PILOT™ Education Transforming PULMONARY CARE

Palliative Medicine in Pulmonology

www.PILOTforPulmonary.org

WHO Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness.

It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

WHO/CDS/IMAI/2004.4 Rev. 1

Palliative Care:
symptom management and end-of-life care

WHO. https://www.who.int/news-room/fact-sheets/detail/palliative-care

WHO: Palliative Care

Addressing suffering involves taking care of issues beyond physical symptoms

- Palliative care uses a TEAM APPROACH to support patients and their caregivers
- This includes addressing PRACTICAL NEEDS and providing bereavement counselling
- It offers a support system to HELP PATIENTS LIVE AS ACTIVELY AS POSSIBLE until death

WHO. https://www.who.int/news-room/fact-sheets/detail/palliative-care

ATS Guidelines Recommend Palliative Care For Patients with IPF…

- Palliative care should be considered as an adjunct to disease-focused care
- Advanced directives and end-of-life care issues should be addressed in the ambulatory setting in all patients with IPF, particularly those with severe physiological impairment and comorbid conditions
- In patients who are bedbound due to IPF, hospice care should be considered

However…

Raghu G, et al. *Am J Respir Crit Care Med*. 2011;183:788–824.

Evidence Indicates a Need to Do Better

Rajala et al. 2018

N = 247 patients with IPF included in study; 92 died and were included in follow-up

Marked deterioration in the QOL during the LAST TWO YEARS OF LIFE

Most prominent declines in HRQOL occurred in physical function, vitality, emotional role, and social functioning

Bajwah et al. 2012

N = 45 patients with progressive idiopathic fibrotic ILD

38% had palliative care team involvement

93% experienced dyspnea in last year of life

Only 18% had preferred place of care, and 13% had preferred place of death documented

Lindell et al. 2015

N = 404 decedents (patients with IPF)

57% died in the hospital

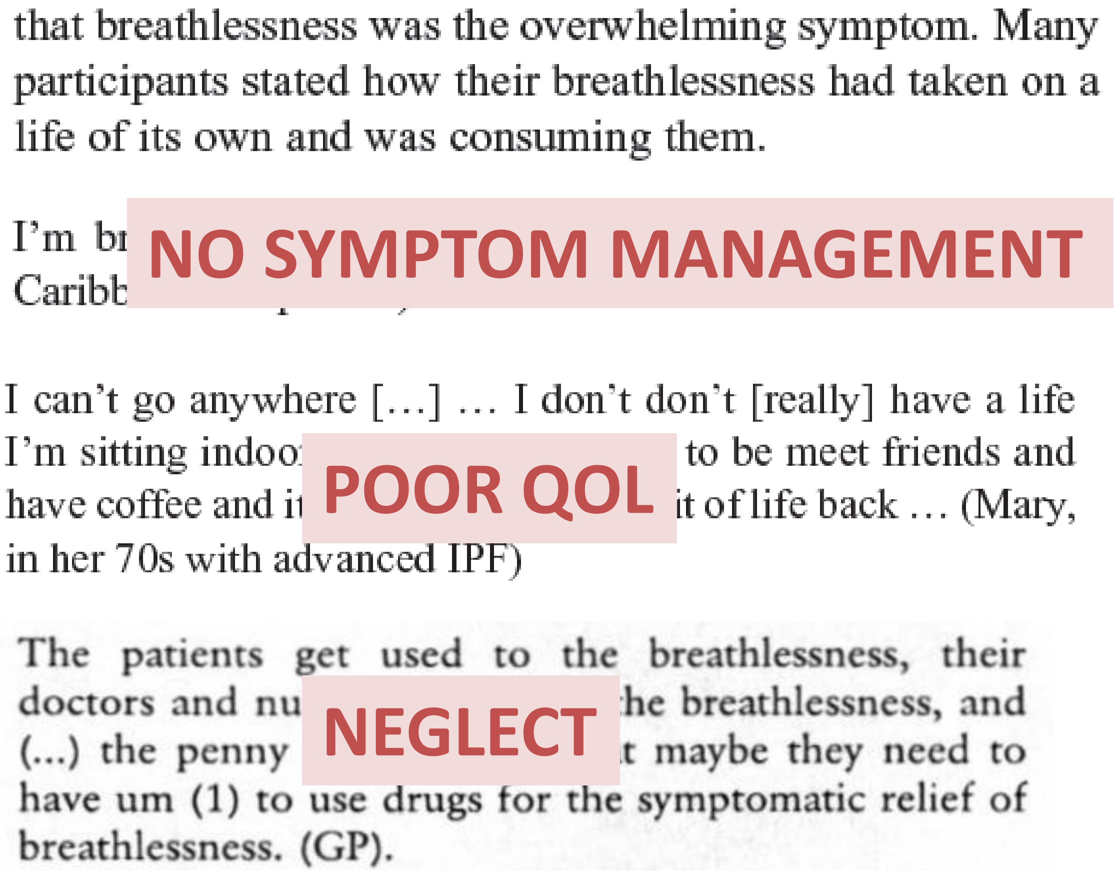
14% had formal palliative care referral

71% referred within last month of life

Rajala K, et al. *BMC Pulmonary Med*. 2018;18:172; Bajwah S, et al. *Lung*. 2012;190:215-220; Lindell KO, et al. *Chest*. 2015;147:423-429.

The Problem: Unmet IPF Care Needs

Patient, caregiver and HCP perceptions of care



that breathlessness was the overwhelming symptom. Many participants stated how their breathlessness had taken on a life of its own and was consuming them.

