care and death	
Carer	
Carer quality of life	Caregiver Quality of Life Index ²¹
Carer anxiety	Hospital Anxiety and Depression scale ²⁰
Carer's assessment of patient's use of services	Service use questions
Carer burden	Zarit Burden Inventory ²²

*After completion of a background systematic review,¹¹ it was decided to use SGRQ instead of the McGill Quality of Life questionnaire to enable comparison of outcomes with a number of other ILD studies. This amendment was made after recruitment and completion of the first patient in the trial.
ILD, interstitial lung disease; SGRQ, St Georges Respiratory Questionnaire.

selection of the interview transcripts and attention of deviant or non-confirmatory cases.

RESULTS

Patients were recruited October 2011–October 2013 and followed up until December 2013 (when the final patients recruited had completed 8 weeks in the trial) (figure 2).

Baseline measures

Baseline demographic and clinical characteristics for patients and carers are presented in table 2.

All analyses were by originally assigned groups.

Primary end point

There was a significantly greater reduction in total POS between baseline and week 4 for the fast-track group than in the waiting list group; mean change (SD) -5.7 (7.5) vs -0.4 (8.0), respectively. The mean change difference between the two arms was -5.3 (95% CI -9.8 to -0.7) independent t test p=0.02; effect size (95% CI) of -0.7 (-1.2 to -0.1) (figure 3).

Secondary outcomes

Patient

For the fast-track group, initial improvements in POS score, King's Brief Interstitial Lung Disease (KBILD) questionnaire,

- What do you feel are the most important aspects of Hospital2Home? Prompts: evidence based guidelines, codifying responsibility, multi-professional working, crisis management, advance care planning
- What have you found particularly helpful? Prompts: evidence based guidelines, codifying responsibility, multi-professional working, crisis management, advance care planning
- Is there anything about the intervention that you found unhelpful?
- What if any improvements would you like to see in the model of care?

Figure 1 Topic guide used for qualitative interviews.

and Hospital Anxiety and Depression scale (HADs) scores at 4 weeks were all sustained or continued to improve further by week 8 (see table 3). In contrast these indices did not significantly improve by week 4 for the waiting list group (and actually worsened for POS and KBILD questionnaire scores) but showed significant improvement once the intervention was delivered (ie, comparison weeks 4–8). There was also improvement in impact and total scores for St Georges Respiratory Questionnaire (SGRQ) scores in the fast-track group compared with the waiting list group. SGRQ scores for symptoms, impact and total scores also improved in the waiting list group once the intervention was delivered.

Positive effects were identified for patient HADs scores at week 4. This effect was sustained in the fast-track group with continued improvement. There was also improvement in the waiting list group for anxiety, depression, and total scores after the intervention was delivered.

There was no improvement in D12 scores in the fast-track group but there was an improvement in D12 scores between week 4 and week 8 in the waiting list group. There was no change in the Medical Research Council scores across both groups over time.

Carer

There was no significant difference in POS between the fast-track and waiting lists groups at week 4. However, there was a marked improvement in waiting list scores between week 4 and week 8 (18.0 (8.4) vs 13.7 (6.3)), respectively. Zarit Burden Inventory score and Carer Quality of Life Cancer burden, disruptiveness, financial and total scores followed a similar pattern with no effect of the intervention at week 4. This was followed by improvement in scores between week 4 and week 8 in the waiting list group.

There were borderline effect sizes of the intervention on depression and total HADs scores (-0.7 (-1.3 to 0.0) and -0.7 (-1.3 to 0.0), respectively). This was followed by improvement between week 4 and week 8 scores for the waiting list group for anxiety (11.7 (5.6) vs 9.8 (4.6)), depression (9.6 (4.9) vs 7.2 (3.9)) and total score (21.3 (9.9) vs 17.0 (8.2)), respectively.

Data related to study

As of study close on 31 December 2013, a greater number of waiting list patients (13 (54%)) had died than fast-track (8 (32%)). Preferred Place of Care and Preferred Place of Death were less likely to be achieved for patients who died in the waiting list group; Preferred Place of Care: fast-track (FT 8) (100%) versus waiting list (WL) 11 (84%), Preferred Place of Death: FT 7 (88%) versus WL 10 (77%). More patients died at home in the fast-track group; FT 5 (62%) versus WL 5 (38%) and in hospital in the waiting list group; FT 1 (12%) versus WL 5 (38%). All three patients who died before being able to receive the case conference were in the waiting list group and all died in hospital.

Qualitative findings

Online supplementary appendix 2 shows the qualitative participants' characteristics. Key quotes are presented in table 4 and the full qualitative findings can be found in online supplementary appendix 2.

DISCUSSION

This fast-track randomised controlled trial of a case conference intervention in patients with advanced fibrotic ILD and carers identified an improvement in symptom control and quality of

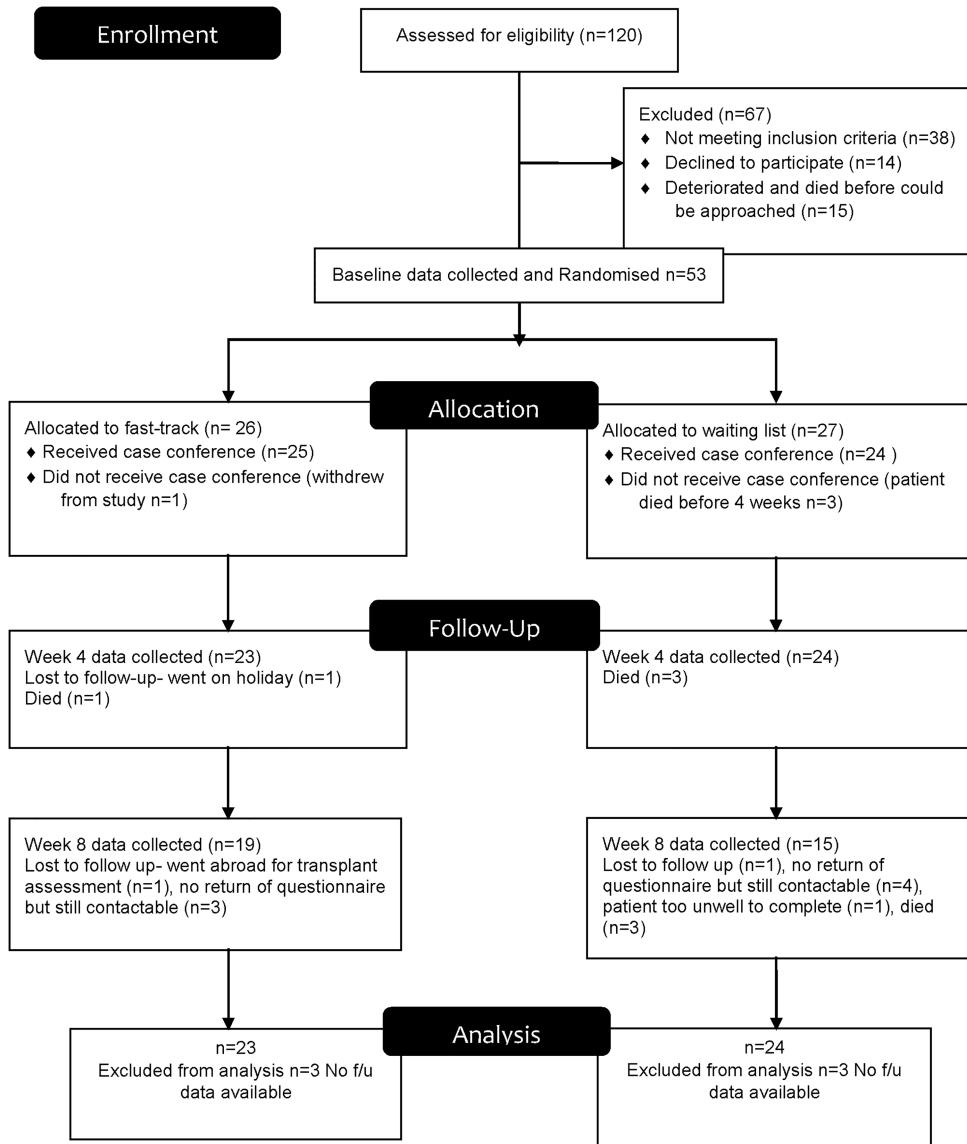


Figure 2 CONSORT diagram showing flow of patients through the study.

life. Of note, there was no worsening of any outcome after receiving the intervention. This suggests that no harm and potentially a prevention of deterioration may have occurred. Mean change difference scores in POS in the fast-track group were 5.7 points at 4 weeks, sustained at 8 weeks. For POS, a variation of one point in individual items is linked to clinical meaningful change.¹⁵ There was also a promising large effect size. Similar improvements in the waiting list POS once they received the intervention suggest that the intervention may improve the palliative care concerns of these patients. Use of evidence based guidelines and a comprehensive palliative care assessment at the case conference, ongoing palliative care involvement and/or added time with care providers may have contributed to this.

