

# Access to Palliative Care

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# Equity of access

People of equal need should have the same access to care

The level of care available should depend only on patients' level of need and not on factors irrelevant to that need

# Outline

- Context and patterns
  - Availability of specialist palliative care (SPC)
  - Clinical and demographic patterns
- Mechanisms
  - Predicting prognosis
  - Determining need
  - Professional factors
  - Professional and patient/ family interface
  - Patient/ family factors

# Availability of palliative care services

- Large differences in provision between countries (Wright et al, 2008)
- Differences within countries
  - Differences in urban/ rural provision (Wilson & Mohnankumar 2012)
  - Lower provision in areas of higher deprivation (Inverse Care Law; Hart, 1972)

# Clinical and demographic variables

- Non-cancer diagnosis
- Age
- Informal carers
- Socio-economic status
- Black and ethnic minority (BEM) groups

# Non-cancer diagnosis

- Worse access for patients with non-cancer diagnosis (Ahmed et al, 2004; Walshe et al, 2009)
- Non-cancer constituted 5% of referrals to SPC in UK (Addington-Hall et al, 1998)  
13% of referrals to H@H (Ewing et al, in press)
- 40% of non-cancer and 62% of cancer patients had contact with SPC (Currow et al, 2008)

# Age and access

- Those over 65 are less likely to be referred to specialist palliative care  
(Ahmed et al, 2004; Burt & Raine, 2006)
- Older patients less likely to be referred to palliative home care or community care  
(Grande et al, 1998; Grande et al, 2006; Walshe et al, 2009)
- People in nursing homes are less likely to be referred  
(Gao et al, 2011)
- No age differences for lung cancer patients within specialist cancer care system (Burt et al, 2010)

# Age and access: trends over time

- Access has improved, still variation based on age (Maddison et al, 2012)
- Older people (>80) in 2010 more likely to receive formal home care in last 3 months compared to 2000 (Kaspers et al 2012)
- Older patients (>90) had higher use of home care, GP contacts, care homes and fewer inpatient days in last 6 months compared to younger patients (Gielen et al, 2010)

# Informal carer availability

- Being married/ having a carer improves access to community palliative care services (Walshe et al, 2009)
- Many palliative home care services require carer to be present

# Informal carer age

- Carer age as important as patient age in predicting access to palliative home care:
  - Carer age predicted access to Marie Curie home care. Both carer and patient age independently predicted access to Macmillan SPC. Patient age predicted access to inpatient hospice care (Grande et al, 2006)

# Socio-economic status

- A range of indicators of socio-economic status are associated with decreased likelihood of use of community home care

(Grande et al, 1998; Walshe et al, 2009)

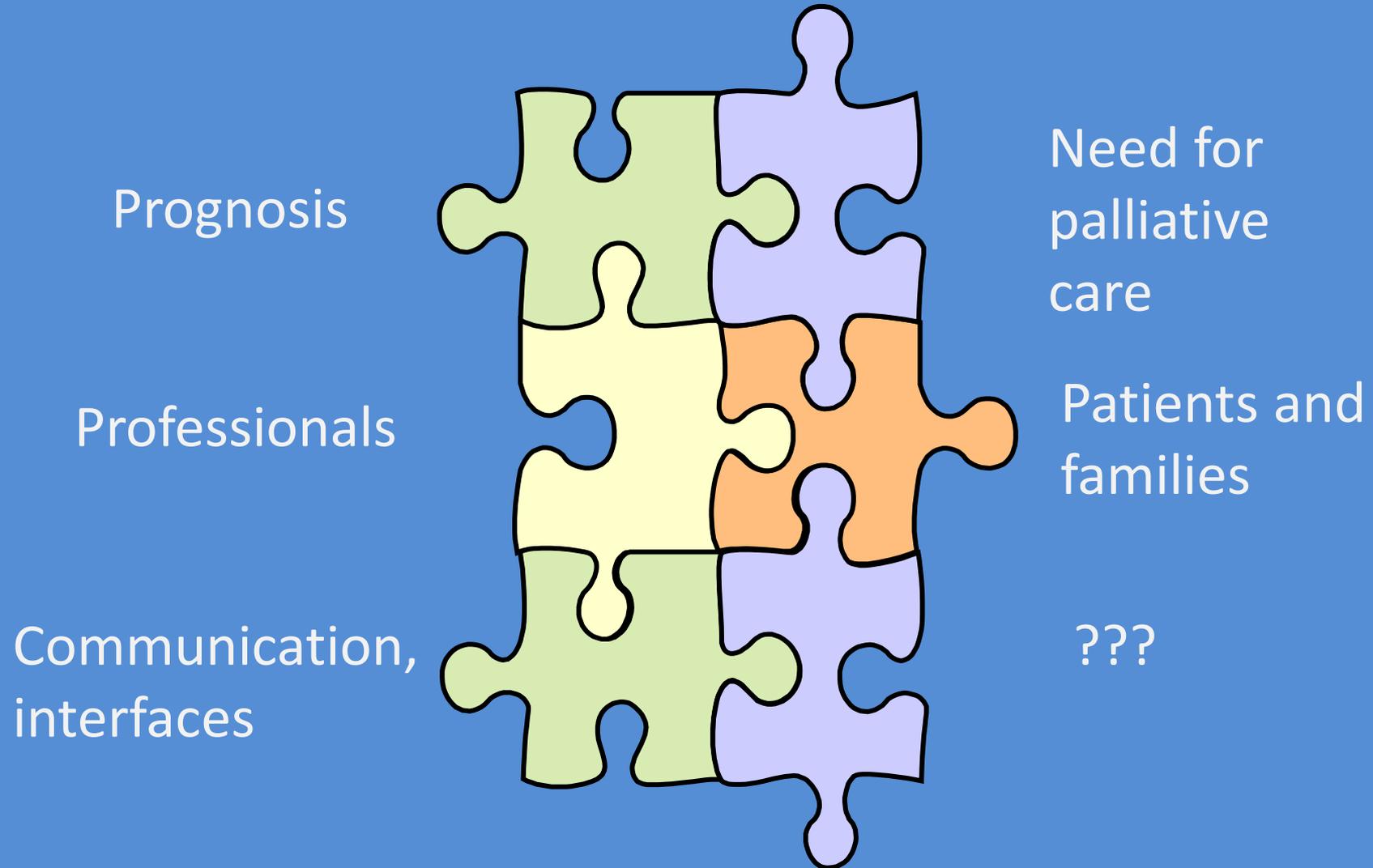
- Patterns persist in areas of equal palliative care provision