I'm br

Caribb

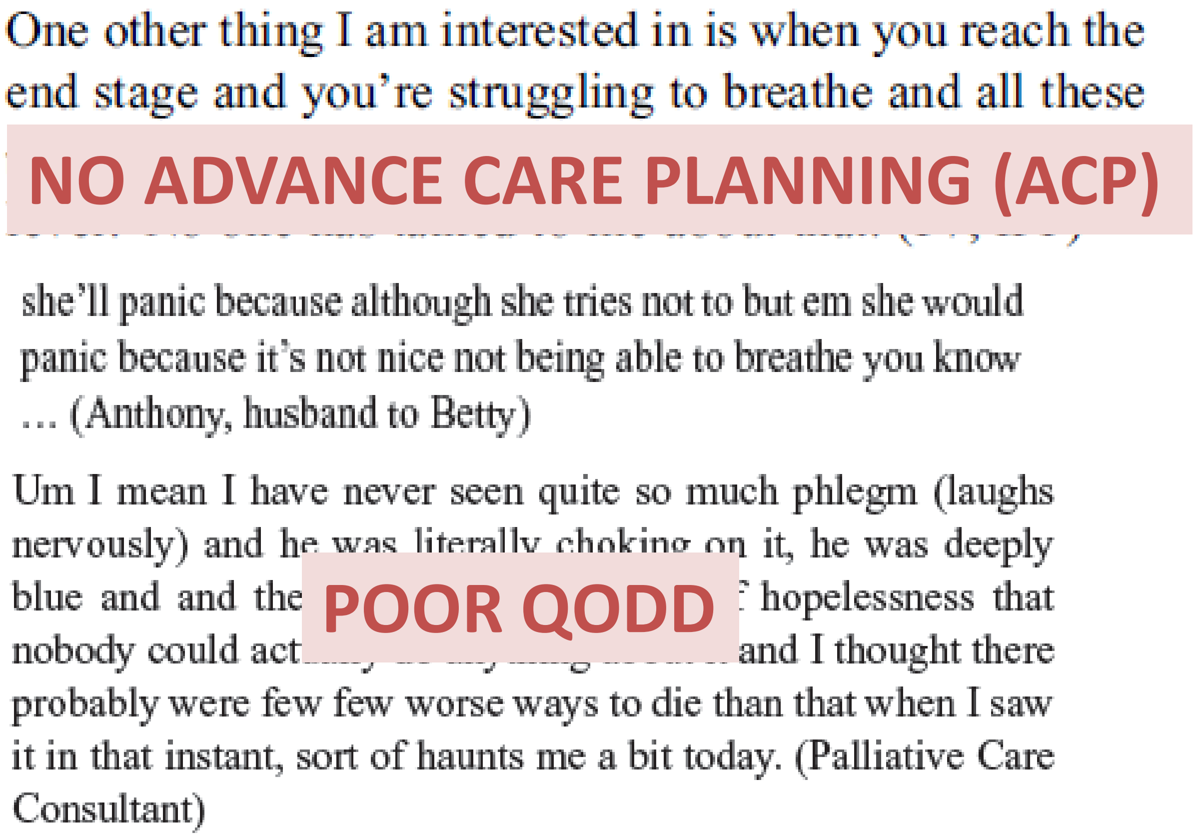
NO SYMPTOM MANAGEMENT

I can't go anywhere […] … I don't don't [really] have a life I'm sitting indoo to be meet friends and have coffee and it it of life back … (Mary, in her 70s with advanced IPF)

POOR QOL

The patients get used to the breathlessness, their doctors and nu he breathlessness, and (…) the penny t maybe they need to have um (1) to use drugs for the symptomatic relief of breathlessness. (GP).

NEGLECT



One other thing I am interested in is when you reach the end stage and you're struggling to breathe and all these

NO ADVANCE CARE PLANNING (ACP)

she'll panic because although she tries not to but em she would panic because it's not nice not being able to breathe you know … (Anthony, husband to Betty)

Um I mean I have never seen quite so much phlegm (laughs nervously) and he was literally choking on it, he was deeply blue and and the hopelessness that nobody could act and I thought there probably were few few worse ways to die than that when I saw it in that instant, sort of haunts me a bit today. (Palliative Care Consultant)

POOR QODD

Bajwah S, et al. *Palliat Med*. 2013;27(9) 869-876.
Bajwah S, et al. *BMJ Support Palliat Care*. 2013;3:84-90.

Patients were asked:

“What does palliative care mean to you?”

“My main goal of therapy for my chronic disease is to maintain quality of life at the best achievable level for the time I have left…”

“Dignity, pain free, and of great benefit to patients and families…”

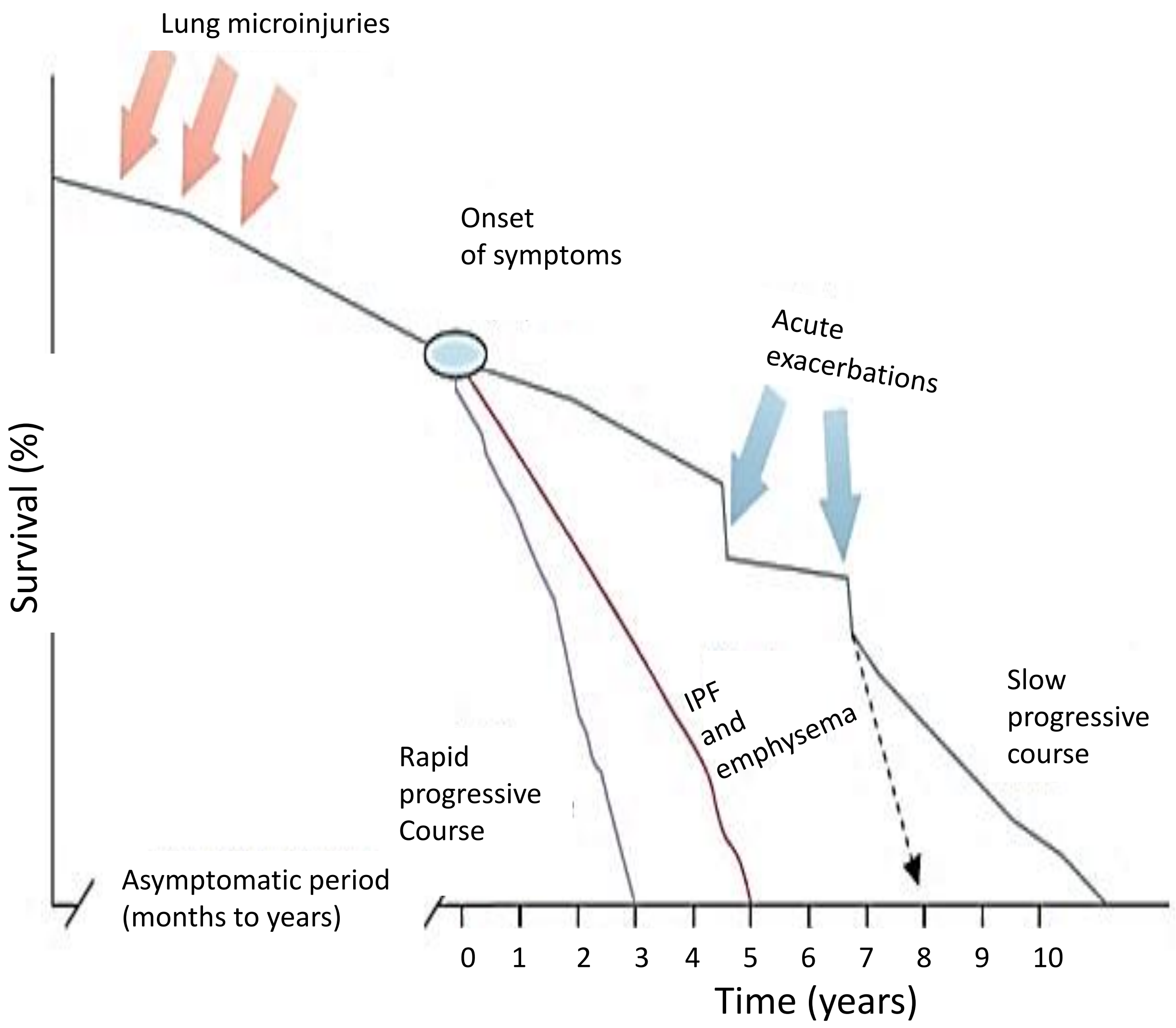
“Before I was sent to the palliative care ward, I was frightened to be demoted for dying but at the same time frightened to suffocate. Palliative care took away my breathlessness and my fears…”

“Palliative care always meant end of life to me but if it helps my quality of life for whatever time I have left, I would be happy to look into it”

“I do not want to be labelled as a doomed man. That's why I do not like to be sent to palliative care…”

Kreuter M, et al. *Lancet Respir Med*. 2017;18:139.

Challenges Specific to IPF: Uncertain Trajectory



King TE Jr, et al. *Lancet*. 2011;378(9807):1949-1961.

Barriers to Effective Palliative Care for ILD
ILD-Related Factors

- Prognostic uncertainty
- Little awareness of ILD in the general population
- Scarcity of evidence for palliative care in ILD
- Only a few established tools
- Few established patient-related outcomes for palliative care

Kreuter M, et al. *Lancet Respir Med*. 2017;18:139.