Baseline scores showed that patients were living with poor quality of life. Improvements were observed in the KBILD and SGRQ impact and total scores at week 4 in the fast-track group. The improvement in the waiting list SGRQ impact and total scores were marked between week 4 and week 8 where both domains showed improvement greater than the Minimal Important Clinical Difference for IPF. Improvements were also identified in anxiety and depression scores. Of note, baseline

mean patient anxiety and depression scores and mean carer anxiety scores in both groups were borderline abnormal or abnormal. Importantly, the waiting list group showed deterioration for all anxiety and depression scores in the patients and carers during the 4 week wait. However, this improved after receiving the intervention. Clinically meaningful improvements in HADs scores of patients and their carers (the Minimal Important Clinical Difference in COPD is 1.5²⁵) were identified. These improvements find correspondence with the qualitative interviews. Before the case conference, patients and carers stated they had very little knowledge of support they were entitled to and were suffering alone. Through the case conference, patients and carers had access to specialist community palliative care services that routinely support patients' and carers' holistic palliative care concerns. Patients and carers felt that this reduced anxiety. Moreover they were grateful for the clear crisis management strategy provided through the individualised care plan. Patients and carers interviewed valued the case conference itself as they felt that it 'laid everything on the table' and importantly addressed concerns and anxieties that had been playing on patients' and carers' minds. This supports findings by Lindell

Table 2 Summary table of baseline demographic and clinical data

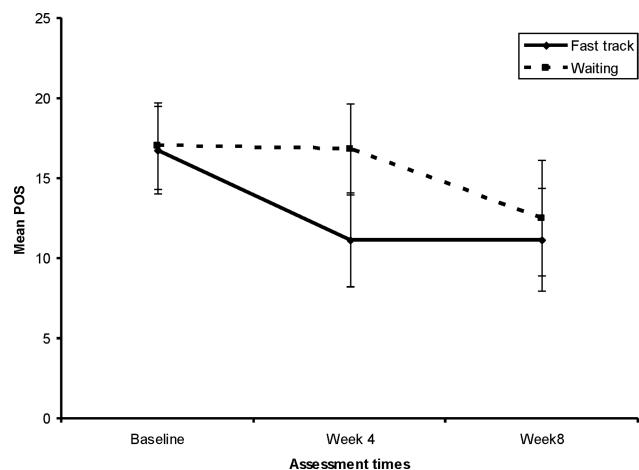
Patients	Fast-track N=26	Waiting list N=27
Age (years)	67.1 (10.9)	70.6 (10.3)
Male	20 (77%)	18 (67%)
Ethnicity		
White UK	21 (81%)	20 (74%)
Black or Black British	1 (4%)	2 (8%)
Asian or Asian British	4 (15%)	5 (18%)
Disease		
IPF	22 (85%)	22 (82%)
NSIP	4 (15%)	5 (18%)
Diagnostic biopsy		
Surgical	8 (31%)	6 (22%)
Not carried out	18 (69%)	21 (78%)
% predicted TLCO		
Mean (SD)	25 (10.7)	23 (5.8)
Not carried out	4 (15%)	4 (15%)
Extent of disease on CT		
Limited (<40%)	3 (12%)	3 (11%)
Indeterminate (40–60%)	9 (35%)	14 (52%)
Extensive (>60%)	14 (54%)	10 (37%)
Extent of honeycombing on CT		
Limited (<15%)	10 (38%)	11 (41%)
Indeterminate (15–35%)	11 (42%)	10 (37%)
Extensive (>35%)	5 (19%)	6 (22%)
Composite Physiological Index		
>50	19 (73%)	27 (100%)
Mean (SD)	66.5 (4.0)	64.8 (3.6)
Not carried out	7 (27%)*	0
Using oxygen		
Yes	20 (77%)	23 (85%)
Litres/h used	3 (1.4)	3 (1.1)
Usage in 24 h	19 (6.6)	21 (5.3)
Comorbidities		
Yes	17 (65%)	13 (48%)
Heart failure	1	0
COPD	4	1
Pulmonary embolism	1	0
TB	0	0
Cancer	1	1
Diabetes	5	4
Other	13	10
Carers	N=19	N=26
Age	61.3 (14.0)	60.3 (13.1)
Male	6 (32%)	6 (23%)
Ethnicity		
White UK	17 (90%)	18 (69%)
Black or Black British	1 (5%)	2 (8%)
Asian or Asian British	1 (5%)	6 (23%)

Data are means (SD) or numbers (%).

*Three patients were recruited who had end-stage disease clinically, did not have extensive disease or honeycombing on CT and were too unwell to complete lung function tests.

IPF, idiopathic pulmonary fibrosis; NSIP, Non-specific interstitial pneumonia; TLCO, carbon monoxide transfer factor.

et al who evaluated an interventional disease management programme in IPF and Higginson *et al*'s²⁶ recent trial of a breathlessness intervention service among 105 patients with refractory breathlessness (including patients with ILD). Both observed improvements in psychological symptoms.

**Figure 3** Line diagram showing change in mean Palliative Care Outcome Scale (POS) with 95% CIs over time in the two groups.

Hospital2Home aimed to facilitate early discussion about disease progression, to improve communication and address end-of-life planning needs. Not all patients wanted to talk about advance care planning decisions such as preferred place of care and preferred place of death. This was similarly identified by Abernethy *et al*¹⁰ where prognosis, end-of-life issues, and previous experiences of death were rarely discussed at the case conference for patients with cancer. For those patients in this trial who did discuss advance care planning, even though it could initially be distressing for relatives, it was seen as incredibly useful. For some patients, the case conference provided them with permission to conduct these important conversations. Interestingly, patients who did not want to discuss advance care planning at the case conference then went on to have subsequent discussions with their community health professionals. This may have been precipitated by those initial discussions by the Hospital2Home nurse and the development of relationships with the community palliative care team after the case conference. For patients who wished to discuss preferred place of death, no patients reported hospital as their preference. The actual place of death for patients having received the case conference was hospital in only 28% of patients. This is much less than observed in a retrospective case note review² where 76% of patients with advanced fibrotic ILD attending two acute hospitals died in hospital. Interestingly, the three patients who died in the waiting list group before receiving the intervention, died in hospital. Patients with IPF experience increased healthcare resource utilisation, and direct medical costs.²⁷ This is important at the end of life. It is possible that the case conference, through documenting end-of-life preferences, establishing links in the community setting, and preventing crisis admissions enabled patients not to die in hospital. The economic impact of this requires further investigation.

The fast-track study design worked effectively and is likely to be an influencing factor as to why consent and recruitment rates were met as all patients received the intervention. However, only 24% of the fast-track group received the case conference within the a priori 14-day allotted time frame. Health professionals were often unable to schedule a case conference within a week's notice. This has been found previously; Abernethy *et al*¹⁰ observed that only 38/167 case conferences in their trial were held within 28 days. When considering the waiting list period, 4 weeks was chosen as this was considered long enough to identify an effect of the intervention on the primary

Table 3 Outcome measure data: outcome data for completed (fully or partially) measures have been presented