(Campbell et al, 2010)

# Black and Ethnic Minority patients

- BEM groups less likely to be referred to palliative care  
(Bestall et al, 2004; Walshe et al, 2009)
- Although fairly consistent patterns re access, not a homogenous group

# Mechanisms



# Prediction of prognosis/ trajectories

- Difficulty in estimating prognosis for cancer  
(Glare et al, 2003)  
but worse for non-malignant disease  
(Coventry et al, 2005)
- Unpredictability of non-cancer disease  
trajectories main barrier to referral  
(O'Leary et al, 2008)
- Older patients proportionally more likely to have  
non-cancer diseases  
(Gott et al, 2001)

# Prognosis: communication and acknowledgement

- Physician reluctance to communicate prognosis (Lamont & Christakis, 2001)
- Patients remain over-optimistic or report not being told (Schofield et al, 2006)
- Older people may prefer not to have overt awareness of dying (Gott et al, 2008b)
- Lack of open discussion of dying within some BEM cultures, family controlling the information (Worth et al, 2009)

# Determining need

- Lack of referral to SPC not necessarily = unmet need
- Disagreement among professionals re who has palliative care needs (Gott et al, 2001)
- Non-cancer patients should have similar needs for palliative care based on symptom prevalence (Franks et al, 2000; Solano et al, 2006)
- Non-cancer patients not receiving SPC had significant unmet needs (Currow et al, 2008)
- Older patients show similar symptoms, problems and needs as younger patients (Teunissen et al, 2006)
- Older hospital patients are more likely to be identified as having palliative care needs than younger patients, but not more likely to be referred (Gott et al, 2001)

# Professional factors

- Generalist provider skill
  - Lack of skill may trigger referral - or lead to failure to recognise need for referral (Walshe et al, 2008a)
  - Professional (self-perceived) skill; scepticism about added value of specialist palliative care (Walshe et al, 2008b)
- Ownership; palliative care valued part of own role (Burt et al, 2006)
- Knowledge of role and remit of specialist palliative care (Burt et al, 2006)
- Personal relationships: respect for individuals' skill and knowledge (Walshe et al, 2008b)

# Professional – patient interface

- Communication
  - Discussion of end of life issues less likely for older patients and those with non-cancer diagnoses
- Shared language?
  - Patients speaking the ‘doctor’s language’ more likely to be referred (Alberts et al, 1998)
  - Middle class patients more articulate and confident in requesting support (Dixon-Woods et al, 2006)
  - Foreign language barriers  
(Karim et al, 2000; Worth et al, 2009)
- Shared identity?
  - Same-generation, economically active patients  
(Lawton, 2000; Dixon-Woods et al, 2006)

# Patient and family characteristics

- Knowledge of palliative care associated with age, SES and ethnicity  
(Koffmann et al, 2007)
- Attitudes to palliative care may be different for older people (Catt et al, 2005) and BEM groups  
(Worth et al, 2009)
- Presence of carers  
(Walshe et al, 2009)

# Ways forward ?

- Better prognosis (PiPS, Gwillam et al, 2011)
- The surprise question (Murray et al, 2005)
- Better understanding of individual trajectories rather than disease trajectories  
(Bausewein et al, 2010)
- Consistent measurement of need (POS)
- ACP and communication (Schofield et al, 2006)

# Ways forward ?

- Multidisciplinary collaboration
  - Joint oncology/ palliative care clinics improve access to home care for older patients with poor performance (Jang et al, 2012)
- Care pathways (GSF, LCP)
- Embedding palliative care in general practice
- Public education
- Name change? (Dalal et al, 2011)