Misconceptions about Palliative Care in the General Population

- Misinterpretation of palliative care as hospice care and end-of-life care
- Little knowledge of palliative care in the general population
- Cultural and religious restraints to palliative care
- Discussions happen too late in the disease course

Health Care Provider and Health System Barriers

Providers

- Little knowledge and lack of awareness
- Insufficient time
- Personal barriers to raising the topic with patients
- Absence of guidelines
- Insufficient awareness of patient's culture, religion or spirituality
- Denial of the patient as the expert of their own disease

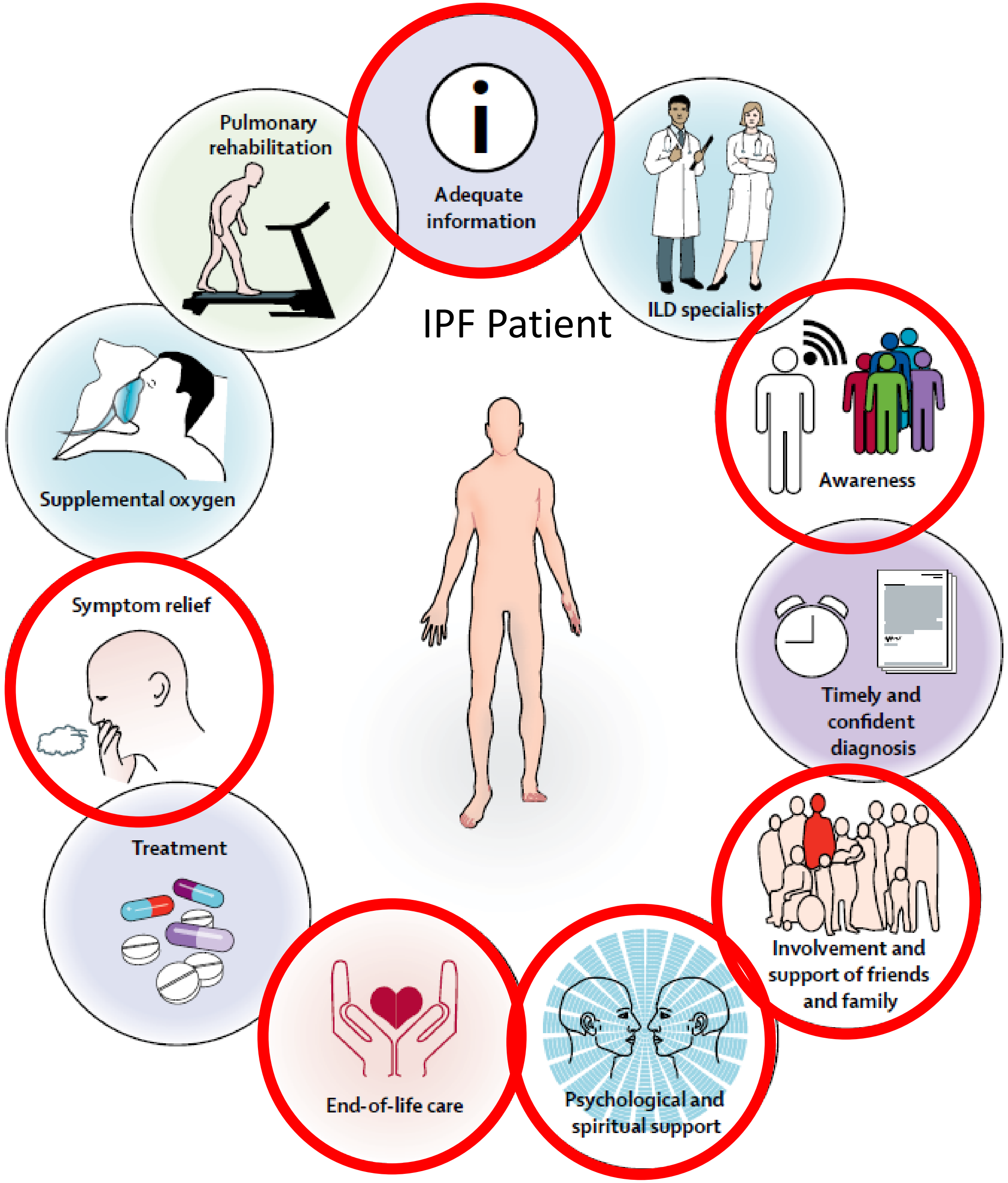
Health Care System

- Insufficient palliative care resources
- Limited access to symptom-based therapies
- Insufficient reimbursement
- Deficient collaboration between primary treatment team and palliative care team
- Overloaded and impractical hospital services

Patient-Related Barriers

- Little understanding of the serious nature of the disease
- Personal beliefs, spirituality, ethnic and cultural identity and traditions
- Misunderstanding of the scope of palliative care
- Communication impairments
- Denial and desire to protect family and loved ones
- Fear of confronting mortality

How to Meet Care Needs?



Proposed components of IPF care model

- How to assess needs and when to start symptom therapies?
- What is the best approach to dyspnea management in IPF?
- What is the best model of ACP discussion to improve communication?
- How to coordinate care, engage and support the family better?

Kreuter M, et al. *Lancet Respir Med*. 2017;18:139.

But how can 1 clinician meet all of these needs?!

Multidisciplinary Collaborative Care Model (MDC)

Developed and implemented in 2012

What?

- Needs assessment, integrated symptom therapies, ACP, community support

Who?

- Clinic → MD, ILD RN and allied health team
- Community → Homecare team (allied health, NP) and primary care

When?

- Start early; at all clinic visits, and ongoing in the community and at home

How?

- Create and train multidisciplinary clinic team
- Identify and partner with community team

Conceptual Framework of Multidisciplinary ILD Collaborative

Patient-Centric Care

Multidisciplinary, ILD Collaborative Clinic
(Physicians, RT, PT, RD, RN)

Early Integrated Palliative Approach

- Symptom management strategies
- Advance care planning from first encounter
- Education

Collaborative Community-Based Support

- Engagement of community allied health care and primary care physicians
- Close communication
- Early detection of changes

Kalluri M, et al. *J Pain Symptom Manage*. 2018:55:420-426.

Meet Harry and His Wife

- 72-year-old male with IPF (after MDD, FVC 79%, DLCO 49%)
  - Tolerating antifibrotic therapy well for six months
  - On CPAP for OSA with acceptable o/n oximetry and on anti-acid therapy
  - During pulmonary rehab found to have exertional hypoxemia, started 2 L supplemental oxygen two months ago and has been compliant after attending an educational session on oxygen therapy
  - He is attending a local support group and finds it beneficial
  - All immunizations are up-to-date

Harry and His Wife

- He presents to our clinic with gradual worsening dyspnea(MRC 4/5) with his wife in attendance
  - Recent HRCT shows progression of UIP
  - 6 MWD: 467 m, baseline Spo2 92%, nadir SpO2 79% on 2 L

Harry’s Care Needs Assessment

Pre-clinic ILD RN assessment

Patient concerns

- What is wrong with me?
- How can I improve my breathing?
- Angry, frustrated with inability to do things and go out

Caregiver concerns

- Anxious, worried and frustrated
- What is going on with Harry?
- How can I help him?
- What can we do when his breathing gets worse?*

Symptoms and function

- MDC approach
- Assess impact on function
  - Daily activities: struggling
  - Work: retired
  - Recreation: no longer playing golf, camping or fishing

*Crisis event: 2-3x week in the mornings, when he showers and is helping with chores

Dyspnea

- Definition per ATS: *A subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity*
- Dyspnea is not unidimensional
  - Need to assess severity and impact
- Framework of dyspnea (MDC approach):
  - At baseline (rest)
  - Episodic (with activity)
  - Dyspnea crisis episodes

Parshall MB, et al. *Am J Respir Crit Care Med*. 2012;185:435-452.