	Fast track				Waiting list				Effect size (95% CI) at 4 weeks
	Baseline (mean (SD) or n (%))	4 weeks (mean (SD) or n (%))	Change score Mean (SD)	8 week (mean (SD) or n (%))	Baseline (mean (SD) or n (%))	4 weeks (mean (SD) or n (%))	Change score Mean (SD)	8 week (mean (SD) or n (%))	
Primary end point	N=26	N=23			N=27	N=24			
POS	16.8 (5.6)	11.2 (7.9)	-5.7 (7.5)		17.0 (6.3)	16.8 (8.9)	-0.4 (8.0)		-0.7 (-1.2 to -0.1)
The mean change difference between the two arms was -5.3 (95% CI: -9.8 to -0.7) Independent t test p=0.02									
Secondary outcomes									
Patients									
POS				N=19					N=15
				11.2 (7.3)					12.5 (6.6)
D12	N=25*	N=22*		N=19	N=27	N=24			N=15
	22.8 (8.7)	21.6 (10.1)	-0.8 (7.2)	20.4 (9.8)	25.9 (8.2)	25.0 (10.7)	-0.6 (21.3)	21.3 (10.5)	-0.3 (-0.9 to 0.3)
KBILD†	N=26	N=23		N=19	N=27	N=24			N=15
	35.8 (13.0)	40.0 (16.2)	3.5 (11.0)	43.2 (18.4)	32.3 (12.9)	30.3 (16.2)	-2.6 (21.3)	34.9 (18.0)	0.6 (0.0 to 1.2)
SGRQ	N=25‡	N=22‡		N=18‡	N=26§	N=24			N=15
Symptoms	62.2 (17.7)	62.0 (20.5)	1.4 (16.5)	52 (20.1)	66.3 (24.5)	65.8 (23.0)	-2.0 (23.7)	60.2 (23.8)	-0.2 (-0.8 to 0.4)
Activity	88.9 (9.7)	85.3 (17.6)	-3.1 (13.6)	87.1 (10.7)	93.7 (5.0)	92.4 (7.8)	-1.6 (6.8)	91.4 (5.2)	-0.5 (-1.1 to 0.1)
Impact	61.6 (18.0)	56.3 (20.3)	-4.0 (19.7)	57.4 (20.8)	71.4 (12.8)	74.8 (14.9)	2.8 (13.3)	62.3 (13.5)	-1.0 (-1.6 to -0.4)
Total	70.0 (13.0)	66.0 (16.4)	-2.8(14.9)	65.7 (14.7)	76.8 (10.1)	78.6 (11.8)	0.7 (10.5)	70.8 (10.8)	-0.9 (-1.5 to -0.3)
MRC	N=26	N=23		N=19	N=27	N=24			N=15
Median	4	4		4	5	5			4
IQR (25–75)	4–5	4–5		4–5	4–5	4–5			4–5
HADs	N=26	N=23		N=19	N=27	N=24			N=15
Anxiety	9.6 (4.6)	8.1 (4.1)	-1.7 (3.3)	7.1 (4.6)	9.7 (5.7)	10.8 (5.5)	1.2 (4.8)	7.9 (5.5)	-0.6 (-1.1 to 0.0)
Depression	9.0 (3.1)	9.4 (3.0)	0.3 (3.2)	8.3 (3.7)	11.0 (4.7)	12.3 (4.8)	1.5 (4.12)	9.3 (4.5)	-0.7 (-1.3 to -0.1)
Total score	18.6 (6.4)	17.5 (6.3)	-1.4 (5.0)	15.4 (7.7)	20.7 (9.0)	23.0 (9.7)	2.8 (8.1)	17.2 (9.4)	-0.7 (-1.2 to -0.1)
Carers									
POS	N=19	N=15		N=13	N=26	N=22			N=15
	17.8 (6.5)	14.7 (6.5)	-2.9 (5.8)	16.1 (6.9)	18.5 (6.2)	18.0 (8.4)	-0.7 (9.6)	13.7 (6.3)	-0.4 (-1.1 to 0.2)
ZBI	N=19	N=16		N=13	N=26	N=23			N=16
	22.2 (15.2)	22.3 (15.3)	0.1 (0.2)	26.2 (13.4)	32.2 (11.7)	31.7 (17.3)	-0.1(0.3)	25.4 (13.4)	-0.6 (-1.2 to 0.1)
HADs	N=19	N=16		N=13	N=26	N=23			N=16
Anxiety	9.3 (4.3)	8.8 (4.8)	-0.5 (4.8)	9.2 (3.7)	11.0 (5.9)	11.7 (5.6)	0.6 (5.3)	9.8 (4.6)	-0.6 (-1.2 to 0.1)
Depression	7.0 (4.9)	6.4 (4.1)	-0.3 (3.5)	7.0 (4.2)	8.7 (5.0)	9.6 (4.9)	1.0 (4.6)	7.2 (3.9)	-0.7 (-1.3 to 0.0)
Total score	16.3 (8.7)	15.2 (8.3)	-0.8 (8.0)	16.2 (7.4)	19.7 (10.4)	21.3 (9.9)	1.7 (8.7)	17.0 (8.2)	-0.7 (-1.3 to 0.0)
CQLC†	N=18	N=15		N=13	N=25	N=21			N=13
Burden	21.9 (8.3)	21.5 (7.1)	-0.6 (6.9)	20.2 (5.7)	25.2 (8.3)	25.2 (8.5)	-0.2 (8.0)	22.1 (9.2)	-0.5 (-1.1 to 0.2)
	7.8 (6.0)	7.1 (6.9)	-0.6 (4.3)	7.7 (4.8)	9.6 (5.4)	9.3 (5.5)	0.0 (4.9)	7.6 (5.9)	-0.4 (-1.0 to 0.3)

Continued

Table 3 Continued

	Fast track	Waiting list	
	Baseline (mean (SD) or n (%))	4 weeks (mean (SD) or n (%))	Change score Mean (SD)
			8 week (mean (SD) or n (%))
Disruptiveness			
Adaptation	15.6 (5.1)	15.8 (6.1)	0.5 (4.3)
Financial	2.8 (3.0)	2.5 (3.0)	-0.4 (2.1)
Total score	60.8 (17.4)	58.5 (15.3)	-2.5 (11.0)
			14.7 (6.8)
			2.4 (3.6)
			66.3 (16.3)
			0.7 (15.2)
			14.4 (5.7)
			2.7 (2.9)
			66.3 (18.4)
			0.7 (15.2)
			16.8 (4.2)
			2.3 (2.1)
			60.2 (23.9)
			0.7 (15.2)
			0.1 (5.3)
			0.3 (2.5)
			60.2 (23.9)
			0.2 (-0.4 to 0.6)
			-0.1 (-0.7 to 0.6)
			-0.4 (-1.1 to 0.2)

All analyses conducted by originally assigned groups.
Lower scores on the SGRQ and higher scores on the KBLID indicate a better quality of life.
*One patient had >three items missing on the D12/QoL and was therefore excluded as per author's instructions.
†Increase in scores indicates improvement.
‡One patient completed McGill quality of life not SGRQ.
§One patient removed as >six items missing on Activity SGRQ.
COLC, carer quality of life cancer; HADS, Hospital Anxiety and Depression Scale; KBLID, King's Brief Interstitial Lung Disease questionnaire; MRC, Medical Research Council Scale; POS, Palliative Care Outcome Scale; SGRQ, St George's Respiratory Questionnaire; ZBI, Zarit Burden Inventory.

outcome, but not result in a high rate of attrition due to death. However, as only a small number of patients (3/27) did not receive the case conference intervention as they died before 4 weeks, this time period could be extended in any future phase III study allowing health professionals in the fast-track group adequate advance notice to attend a case conference.

Patients, carers and health professionals alike praised the Hospital2Home model of care. General practitioners have previously reported that a case conference allows them to be better informed, makes discharge planning easier and gives clear delineation of the role between primary care and specialist services,²⁸ findings supported by this trial. However, compared with patients with cancer, fewer general practitioners attended the case conferences (less than a third in the fast-track and less than 50% in the waiting list group; 100% for patients with cancer). Further, in some instances community palliative care declined referrals despite clear explanations of the nature of the study and patients' palliative care needs. This is likely to reflect the lack of understanding among community health professionals of the terminal nature of advanced idiopathic fibrotic lung diseases and their associated palliative care needs. This requires ongoing education. The qualitative work also identified lack of early referral to palliative care by community health professionals, despite requests from patients and carers, and some gatekeeping by hospital health professionals. It is clear that there is still a misconception that palliative care is a last resort and referral should only be made at the end of life. This exists in spite of WHO's advice that palliative care should be delivered in parallel to active care once a life-limiting illness has been identified. Recommendations of the British Thoracic Society²⁹ and the National Institute for Health and Care Excellence³⁰ support this; palliative care teams should be involved in management of patients with IPF to ensure adequate symptom control and psychological support. If palliative care is only delivered at the end of life, patients and carers may be denied valuable symptom control and psychosocial support in earlier stages of the disease and important decisions around end-of-life preferences may not be identified and acted upon. Strategies on improving the knowledge of patients, carers and health professionals on the benefits of early palliative care need to be explored.

The recent National Institute for Health and Care Excellence guidance for IPF has stated that the ILD specialist services ought to be able to manage the palliative care needs of patients and to refer to the appropriate community services.³⁰ In addition, only patients whose palliative care concerns cannot be met by the ILD services ought to be referred to specialist palliative care services.³⁰ However, despite involvement of specialist ILD services, patients and carers continue to have unmet palliative care concerns and limited community support.³ In reality, the pressure of busy ILD clinics is likely to mean that concerns are not assessed and remain neglected. Hospital2Home may enable these concerns to be examined and managed through an individualised care plan while facilitating development of important relationships with community health professionals.