Harry’s Dyspnea Assessment

MDC approach*

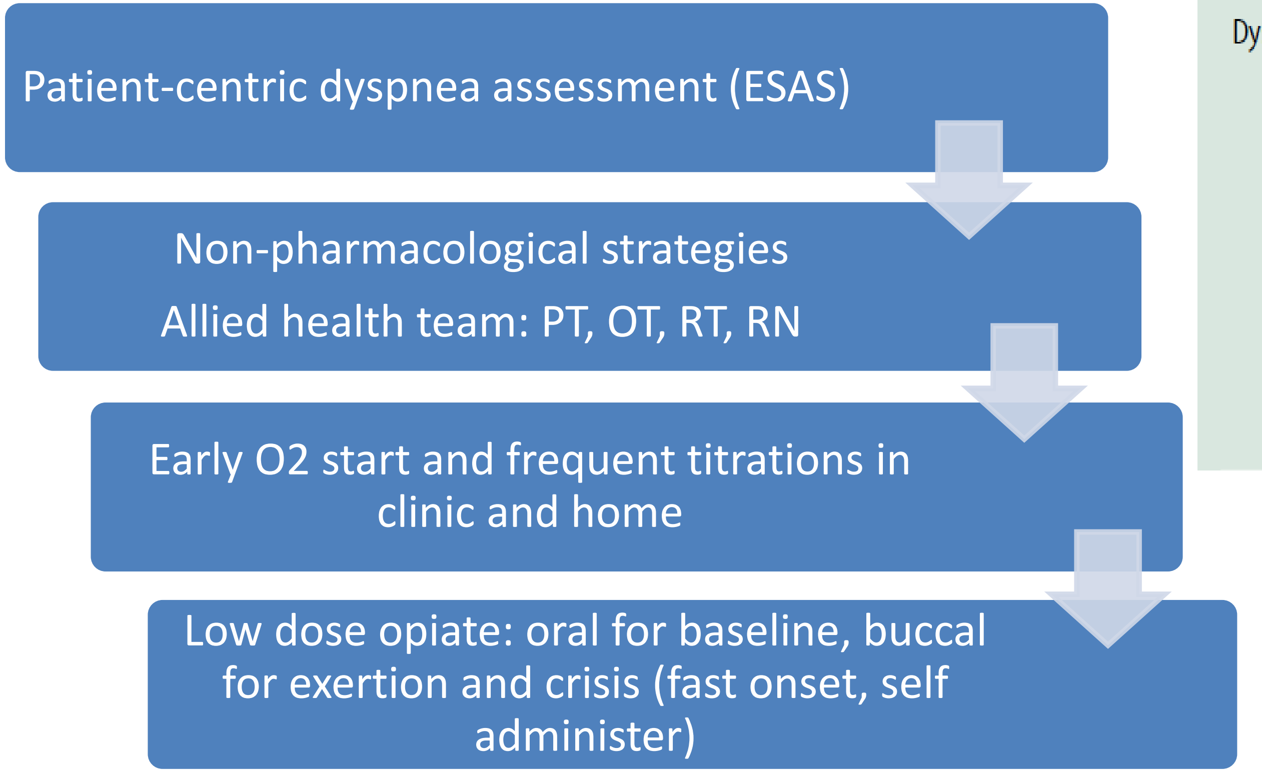
- Numerical rating scale is easy to administer, track, sensitive to changes in ADL
- MRC is not detailed enough (ADL)
- 0-10 (mild/mod/severe)
- Track crisis events
- Facilitates early detection of changes and personalized treatment advice
- Interdisciplinary team

Dyspnea	Harry’s Score?
Baseline (at rest)	
Episodic	
Crisis episodes	

*Kalluri M, et al. *J Palliat Care*. 2014;30:188-191.
Kalluri M, et al. *J Pain Symptom Manage*. 2018:55:420-426.

Breathing is Not an Option: Dyspnea is!

MDC Approach*



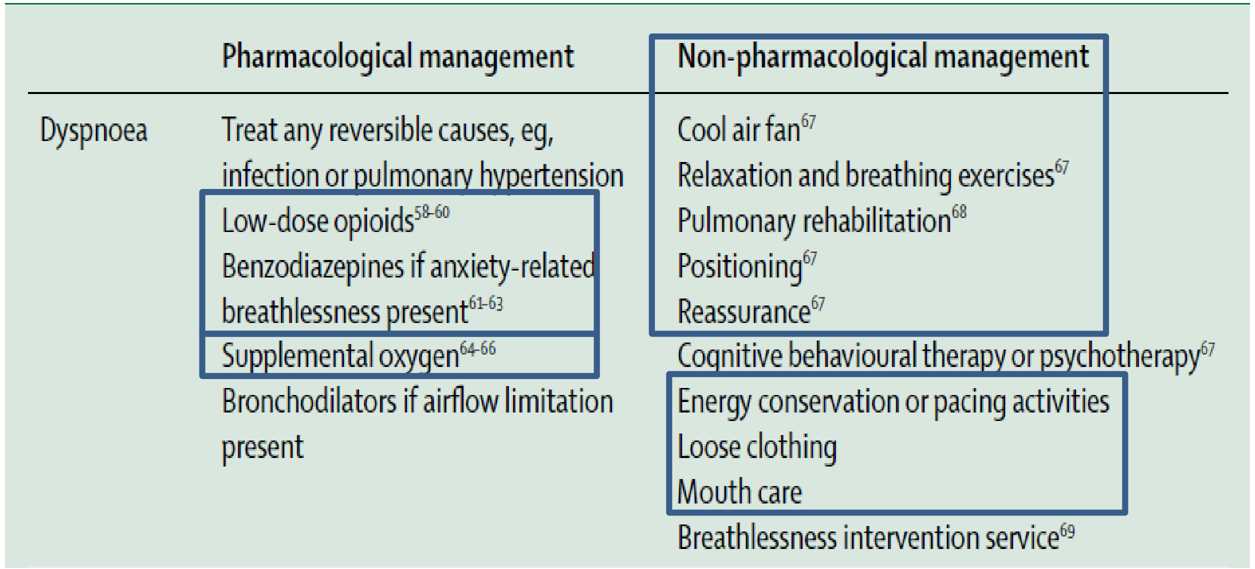
Patient-centric dyspnea assessment (ESAS)

Non-pharmacological strategies

Allied health team: PT, OT, RT, RN

Early O2 start and frequent titrations in clinic and home

Low dose opiate: oral for baseline, buccal for exertion and crisis (fast onset, self administer)



	Pharmacological management	Non-pharmacological management
Dyspnoea	Treat any reversible causes, eg, infection or pulmonary hypertension Low-dose opioids[58–60] Benzodiazepines if anxiety-related breathlessness present[61–63] Supplemental oxygen[64–66] Bronchodilators if airflow limitation present	Cool air fan[67] Relaxation and breathing exercises[67] Pulmonary rehabilitation[68] Positioning[67] Reassurance[67] Cognitive behavioural therapy or psychotherapy[67] Energy conservation or pacing activities Loose clothing Mouth care Breathlessness intervention service[69]

*Kalluri M, et al. *J Palliat Care*. 2014;30:188-191.
Kalluri M, et al. *J Pain Symptom Manage*. 2018:55:420-426.
Kreuter M, et al. *Lancet Respir Med*. 2017;18:139.