There are a number of limitations to this trial. POS has not been validated in ILD, however, nor have other holistic palliative care measures. This phase II trial was not adequately powered to identify efficacy, therefore results must be interpreted with caution. Despite this the trend towards positive differences between groups was observed and strongly suggests a further adequately powered study that is informed by the learning from this study. Referrals to community services for the waiting list group were made at randomisation and beyond the control of the study, a few community services contacted

Table 4 Presentation of qualitative findings (all names have been changed to ensure confidentiality)

Theme	Participant	Example quote
Support in the community	Ann, 72-year-old wife of Stephen who had advanced NSIP	"I was bit nervous before hand you didn't have anyone to turn to really.....we have one son in xxxx but he's far away and (2) I have a sister in xxxx which phones me up every day but [coughs] otherwise that's I felt alone" "and how do you feel now?" (SB)"I feel better..... 'cause I have all the phone numbers and people phone me up...."
Individual care plans and practical problems addressed	Community palliative care CNS	"[the H2H CNS] contacted us afterwards to check everything we had said we were going to do we'd done which we had erm::: and we had her number to be able to contact if he had any problems as well so::: erm it went all quite smoothly really..."
Coordination of care and efficiency	GP	"if it wasn't for this (2) I can see a completely different scenario where this guy would be lost in the communityhe::: would be trying to find out who::: the respiratory nurse is [laughs] trying to get out who's the oxygen supplier trying to find out from his GP which one's going to be in charge of his care in the general practice which one's going to be helping him with his symptoms (1) you know it it would have become a huge::: hassle and I don't think he::: realises how lucky he is actually to be part of this trial (2) because everything's there for him (2) there's no other issue..."
Crisis management	Peter, 63-year-old with advanced IPF	"and now I've got all erm (2) they as I say they phone and I've got er a whole list of numbers that I can phone any time day or night erm if I need to, you know....oh yes yeah and (1) and (2) as I say I've got erm the telephone numbers... of of people that I can phone erm 24 seven which is ideal I mean before that erm the most I could do was dial 999"
Palliative care, psychological support	Ted, 55-year-old patient with advanced IPF	"I must say to everybody (2) definitely it is it's (2) I don't know how long I've got left but (2) whatever time I've got left (3) this palliative care is going to make that time better for me and it's better and if it's better for me it's better (2) for us as a family....I've been telling everybody (2) how important (3) you know I just wish I could get GPs in to buy into the (2) palliative care cause its makes such a difference (2) made such a difference to me..... I have weeks when (2) er like last week I wanted to talk about (3) you know (2) my illness and stuff...and they're there then (2) for me to be able to tap into.. which I am happy for because (3) when you're in in my my sort of position when you know your life limited (1) is your life is limited often at home (3) you tend you live a lie say to people you live a lie I think because say how do you feel you just say I feel fine but because you don't want to be worrying people all the time but (1) when you've got a palliative care team round you you can get that out of your system which is something we didn't have for the first 18 months two years of this disease"
Symptom control	ILD Consultant	"We would start:::t er symptom control in hospital whether that was a little bit of Oramor:::ph or lorazep:::am and then it was really we wouldn't often see the patient for another 3 or 4 months time and it was then back to the GPs han:::ds to sort of titrate and change that as needed um and it it didn't always go successfully the things weren't re-prescribed or wrong doses were given but knowing that er (1) you and your team are now doing that again we've had patients say that it's been very useful for them to have sort of continuity of care and someone taking overall view of that...."
Empowering HP	ILD CNS	"It's certainly enhanced my practice, um, certainly there's an huge (1) element of my job which is dealing with um the palliative care and end of life of patients, and I think, seeing how palliative care interact with patients and bring up (1) uncomfortable::: (2) subjects for us as healthcare professionals, certainly has enhanced my practice....We need to::: (1) understand that these aren't necessarily subjects that patients don't want to discuss...sometimes some of the anxiety around the issues can be discussing what the future is, discussing, (1) you know, having those uncomfortable conversations. I think, H2H has facilitated that, helped patients be more organised and think around what they're doing and also highlighted to us how to go about those conversations, and that those conversations are (1) ok to have."
Advance care planning	Leslie, 54-year-old wife of Ted who had advanced IPF	"For us it was a bit traumatic you know everything being coming to life that actually these things are happening I think you can go to hospital appointments and still sort of brush it aside that you know [laughs] erm (2) but once everybody was sat round the table and we talked about DNRs ...and erm (4) advanced directives and all this sort of stuff it did bring it home and it did get a little bit (3) upsetting but (3) I still do believe that it was better at that point than when (1) somebody's actual laid on their bed and you think it could be any day::: and (2) erm (1) you know I think you can deal with it better at that stage"

CNS, Clinical nurse specialist; DNR, Do not resuscitate; GP, General practitioner; H2H, Hospital2Home; HP, Health professional; ILD, interstitial lung disease; IPF, idiopathic pulmonary fibrosis; NSIP, Non-specific interstitial pneumonia.

patients and carers before the case conference. This coupled with the delay in delivering the case conference to the fast-track group may have affected comparison of the efficacy of the intervention at the primary end point of 4 weeks. However, these factors are likely to have underestimated rather than overestimated any effect. The high resolution computed tomography/composite physiologic index criteria for excluded patients were not recorded which may have provided valuable clinical information. The Hospital2Home intervention is a complex intervention with multiple different components. Attempts were made to standardise delivery as much as possible with pro-

forma and evidence based guidelines. Despite this, there is likely to have been some variance in delivery. Due to constraints of the study, outcome measures were not collected after the 8 week mark. This may have provided valuable information of possible effects of the intervention over time.

CONCLUSION

Preliminary evidence from this trial reveals a positive effect on patients and carers of the Hospital2Home intervention on palliative care concerns, quality of life and anxiety and depression. In addition, the intervention managed uncertainty by facilitating

early discussion about disease progression, improving communication and addressing end-of-life planning needs. The Hospital2Home intervention therefore appears to be feasible, acceptable and effective across a number of domains.

As this is a phase II study, any positive effects may be promising but would need to be further examined in a multicentre phase III study before conclusions about wider effectiveness may be drawn. However, the information obtained from this trial will allow sample size calculation in future studies. In addition, this study has provided valuable information about the patients and carers affected by advanced idiopathic fibrotic ILDs as well as the potential effects of the Hospital2Home intervention in this group.

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APPENDIX 1

Outcome measures used

The D12 scale is an overall score for breathlessness severity that incorporates seven physical items and five affective items.[1] Participants complete the D-12 in reference to their experience of breathlessness “these days” at baseline and follow-up. D-12 consists of 12 descriptor items on a scale of none (0), mild (1), moderate (2), or severe (3). Total scores from the D-12 range from 0 to 36, with higher scores corresponding to greater severity. It has not been validated in ILD.

The King's Brief Interstitial lung disease is a 15 item questionnaire consisting of three domains (breathlessness and activities, chest symptoms and psychological).[2] It has been validated in all ILD disease groups including IPF. A higher score indicates a higher quality of life (Qol). Scores range from 0-100 with the minimal important difference of 8 units of the total score.[3]

The St George's Respiratory questionnaire [4] is a 50 item instrument designed to measure impact on overall health, daily life, and perceived wellbeing in patients with obstructive airways disease. Part 1 has a symptoms component (frequency and severity) with a 1, 3 or 12 month recall (several scales); Part 2 has a activities component looking at activities that cause or are limited by breathlessness and an impact component looking at social functioning, psychological disturbances resulting from airways disease and referring to current state as the recall (dichotomous (true/false) except last question (4 point Likert scale).[5] The MID for IPF in each of the SGRQ domains is Symptoms 8 units, Activity 5 units, -Impact 7 units and Total 7 units.[4] A lower score indicates a better quality of life. The generic SGRQ version has been validated in IPF.[4]

The Medical Research Council (MRC) dyspnoea scale (score range, 1-5, with higher scores indicating greater impairment) [6] is used to classify participants according to activity limitation. The MRC scale comprises five statements that describe almost the entire range of respiratory disability from none (Grade 1) to almost incapacity (Grade 5). It is self-administered by asking subjects to choose a phrase that best describes their condition. The MRC breathlessness scale does not quantify breathlessness itself. Rather, it quantifies the disability associated with breathlessness by identifying that breathlessness occurs when it should not (Grades 1 and 2) or by quantifying the associated exercise limitation (Grades 3–5).