Harry’s Individualized Care Plan Based on Needs

Patient-centric dyspnea assessment: measure severity and impact ; at rest, various ADL, track crisis

Baseline				Episodic					Crisis
Activity	**Rest**	**Eating**	**Talking**	**Light exertion**	**Stairs**	**Exercise**	**Bath/ shower**	**BM**	**Crisis**
Dyspnea 0-10	3	4	4	7	-	7	7	1	8/9 showering

- **1 Very slight**
- **2 Slight**
- **3 Moderate**
- **4**
- **5 Severe**
- **6**
- **7 Very severe**
- **8**
- **9 Extremely severe**
- **10 Maximal**

Systematic dyspnea management using MDT approach

PT

How to manage dyspnea with golf, camping, fishing and ADL?

- Pacing, activity and behavior modification
- Arrange for home assessment, environment modifications
- Develop an exercise plan
- Refer to pulmonary rehabilitation program

Harry’s Individualized Care Plan Based on Needs

Patient-centric dyspnea assessment: measure severity and impact; at rest, various ADL, track crisis

Baseline				Episodic					Crisis
Activity	**Rest**	**Eating**	**Talking**	**Light exertion**	**Stairs**	**Exercise**	**Bath/ shower**	**BM**	**Crisis**
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Systematic dyspnea management using MDT approach

<u>RT</u>

How to manage dyspnea with daily function and pleasure (golfing, camping, fishing)?

- Oxygen titration to keep nadir exertional SpO2>90%
- Review flows (Cont vs pulse) 24/7 use
- Type of equipment
- Nasal care
- Oxygen and travel (air travel)

6 MWD: 467 m
Baseline SpO2 92%,
Nadir SpO2 79% on 2 L

Harry’s Individualized Care Plan Based on Needs

Patient-centric dyspnea assessment: measure severity and impact; at rest, various ADL, track crisis

Baseline				Episodic					Crisis
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Systematic dyspnea management using MDT approach

RD (Dietitian)
- Reflux education
- Weight management
- Safe swallow
- Diet modifications for dyspnea as needed

Harry’s Individualized Care Plan Based on Needs

Patient-centric dyspnea assessment: measure severity and impact; at rest, various ADL, track crisis

Baseline				Episodic					Crisis
Activity	**Rest**	**Eating**	**Talking**	**Light exertion**	**Stairs**	**Exercise**	**Bath/ shower**	**BM**	**Crisis**
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Systematic dyspnea management using MDT approach

RN

- Disease & symptom education
- Antifibrotic therapy management
- Provide clinical trials info
- Written action plans and instructions
- Caregiver education
- Facilitate connection to support group
- Care coordination

Harry’s Individualized Care Plan Based on Needs

Patient-centric dyspnea assessment: measure severity and impact ; at rest, various ADL, track crisis

Baseline				Episodic					Crisis
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Systematic dyspnea management using MDT approach

<u>MD</u>:
- Diagnosis, disease specific therapies
- Advance care planning
- Symptom management, action plans
- Refer to refer to community supports

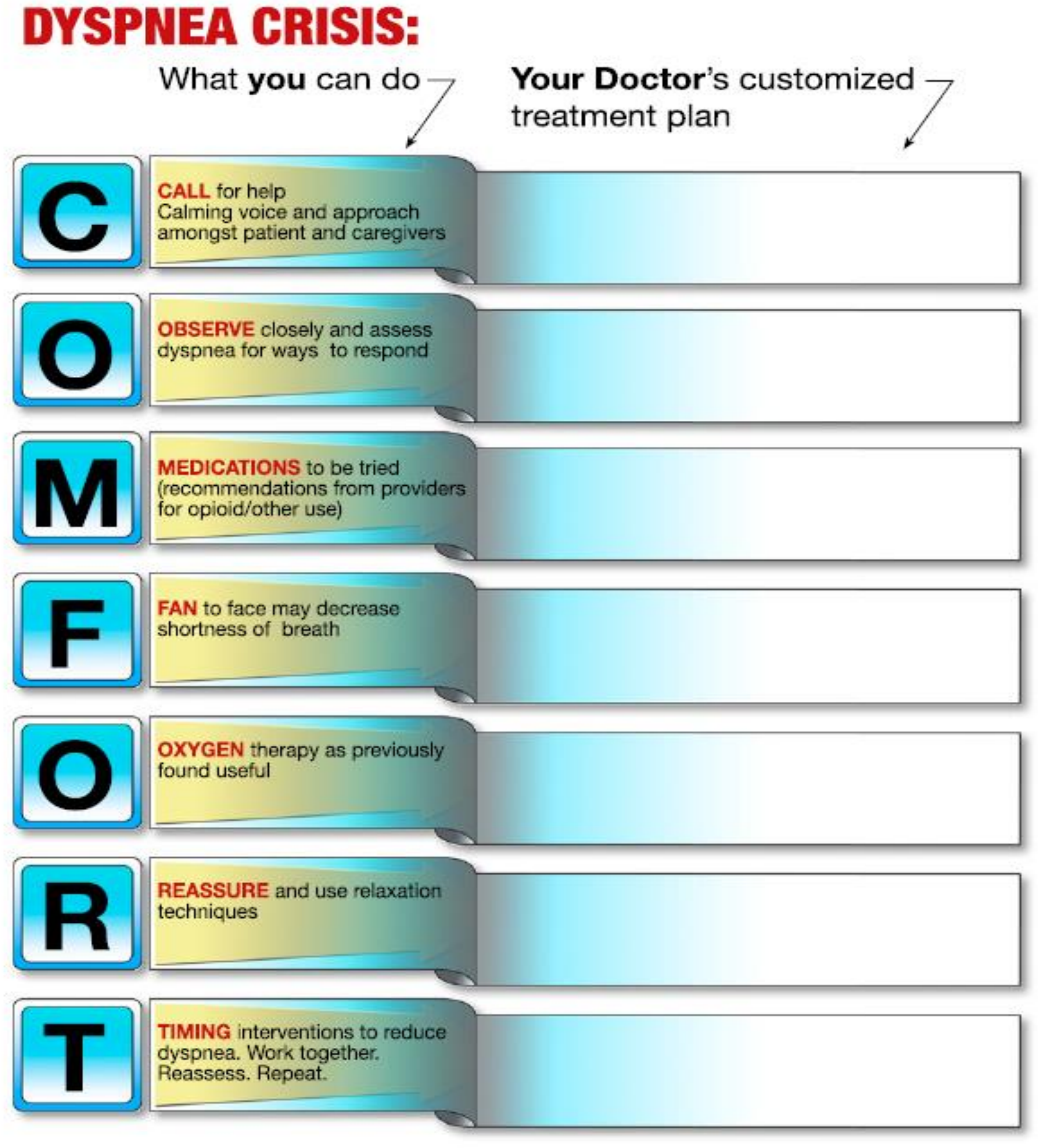
Harry's Individualized Care Plan

Dyspnea Prescription

- Pacing, behavior and activity modification
- Oxygen flows (rest 3L/exertion 9L/exercise 10L)
- Low dose opiates:
  - Baseline (rest): Oral 0.1 mg hydromorphone QID
  - Exertional (episodic): 0.2 mg buccal 10 min preactivity
  - Crisis: 0.2 mg buccal every five minutes until relieved, lorazepam 0.5 mg SL q30 min; call home care RT
- Provide action plan[†]

[†] Mularski RA, et al. *Ann Am Thorac Soc.* 2013;10:S98-S106.

Action Plan for Episodes of Crisis Dyspnea



DYSPNEA CRISIS:

	What **you** can do	**Your Doctor**'s customized treatment plan
C	**CALL** for help Calming voice and approach amongst patient and caregivers	
O	**OBSERVE** closely and assess dyspnea for ways to respond	
M	**MEDICATIONS** to be tried (recommendations from providers for opioid/other use)	
F	**FAN** to face may decrease shortness of breath	
O	**OXYGEN** therapy as previously found useful	
R	**REASSURE** and use relaxation techniques	
T	**TIMING** interventions to reduce dyspnea. Work together. Reassess. Repeat.	

Mularski RA, et al. *Ann Am Thorac Soc*. 2013;5:S98-106.

Advance Care Planning

- An organized ongoing process of communication to help an individual identify, reflect upon, discuss, and articulate her or his values, beliefs, goals, and priorities to guide personal care decision making including end-of-life care
- For patients with IPF, either this isn't happening or when it does it is implemented too late

Simpson C. *Chronic Respir Dis*. 2012;9:193-204.
Rajala K, et al. *BMC Pulmonary Med*. 2018;18:172.
Bajwah S, et al. *Lung*. 2012;190:215-220.
Lindell KO, et al. *Chest*. 2015;147:423-429.

Advance Care Planning in IPF

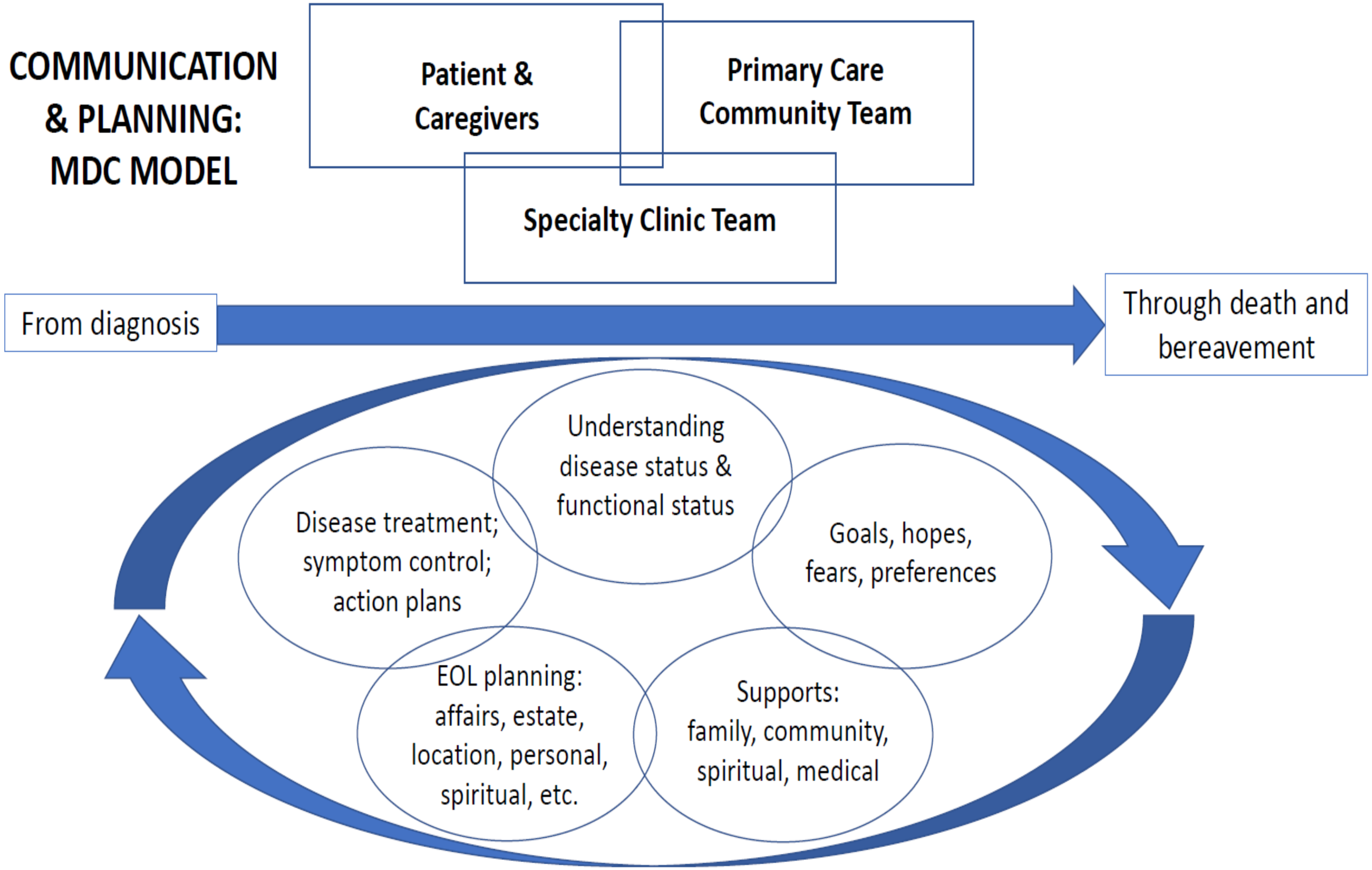
PATIENTS WANT:

- Open and honest discussion on progression, what to expect, how to prepare and what death looks like (“elephant in the room”)
  - *Well I haven’t got a very long future so ah, I suppose I’d like a bit of honesty from them… I’ve been sort of kept in the dark a little*

- Provide hope by discussing how symptom treatment can improve QOL
  - *One other thing I am interested in is when you reach the end stage and you’re struggling to breathe and all these things, what can be done about it to reduce my anxiety level? No one has talked to me about that*
  - *What I still need to find out is how to manage that cough, so that it’s not something that embarrasses me and other people when I’m in public… there might be strategies that you can use to control it*

Holland AE, et al. *Chron Respir Dis*. 2015;12:93-101.

Advance Care Planning in IPF- MDC approach



COMMUNICATION & PLANNING: MDC MODEL

Patient & Caregivers

Primary Care Community Team

Specialty Clinic Team

From diagnosis

Through death and bereavement

Understanding disease status & functional status

Goals, hopes, fears, preferences

Supports: family, community, spiritual, medical

EOL planning: affairs, estate, location, personal, spiritual, etc.