It has not been validated in ILD patients.

The 14-item Hospital Anxiety and Depression Scale (HADS) is a widely used tool for assessing psychological distress.[7] The HADS comprises seven items that tap anxiety (score range, 0-21) and seven items that tap depression (score range, 0-21), with higher scores corresponding to greater distress. Scores of 0-7 are classed as normal, 8-10 borderline abnormal and 11-21 abnormal. The HADS may be completed by both patient and informal caregiver. The HADS has not been validated in IPF. The MID in COPD is 1.5.[8]

The Carer Quality of Life Cancer (CQOLC) measures four conceptual domains of QoL: physical functioning, emotional functioning, family functioning and social functioning.[9] The CQOLC consists of 35 items that have a five-point Likert format that range from 0 (not at all), 1 (a little bit), 2 (somewhat), 3 (quite a bit) and 4 (very much): ten items relate to burden, seven to disruptiveness, seven to positive adaptation, three to financial concerns and eight single items to additional factors (disruption of sleep, satisfaction with sexual functioning, day-to-day focus, mental strain, informed about illness, protection of patient, management of patient's pain and family interest in caregiving). The CQOLC scale is scored by adding up the score on each item to yield a total score for the instrument and scores can range from 0-140. For all items and domains that measure QoL, a higher score represents a

better QoL.[9] There is no current tool to measure informal caregiver QoL in non-malignant respiratory disease. Therefore the CQOLC was used which has been validated in cancer patients.

The Zarit Burden Interview (ZBI) was developed to measure subjective burden among informal caregivers of adults with dementia.[10] Items were generated based on clinical experience with informal caregivers and prior studies resulting in a 22-item self-report inventory that examines burden associated with functional/behavioural impairments and the home care situation. The items are worded subjectively, focusing on the affective response of the informal caregiver.[11 12] Each question is scored on a 5 point Likert scale ranging from - never to nearly always present. Total scores range from 0 (low burden) to 88 (high burden).

There is no validated tool to measure caregiver burden in ILD.

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APPENDIX 2- Table showing qualitative participants' characteristics (names have been changed to ensure confidentiality)

Study ID	Study name	Profession	Ethnicity	Age	Number of patients involved with who had H2H CC	Field notes (if any)
HP1		ILD Consultant	White other	37	18	
HP2		ILD CNS	White British	31	32	
HP3		Community Matron	Philipino	30	2	Involved in the care of 2 patients that died at home as planned. Although consented to interview, this subject was very hesitant to make any comments that might be perceived as negative.
HP4		Community Palliative Care Nurse	White British	31	1	
HP5		GP	Asian British	42	1	GP very keen to take part in interview and feedback his views. GP for 34 year old patient with IPF.
P1	Alfred		White British	64		Patient with advanced IPF (no carer) on transplant list. Patient admitted for trial of NIV. Happy to take part in interview.
P2	Michael		White British	63		Advanced IPF with no carer. Patient unhappy with the state of NHS. Interviewed at home.
P3	Peter		White British	63		Advanced IPF with carer. Interviewed on day unit. Patient wearing oxygen. Struggling at times with SOB
P4	Stephen		White British	81		Fibrotic NSIP. Patient interviewed at home. Wife also interviewed as carer. Both interviewed separately.
P5	Mary		White Irish	84		Patient (NSIP) interviewed at home- relatively well at time- daughter interviewed
C1	Ann		White British	72		Wife of P4- interviewed at home.
C2	Sue		White Irish	48		Daughter of P5. Interviewed alone.
C3	Rachel		Black Caribbean	47		Daughter of 75 year old patient with IPF (not interviewed). Sole carer for patient.
C4	Leslie		White British	54		Wife of Ted- patient 55 year old patient with IPF. They have a 23 year old son with cerebral palsy which Ted is the main carer for. Interviewed at home with husband present.
C5	Penny		White British	63		Wife of 67 year old patient with IPF. Interviewed alone. Patient not interviewed

Recruitment for the qualitative study was conducted between May 2013 and November 2013. 5 patients, 5 carers and 5 health professional participants were recruited. Health Professionals (HP) recruited were an ILD Consultant, ILD CNS, community matron, community palliative care nurse and a GP. The qualitative results will be discussed in the following themes: 1)*Support in the community* 2)*Individual care plans and practical problems addressed* 3) *Co-ordination of care and efficiency* 4)*Crisis management* 5) *Palliative Care and psychological support* 6) *Symptom control* 7)*Empowering HP* 8) *Advance care planning* 9) *Feasibility and acceptability of intervention.*

Examples of quotes have been used to illustrate themes. Names have been changed to ensure confidentiality.

Theme 1 Support in the community

Previous to the Case Conference (CC), both quantitative and qualitative data showed that patients and carers were poorly supported. Patients and carers interviewed received routine care from their primary care physician. However, no patient or patients looked after by carers had any other professional help. Importantly, as well as not receiving support from HP in the community, no patients or carer participants interviewed were aware of the services that were available to them. In addition, if the patient or carer participants needed help, they often relied on the specialist ILD centre. However, the distance to RBH often caused patient and carer participants concern. This was typified by Leslie, 54 year old wife of Ted who had advanced IPF:

“What was it like erm before you had the CC what sort of input and help were you getting?” (SB)

“nothing we weren’t getting anything not from (2) not locallyreally (2) anything we needed we had to either go to or phone London.....and it’s like so it’s a 2 hour [laughs] it’s a 2 hour round trip.....but (1) that was quite scary cause you sort of think you know it’s a long way away you know if we need (4) u:::m (1) so local support just wasn’t there.....” (Leslie, 54 year old wife of Ted who had advanced IPF).

Patient participants such as Stephen, a 81 year old patient with NSIP, had felt that prior to the CC they had not known what they were doing. Importantly, through the CC patient, carer and HP participants became more aware of the services that patients and carers were entitled to. All participants reported that through the CC, patients and carers received support from a variety of community HP. Patients and carers commented that they were regularly contacted by community HP to check that they were "okay". The community HP would not necessarily visit every week but would phone to touch base with the patient and carers. Patient and carer participants commented on how it was reassuring that someone was checking on them and that this made them feel "safe" and how they were grateful for all the help that they were now receiving.

"I think] I'm very lucky....I didn't think that help was there" (Mary, 84 year old with NSIP)

Carers felt happier to have access to a support network in the community. For example, carers such as Ann, 72 year old wife of Stephen who had advanced NSIP, reflected on how they had felt isolated and were required to muddle through before:

"I was bit nervous before hand you didn't have anyone to turn to really.....we have one son in xxxx but he's far away and (2) I have a sister in xxxx which phones me up every day but [coughs] otherwise that's I felt alon:::e" (Ann, 72 year old wife of Stephen who had advanced NSIP)

"and how do you feel now?" (SB)

"I feel better..... 'cause I have all the phone numbers and people phone me up...." (Ann, 72 year old wife of Stephen with advanced NSIP)

Patients like Peter (63y with advanced IPF) were grateful for having been involved in the study and receiving support which he felt he would not have got if it had not been for the CC. Touchingly, he reflected on those who were still not receiving support. He stated:

".....because before that [CC] erm well I say they they wouldn't have known about me anyway erm (3) but (2) its [coughs] for people that are maybe not coming her:::e erm they they can be sitting indoors erm with no no help and not

knowing where to get it which is a shame” (Peter, 63 year old with advanced IPF).

Theme 2 Individualised care plan and practical problems addressed

Through the CC, an individualised care plan specifically meeting the patients' and carers' palliative care needs was developed. Using the evidence based guidelines, symptom control issues were addressed. Specific action points were allocated to each HP codifying responsibility. After the CC, the H2H CNS contacted the patient and followed up with the HP to ensure tasks were completed. In addition, in the care plan patients and carers had the contact details of how to contact each of the HP directly if there were any issues. This process is illustrated by the Community Palliative Care CNS:

[the H2H CNS] contacted us afterwards to check everything we had said we were going to do we'd done which we had erm::: and we had her number to be able to contact if he had any problems as well so::: erm it went all quite smoothly really...” (Community Palliative Care CNS)

Many patients and carers had practical problems that needed to be addressed. Both patients and carers expressed how quickly after the CC these practical issues were attended to especially as many patients had been waiting a long time for these issues to be addressed. Rachel (47 y), whose mother had not received any care prior to the CC, reflected on how after the CC things moved very quickly.