Disease treatment; symptom control; action plans

Kalluri M. Manuscript in submission

Advance Care Planning at First Visit

Harry, his wife and the team

Goals and Wishes

- Remain active: **HUNTING, FISHING, TRAVELING, CAMPING**
- Avoid hospitalization
- **HOME DEATH**

Fear

- Suffocation
- Death and dying, being a burden to family

Self-Management

- **DISCUSSED STRATEGIES** for symptoms (QOL, achieve goals)
- Provided information, options for care/location, implications

Engage Caregiver

- Wife willing to support home death
- Wanted to learn how to help with breathing

Documentation

- Goals of care (AHS), preferred place of care and death
- Encourage EOL planning: POA, advanced directives, personal affairs, bucket list

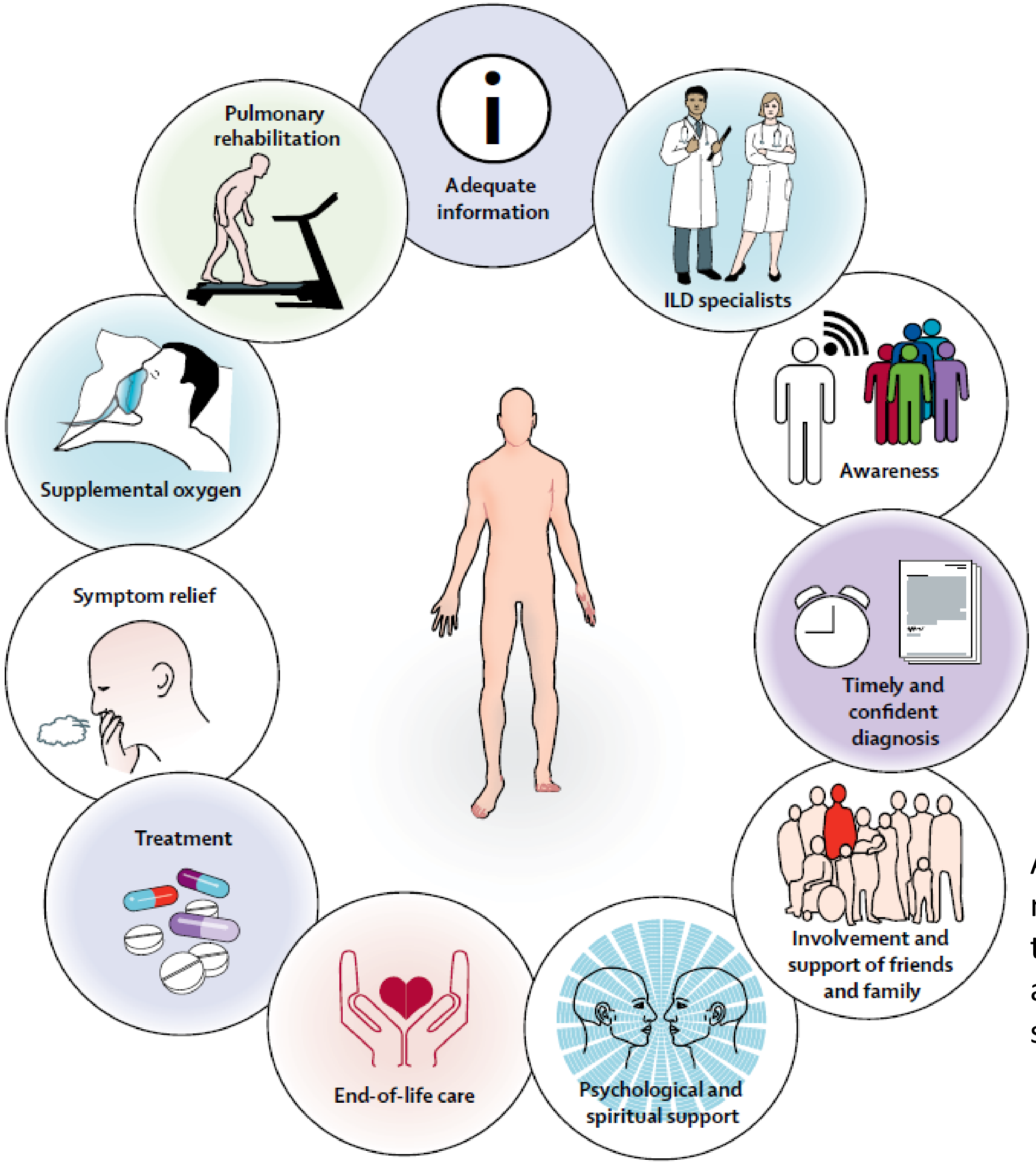
Multidisciplinary Clinic Visit Summary

Patient and family-centered care

3L rest
9L exertion
10L exercise
Education, nasal care
Addressed O2 needs for golf, travel, camping

Pacing, activity modification, exercise, discussed energy conservation measures for golf, camping

Opiates and BDZ, ACP, written actions plans, network with community teams



Diagnosis
Antifibrotic
PPI
Rehab
Education
Immunization

Assess family needs, connect to home care and patient support group

1 Month Later- a Home Visit by RT Meeting Needs Outside Clinic

Baseline				Episodic					Crisis
Activity	**Rest**	**Eating**	**Talking**	**Light exertion**	**Stairs**	**Exercise**	**Bath/ shower**	**BM**	**Crisis**
Dyspnea 0-10	1	1	0	3	4	3	3	1	NA

1 Very slight	**2 Slight**	**3 Moderate**	**4**	**5 Severe**	**6**	**7 Very severe**	**8**	**9 Extremely severe**	**10 Maximal**

- Home walking oximetry leads shows nadir Spo2 84%, exertional oxygen increased to 10L

> **Early detection and rapid intervention**
> **Support at home**
> **Care aligned to patient wishes**

Collaboration with Community Teams

- **Addressing symptom crisis Outside of Clinic Visits**

Worsening dyspnea

Communication between patient/caregiver and team

~~ER/Office~~

Multidisciplinary team assessments at home

Identify and treat reversible causes. Modification of dyspnea management action plans

Dyspnea improved, resumes prior activities outside home (camping, fishing, running errands)

Disease progression

- ➢ **Avoids needless acute care use**
- ➢ **Increase days spent at home: patient-centered goal**
- ➢ **Maintain QOL**

Harry’s Journey Over the Next 2 Months

Baseline				Episodic					Crisis
Activity	**Rest**	**Eating**	**Talking**	**Light exertion**	**Stairs**	**Exercise**	**Bath/ shower**	**BM**	**Crisis**
Dyspnea 0-10	4	4	4	5	-	6	6	1	NA

1 Very slight	**2 Slight**	**3 Moderate**	**4**	**5 Severe**	**6**	**7 Very severe**	**8**	**9 Extremely severe**	**10 Maximal**

Clinic 3 Month F/U

- Worsening dyspnea, PFTs
- Investigations: HRCT, no reversible cause
- Oxygen titration 10LPM at rest
- Opioid titration (0.5 mg hydromorphone oral tid, 0.5-1 mg buccal before activity)
- Transition to home care based on patient wishes