She said:

“....the district nurse she was just making sure that erm mum is comfortable erm cause at the I think that was the time when they all came mum was suffering with bed sore:::s....so that was erm (2) a problem and I mean (1) it was dealt with fantastically because erm (3) xxxx (2) made sure that a bed (1) hospital bed was delivered within two three days...” (Rachel, 47 year old daughter of patient with advanced IPF)

The GP felt that as responsibility was codified and patients/carers had contact numbers for all HP on the care plan, HP were more likely to follow through on tasks.

Importantly, the individualised care plan holistically focussed on the needs of the patient, carer and where applicable, other family members. Patients and carers during the qualitative interviews reported how beneficial this was. Quantitative data also showed a significant change in patient POS (measuring holistic palliative care needs of the patient) score for the FT group at week 4 and the WL group at week 8. Leslie discussed how the CC allowed their concerns for their son (which were at the forefront of their minds and fundamental to improving their quality of life) to be addressed by the social worker attending the CC:

“our erm (2) youngest son’s got cerebral palsy.. so erm after that meeting [CC] it was put in place for him to have erm (4) erm counselling erm (3) and to explain to him (2) erm what was happening... and so he has a better understanding now erm (2) because it’s difficult to know you know you need somebody really from the erm (2) special needs to (2) to get through to them in in the way that needs to be done rather than (1) so we had that put in place as well after the meeting [CC]” (Leslie, 54 year old wife of Ted who had advanced IPF).

Theme 3 Co-ordination of care and efficiency

Before the CC, patients and carers stated that there was a lack of co-ordination and efficiency in the care that was delivered. Stephen, a 81 year old patient with NSIP, expressed his frustrations with the lack of effectiveness of the health system:

“there was a lot of people didn’t know what to do with me a- quite I I suspect um I I can’t say for sure [deep intake of breath] and it seemed to be I’ve (1) been pushed from one to another or pushed round and round in circles I was taking a lot of erm (1) tests (2) and they were all being sort of duplicated” (Stephen, a 81 year old patient with NSIP)

Post CC there appeared to be some improvement; Alfred, 64 year old patient with advanced NSIP and no carer felt that the CC allowed everyone to “sing from the same hymn sheet” improving efficiency of the care delivered. In addition if an admission did occur, the care plan gave clear

information about who was involved in the patient's ILD care. Carers such as Sue felt that having the care plan cut down a lot of time as she could just hand the care plan to any HP if needed.

Prior to the CC, HP participants such as the ILD Consultant recognised that there had been poor communication and a lack of joined up thinking. HP were in agreement with patient and carer participants about inefficiencies prior to the CC and that the CC had improved communication across the primary and specialist care setting:

"actually quite nice we don't generally get those we generally get you know the referral and then we have to ring up and get more information and find out you know do they know their (1) their prognosis and you know has has his advanced care planning been discussed etc etc so having to like tease all the information out and then sometimes when we get there actually bring up it they say that it hasn't been discussed even though sometimes the hospital say it has so it [the CC] was very helpful in that respect" (Community Palliative Care CNS)

All HP were in agreement that having the patient and carer at the CC, involved in planning and fully aware of treatment plans for the future, was very helpful and allowed concerns to be prioritised focussing on the patients' and carers' needs. The ILD Consultant felt that as the specialist centre, they did not have time to address palliative care needs in busy clinics. As a result, these needs had dropped to the wayside. He was grateful for H2H. He stated:

"certainly knowing that that aspect of the care was being taken care of it's not (1) its just so difficult to provide that sort of level of fine detail in this hospital with so many patients coming through and as a referral centre that there just isn't the the manpower to be able to focus on that sort of (1) erm specific symptom control and again knowing that you guys are doing it is a is a is sort of (1) often then it removes that from something we need to worry about....." (ILD Consultant)

The many different ways of referring to community palliative care teams and the variance in the community support received was seen as a barrier to referral by the ILD teams. Patients receiving H2H had the H2H CNS making all the referrals to the appropriate community HP. She would also try

to ensure that the care remained co-ordinated by checking in with the patient at 2 weeks, one month and 2 months after the CC. Patients, carers and HP could contact the H2H CNS if there was a breakdown in care which she would try to resolve. This was reflected on by the GP who felt that co-ordination of care for patients who weren't involved in the study was "patchy" and "haphazard". The GP expressed that it was an unknown for patients, carers and HP as to which HP may be involved in the patient's care and a lottery as to which HP would subsequently visit the patient at home. He stated:

"if it wasn't for this (2) I can see a completely different scenario where this guy would be lost in the communityhe::: would be trying to find out who::: the respiratory nurse is [laughs] trying to get out who's the oxygen supplier trying to find out from his GP which one's going to be in charge of his care in the general practice which one's going to be helping him with his symptoms (1) you know it it would have become a hug:::e hassle and I don't think he::: realises how lucky he is actually to be part of this trial (2) because everything's there for him (2) there's no other issue..." (GP)

This was reiterated by the ILD CNS who felt that having the H2H CNS co-ordinate care and be available if needed gave extra support to patients and added an extra layer of support for the patient and carer to turn to if there was a breakdown of care in the community.

During the CC, HP were codified responsibility to address issues raised at the CC. In doing so, contact numbers were available to both the patients and carers for each HP and their allocated task. HP participants commented that having contact numbers of HP involved in patients' care clearly documented on the care plan was helpful. HP participants such as the community matron reflected on how she wasn't aware how to get in contact with the specialist teams prior to the CC and as a result would not have done. She felt that the contact numbers on the care plan facilitated approaching the specialist centre if needed and as a result improved care. Community HP interviewed also felt that having the H2H CNS at the CC fostered the relationship between the specialist and community settings and made it more likely that they would approach the specialist centre if needed for advice on how to manage the patient's care.

Interestingly, being involved in the study led to recognition by HP of the serious nature of the disease. As a result, not only did patients receive more HP input but patient participants and patients looked after by carer participants stated that they also gained easier/priority access. Carers such as Sue, 48 year old daughter of Mary who had NSIP, expressed that prior to the CC, she would often try to contact her GP at the local surgery which was often a time consuming and long process. However, post CC, things had improved immensely:

"the practice nurse has a system where something will come up where erm it's noted it will flag up that mum's in this home to care [H2H] process.....she can bypass a lot of the (1) the red tape" (Sue, 48 year old daughter of Mary with NSIP)

This was also recognised by the HPs interviewed. The GP commented that as a result of the study, patients had received FT access to all HPs. The GP reflected that this was empowering for the patient and carer. He stated:

"the patient is in charge of their own care:::for somebody like this yea:::h I think it's really useful for them because then (1) they can sort of direct their questions to the right people cause they're they're fully aware" (GP)

Theme 4 Crisis management

Carers such as Penny (63y wife of patient with IPF) felt that prior to the CC, they would have rung 999 if her husband needed help out of hours. All patient and carers expressed relief that the CC had set out clear crisis management plans with direct contact numbers for HP 24 hours a day:

"that's right (1) um (3) one of the things that I do (2) imme::diately was that (2) as soon as I had the telephone number of one of the (1) people I contact, was straight into the into the telephone d- line, dial in directly (2) ah (2) both my old telephone [laughs] and my (1) mobile, so its its there so I can contact them."
(Alfred, 64 year old patient with advanced NSIP and no carer)

As did Peter, 63 year old with advanced IPF, who felt that having access to contact numbers and a clear crisis management plan was a vast improvement:

"and now I've got all erm (2) they as I say they phone and I've got er a whole list of numbers that I can phone any time day or night erm if I need to, you know"
(Peter, 63 year old with advanced IPF).

"do you find that helpful?" (SB)

"definitely] erm (1) it gives you (1) definitely gives you peace of mind, definitely"
(Peter, 63 year old with advanced IPF).

".... Do you think that er you would know what to do in a crisis no:::w, so if something went wron:::g?" (SB)

" oh yes yeah and (1) and (2) as I say I've got erm the telephone numbers... of people that I can phone erm 24 seven which is ideal I mean before that erm the most I could do was dial 999" (Peter, 63 year old with advanced IPF).

In addition, HP such as the GP and ILD Consultant felt that having access to all the contact numbers was likely to help prevent hospital admissions.

Theme 5 Palliative Care and psychological support

Patients and carers felt that they had not been able to access palliative care prior to the CC. The main barriers to referral were misconceptions of what palliative care is and a misunderstanding of which patients were suitable for referral:

"our doctor we did speak to him (1) about (1) local care but our doctor actually said to us that they don't look at palliative care till you're bed ridden [laughs] (4) erm (4) but you need the support a long time before that (2) erm" (Leslie, 54 year old wife of Ted who had advanced IPF)

HPs were not the only ones that had preconceptions of palliative care. Patients and carers expressed that prior to the study they thought that a hospice would be somewhere where the "*walking dead*"

attended. Despite being involved in a palliative care study, some patients and carers were surprised to be contacted by the local hospice:

"we were a bit surprised er er to hear from the hospice (1) you know I mean er first first reactions when somebody (1) erm (1) one second [clears throat] wants to get a hospice involved you think like you've got to go in and er [laughs] you're not coming out" (Peter, 63 year old with advanced IPF).

Because of these misconceptions, patients and family members required repeated clear explanations of the remit of palliative care during the study. The appropriateness of palliative care/hospice teams in supporting patients for symptom control and psychological support throughout the disease journey was explained on entry to all patients and carers but needed to be repeated, especially if other family members became involved/attended the CC.

Interestingly, both patient and carer participants who had been hesitant of palliative care/hospice involvement at the start of the trial, subsequently expressed how much they valued the support they received from attending the day hospice and receiving regular palliative care input.

"I must say to everybody (2) definitely it is it it's (2) I don't know how long I've got left but (2) whatever time I've got left (3) this palliative care is going to make that time better for me and it's better and if it's better for me it's better (2) for us as a family....I've been telling everybody (2) how important (3) you know I just wish I could get GPs in to buy into the (2) palliative care cause its makes such a difference (2) made such a difference to me" (Ted, 55 year old patient with advanced IPF)

In fact, being involved with the study and receiving community palliative care was seen as beneficial for both patient and carers in improving psychological symptoms. Sue commented that prior to the CC, her mother had been depressed. She felt that focussing on current and future care needs through the CC and accessing a support network had focussed her mother and improved her mood. Ted expressed that attending the day hospice allowed him to talk about his feelings if he wanted to:

"I I have weeks when (2) er like last week I wanted to talk about (3) you know (2) my illness and stuff...and they're there then (2) for me to be able to tap into.. which I am happy for because (3) when you're in in my my sort of position when you know your life limited (1) is your life is limited often at home (3) you tend you live a lie say to people you live a lie I think because say how do you feel you just say I feel fine but because you don't want to be worrying people all the time but (1) when you've got a palliative care team round you you can get that out of your system which is something we didn't have for the first 18 months two years of this disease" (Ted, 55 year old patient with advanced IPF)

"do you mean that then you can be honest about how you feel?" (SB)

"yeah I can I they cause sometimes it's just about releasing it.... it's not it's not necessarily who you even talk to [laughs] it's yeah it's just somebody who cares but that means then I can come home and life is better at home" (Ted, 55 year old patient with advanced IPF)

Importantly, there was recognition that the disease affected the whole family and that support for loved ones and carers was needed. Support from the palliative care teams for carers was appreciated by both patients and carers:

"I started to go the day hospice once a week for 6 weeks and also er which I thought was a very good thing erm (1) they asked my wife if she wanted to go over there erm once a week erm (1) to a carers (1) erm (1) sort of meeting and er (1) also (1) erm (2) they they what else are they doing for her oh they do a she (1) tends to get swollen a ankles quite a bit erm and they (1) they massage them" (Peter, 63 year old with advanced IPF).

Theme 6 Symptom control

During the CC, the evidence based guidelines on managing the palliative symptoms of patients with ILD were distributed to all HP involved in the patient's care (whether attending the CC or not) and also

to the patient and carer. HP, patients and carer participants found these guidelines helpful. HP participants such as the GP felt the evidence based guidelines were useful in improving symptom control with clear options of what to prescribe patients if they deteriorate. The community palliative care CNS also felt that the intervention improved symptom control through increased confidence in their current practices and allowing community HP ready access to specialist teams in the hospital if needed. She stated:

"I think it was helpful to get because obviously we don't get a huge volume of these types of patients and er and therefore our knowledge isn't as as great as as some of other knowledge on other patients that we get a lot of it was quite nice to know erm the exact plan for them really....it's quite nice to speak to a specialist and say you know what what particular drugs do you think work better you know we know what you use for ours but is there anything in particular and there wasn't anything hugely different but it's just nice to have somebody who specialises a bit more in the you know because the the diseases" (Community Palliative Care CNS).

ILD HP participants such as the ILD Consultant also felt that the intervention had been helpful in improving symptom control. He stated:

"we would start er symptom control in hospital whether that was a little bit of Oramorph or lorazepam and then it was really we wouldn't often see the patient for another 3 or 4 months time and it was then back to the GPs hands to sort of titrate and change that as needed um and it it didn't always go successfully the things weren't re-prescribed or wrong doses were given but knowing that er (1) you and your team are now doing that again we've had patients say that it's been very useful for them to have sort of continuity of care and someone taking overall view of that...." (ILD Consultant)

Carers such as Sue expressed that as a result of the CC she was made aware of all the options of delivery of care available to her mother. For example, she was not aware that if needed, her mother could have intravenous antibiotics at home so an admission to hospital was not always necessary. In

addition, having a documented clear strategy on how to manage each symptom within the care plan was seen as invaluable by all participants. Carers felt that it allowed them to manage their loved ones symptoms better and sometimes prevented hospital admission.

Theme 7 Empowering HP

The CC was seen as empowering by both the specialist and community HP participants interviewed. The ILD CNS commented on how a large part of her job as an ILD CNS was to deal with end of life issues and it was helpful to see how end of life conversations were handled by the H2H CNS. Being involved in the CC guided HP participants in how they ought to be conducting conversations around advance care planning:

"it's certainly enhanced my practice, um, certainly there's an huge (1) element of my job which is dealing with um the palliative care and end of life of patients, and I think, seeing how palliative care interact with patients and bring up (1) uncomfortable::: (2) subjects for us as health care professionals, certainly has enhanced my practice....We need to::: (1) understand that these aren't necessarily subjects that patients don't want to discuss...sometimes some of the anxiety around the issues can be discussing what the future is, discussing, (1) you know, having those uncomfortable conversations. I think, H2H has facilitated that, helped patients be more organised and think around what they're doing and also highlighted to us how to go about those conversations, and that those conversations are (1) ok to have." (ILD CNS)

All patients attending the Royal Brompton were given routine 3 monthly out-patient appointments in the ILD clinic. Previously, these patients had been reliant on attending these appointments, especially as there was little support being accessed in the community and patients did not have confidence in community HP in managing their disease. Through being involved in the study, patients and carers were linked in to their local community health services. Patient and carer participants reflected that they had started to develop support networks locally. This appeared to cause a change in the

relationship with the specialist centre where patients and carers began to question the aim of attending hospital appointments that were now viewed as stressful and burdensome:

"we are getting to the stage no:::w (1) where (5) we won't be going to London so often I mean already xxxx has to go by (1) ambulance cause he's having 6 litres of oxygen... erm (3) and obviously as he gets more poorly you know the trips just really aren't going to be (3) erm (3) beneficial to to him.. but that's no because already now they're they're just really a chin wag across the table .. to and cause they can't do anything now.. so (2) to know that you've got what you need here now in xxxxxx you know right here (2) is what we need you know not hundred miles down [laughs] the road" (Leslie, 54 year old wife of Ted who had advanced IPF).

This was also recognised by the ILD HP participants in the specialist centre:

"stratifying actually what (1) erm, (1) what hospital appointments patients are going to attend...has been very useful.....patients feel that they have to attend and then it's very stressful for them to ma-, you know make that trip in, so it's been very good for that angle as well." ILD CNS

However, even though patients and carers recognised that there wasn't anything that the specialist centre could do, they still preferred to have the option of being able to attend RBH (ie keeping it as a "safety net" if needed). Patient's and carers' confidence in the community teams was a gradual thing which seemed to develop over time as patients and carers had more contact with the HP. As confidence in the community teams grew, this affected whether they felt the need to attend out-patient appointments and investigations at the specialist centre. Appointments were often moved to 6 monthly and tests cancelled as patients and carers gained trust in the community HP and felt better supported. However, the "door was always left open" which was important for maintaining hope and patients' psychosocial wellbeing:

"patients when can't practically offer them any more treatment they're very reluctant to be discharged whether they've had a bad experience with their local

hospital or they (2) you know they think ok there might a new drug coming up round the corner" (ILD Consultant)

The initial CC with the H2H CNS was reassuring for GP and the other HPs. The community matron expressed that having a “specialist” (the H2H CNS) offer to give their mobile number and welcoming contact was very empowering to the community HP and instilled confidence in their abilities. The Community Palliative Care CNS reflected on how she hadn’t always felt confident in dealing with these patients and how the CC helped in directing her in delivering appropriate care:

“we don't get a huge volume of these types of patients and er and therefore our knowledge isn't as as great as as some of other knowledge on other patients that we get a lot of it was quite nice to know erm the exact plan for them really...” (Community Palliative Care CNS)

The GP also commented that having easy access to specialists also made them more confident in delivering care as they knew that if there were any “issues, they had access to experts in the field”.