HM: hydromorphone

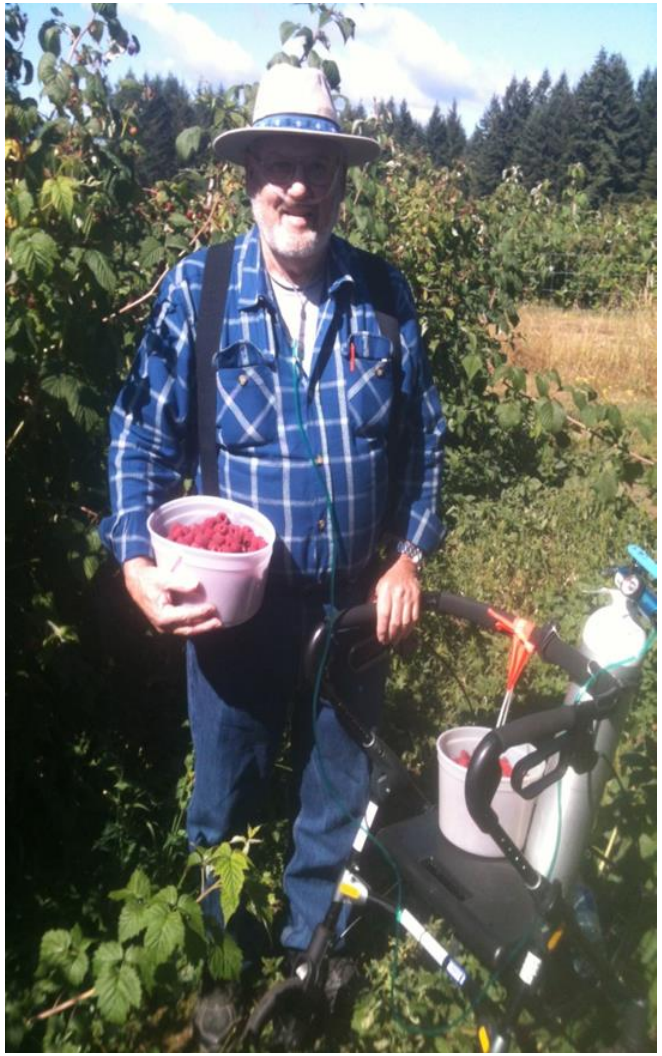
Harry’s Journey Over the Next 2 Months

Care at home

- NP/RT/MD
- Dyspnea assessment
- Oxygen titration (15 L)
- Opioid dose titration to meet patient needs
- Education and support
- Reassess patient goals: Last wish to travel to BC

Team work to facilitate patient goal

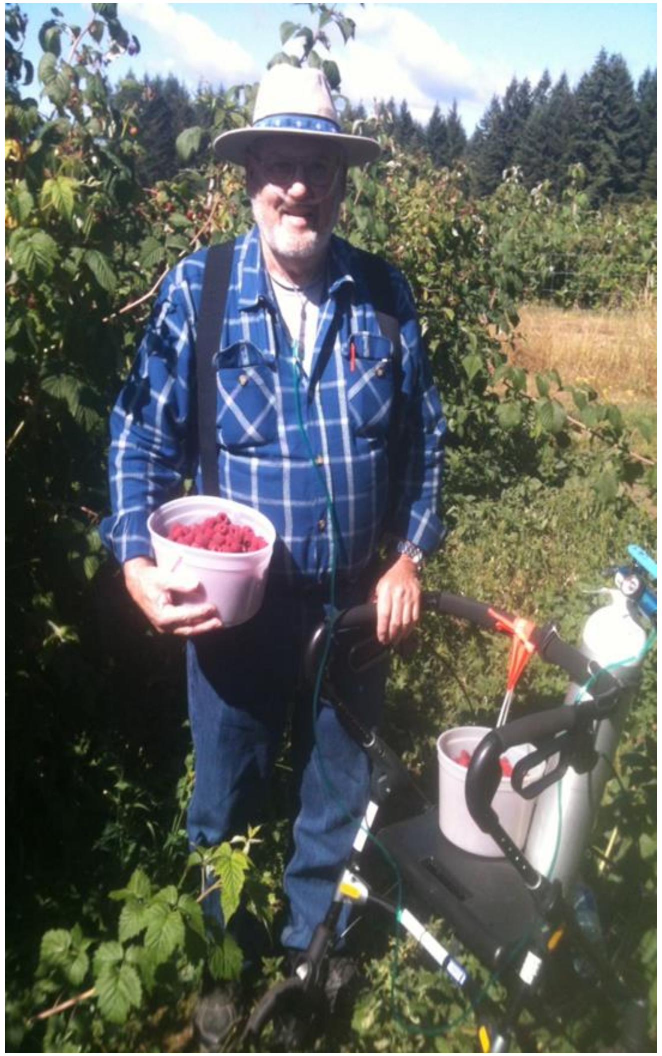
- NP/RT/MD
- Anticipate, educate, prepare
- Arrange oxygen for trip
- NP and MD: developed crisis action plans, meds on hand, who to call



Harry’s Journey Over the Next 2 Months

End-of-life at Home

- 1 week after trip to BC, family calls home care
- Team: Anticipates death and prepares family
- Dyspnea assessment
- Oxygen: 18-19 lpm via O2 concentrators + 5 lpm via E cylinder for rest and increase to 10-15 lpm for exertion
- Oral hydromorphone 2 mg qid for baseline; 2 mg buccal preactivity; 4 mg buccal q10 min prn
- Patient passes away peacefully at home, according to his preference



HM: hydromorphone

Impact of Multidisciplinary Collaborative Care

Living with IPF with Dignity

- Patient needs assessed and goals prioritized
- Early integrated palliative approach & Support system engaged early
- Regain hope, meaning and purpose
- Maximize function with QOL maintained
- Maintain sense of control and empowerment

Dignity in Dying and Death

- Patient EOL wishes respected and goals prioritized
- Symptoms well managed
- Avoid hospitalization
- Remain independent and functional
- Die peacefully at home with family prepared and supported

Impact of Multidisciplinary Collaborative Care

- Analysis of outcomes pre- and post-MDC care model (32 IPF decedents 2009-2016)
- 55% increase in home deaths and 62% decrease in hospital deaths

90% ↑ Needs assessment led to early opiate start in 95%

150% ↑ Prioritization of ACP led to documentation in 100%

55% ↑ Early interventions lead to improved EOL Care
Greater adherence to patient wishes; 71% died in preferred location
Reduced acute care use and decrease in hospital deaths by 62%

Kalluri M, et al. *J Pain Symptom Manage*. 2018:55:420-426.

Early Integrated Palliative Approach for Patients with IPF: Experiences and Perceptions of Bereaved Caregivers

Key Findings:

Narratives support early integrated palliative approach in care

Reduced symptom burden and related anxiety and distress

Good quality of life, death and dying, and bereavement due to collaboration and open communication among patients and care team

ACP enabled caregivers to feel informed, prepared and supported when death was near

Pooler C, et al. *Palliat Med.* 2018;32:1455-1464.

Early Integrated Palliative Approach for Patients with IPF: Experiences and Perceptions of Bereaved Caregivers

“*ILD is absolutely a death sentence, but how you get from the diagnosis to the end can be managed in a whole bunch of different ways. When you create care teams who are really good at what they do, and really believe in being patient centered, then this is the thing that you end up with, people who are absolutely devastated by the passing of their mom but not traumatized by it.* (SR, bereaved caregiver)

Not a single thought was spent wondering if we could do more (except existentially) or worrying about her care, or who to call or what to do. Do you or the administrators, or anyone who has not experienced this, truly understand how profound a gift this is to give to the dying and her family? Take heart in this work, it is meaningful and real and deeply important. (GL, RN, PhD bereaved caregiver)”

Summary

- IPF is a fatal disease with high symptom burden and unmet care needs
- Early interventions for symptoms, ACP, better communication and coordination of care facilitate better QOL & QODD
- Use of needs assessment tool can trigger early and individualized symptom based interventions
- Interdisciplinary approach with appropriate oxygen titrations and low-dose opiates are effective in dyspnea management
- Prioritization of ACP by inclusion in care can increase rates of success and improve communication
- Networking with community team can support patients at home and improve coordination of care