Theme 8 Advance Care Planning

Previously, the two specialities of ILD and palliative care were not seen to run alongside each other and it was usually an either/or scenario. H2H appeared to help to assist in that transition and allowed palliative care to be introduced alongside attendance at the specialist centre whilst active ILD management was ongoing. In fact, patients were often still on active treatment such as pirfenidone when they were referred to the trial. The ILD Consultant recognised that the shift between discussing ILD treatment options and palliative care was one that was difficult to do therefore difficult conversations about palliative care were often avoided:

“because of the nature of this unit I don't think we deal that particularly well when we've run out of treatment options (2) to then put them onto a palliative care pathway and whether that's because they see different people and in different adm- you know different clinic visits (2) or if we ourselves as as health care professionals just don't like dealing with that kind of stuff....” (ILD Consultant)

ILD HP participants also recognised that important discussions surrounding advance care planning (such as preferred place of care and death) were not something that were done well by the ILD teams even though there was recognition that they were likely to prevent unnecessary hospital admissions. It was appreciated that the CC facilitated these discussions.

Through the CC, frank and open advance planning discussions were conducted. Prior to the CC, the H2H CNS (with a background in palliative care training) would ascertain with the patient whether they were happy to have discussions surrounding preferred place of care (PPC) and preferred place of death (PPD). Not all patients were ready to talk about PPC or PPD at the CC. However, patients and carers participants interviewed were grateful to talk about these issues- especially to find out more information about all the options available to them. Interestingly, the CC became a vehicle to facilitate frank and open discussion with family members which may not have occurred otherwise. The GP felt that the CC empowered patients to have conversations about end of life and to make sure that their views were communicated to their loved ones and the HP involved in their care.

Rachel whose mother had been going in and out of hospital for the last 2 years found the discussion and communication of the decision at the CC difficult:

*"mum has made up her mind that she doesn't want to go back to the hospital
erm mum wants to stay hom:::e so erm I have decided as much as this is very
hard I've decided not to::: fight against my mum's wishes (1) er:::m (1) I do
understand that my mum's (2) condition (2) is (3) far gone" (Rachel, 47 year old
daughter of patient with advanced IPF)*

However, there was a realisation that even though the conversations were difficult, they needed to occur: Ted touchingly commented alongside Leslie on how the CC forced him to open up to his grown up children about the future:

*"...and that was the thing with the (2) I mean I did get upset at the initial (4) thing
sitting round the table but that was the first time and it was probably as much
because it was the first time (1) I'd had my children (3) the children were there
(3) but they're not children but my my children (2) there::: erm I was able to say
anything (3) and tell them let them know how I really felt so that's why and you*

feel a bit weepy because you think (1) should be hiding it as a father you think (2) but it's not not (4) you know it's not you're not pre-programmed to (1) be talking about your own death...so (3) it's not an easy one to (1) discuss...so (2) that's the only (3) but I don't I think the (1) the way (1) you've bought everybody together is fine because you're also getting a shock to the system like I found but I'm just talking in front of [laughs] my children and kids so be completely open about it." (Ted, 55 year old patient with advanced IPF)

"and looking back (2) do you think that was a good thing?" (SB)

"oh definitely it was a good thing cause [it made]" (Ted, 55 year old patient with advanced IPF)

"I don't think] you would have (2) opened up [to them" (Leslie, 54 year old wife of Ted who had advanced IPF).

"I don't think] I don't think I ever would have I don't think I ever would have opened up without (2) you setting (1) that (2) in place that's the thing (2) I don't I still think I would have been (2) yeah I'm feeling I'm not feeling very good or I'm feeling you know I'm feeling alright I still don't think I would have really faced up to it" (Ted, 55 year old patient with advanced IPF)

Leslie also reflected on her experience of advance care planning at the CC and the appropriateness of the timing of these conversations:

"for us it was a bit traumatic you know everything being coming to life that actually these things are happening I think you can go to hospital appointments and still sort of brush it aside that you know [laughs] erm (2) but once everybody was sat round the table and we talked about DNRs ...and erm (4) advanced directives and all this sort of stuff it did bring it home and it did get a little bit (3) upsetting but (3) I I still do believe that it was better at that point than when (1)

somebody's actual laid on their bed and you think it could be any day and (2) erm (1) you know I think you can deal with it better at that stage" (Leslie, 54 year old wife of Ted who had advanced IPF).

Interestingly, as patients developed closer relationships with community HP and especially the community palliative care team, this led to more discussions about end of life preferences and changed preferences. This may have reflected an increased confidence in the community teams and development of relationships with the community palliative care teams over time after the CC.

Theme 9 Feasibility and acceptability of the intervention

The timing of the intervention was thought to be appropriate and the earlier in the disease process it occurred, the more perceived benefit there was:

"it is (1) better (3) than (3) later you know if all these things happen once you're bed ridden (2) erm (3) you know you've got people coming in (2) that you don't know at least you know this way I mean we know the nurses...you know we know them first name terms erm you know you feel comfortable with them erm (5) you know I do thinks it's definitely it needs to be done that way erm and that much earlier." (Leslie, 54 year old wife of Ted who had advanced IPF).

The length of questionnaires was deemed to be acceptable. In addition, the interval between questionnaires was also deemed to be appropriate; a 4 week interval between questionnaires was felt to be adequate to capture any changes in symptom control or quality of life. In addition, the questionnaires used were also felt to assess change satisfactorily by patients, informal caregivers and HP with the right outcome measures being used. One patient (Alfred) had felt that there was some repetition between questions in outcome measures and had become confused at times as some measures had asked about experiences over last 3 days (POS) and others over last 2 weeks (SGRQ).

Patients and informal caregivers alike did not feel that the questionnaires caused distress. There was a recognition that questions about death and dying were necessary but patients and informal caregivers alike did not feel that these caused suffering.

At the CC, patients and informal caregivers as well as the HP were given the evidence based guidelines. Both patients and informal caregivers were grateful for the guidelines (even though they weren't specifically tailored to the lay person). Patients such as Alfred felt that they encouraged him to research areas that were not familiar but found it encouraging that he was using the right things in other areas.

All HP were extremely grateful for the guidelines. For example, the ILD Consultant found them very useful and he felt they allowed systematic evidence based symptom control rather than ad hoc delivery of symptom control as he had previously done. Generalists such as the GP found them invaluable and specifically appreciated having guidance from specialists which again reassured him and instilled confidence that he was doing the right thing and guided him on aspects of symptom control he wasn't sure about.

Patients and informal caregivers interviewed did not feel that there was any problem with the FT design. One informal caregiver in particular (Penny, wife of a 67 year old patient with IPF) did not feel it was a problem to have to wait one month for the intervention as she did not feel that her husband's prognosis was so short that waiting would matter. However, the Community Palliative Care CNS did feel that it mattered especially if a patient was particularly unwell, she felt the wait could affect the care:

"I do think with some of them that it would cause problems. Erm I think that it would have been too late particularly if they're very poorly.... and you can't necessarily predict that with everybody and actually some of them (1) 4 weeks (2) would be too much without all that help...." (Community Palliative Care CNS)

However, there was an understanding from those with a research background such as the ILD Consultant that 4 weeks was a reasonable time period for the WL group to wait before receiving the intervention as it often took longer than that to set up support in the community.

All patients and informal caregivers interviewed were grateful for having taken part in the study:

“...just to say I'd like to thank you erm (1) for giving me the opportunity to go on this in- like on this survey [study] and to get the help that I've I've now got I really do appreciate it.....” (Peter, 63 year old with advanced IPF).

“I think the study's excellent” (Stephen, a 81 year old patient with NSIP)

In addition, HP also felt extremely positive about the CC and reported that patients and informal caregivers had fed back to them about their experience:

“we've had good (1) er quite a lot of good feedback from patients as well that it's been very useful for them with regards to symptom management and having someone coordinate their overall care” (ILD Consultant)

*“on every level I found it very very (3) er::: (4) useful.....I think it's brilliant...”
(GP)*