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Discussion about preferences for the future: the views of people affected by lung cancer

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Content

- Definition of Advance Care Planning (ACP)
- Background
- Preliminary study
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- Aim/Method
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- Summary
- Future research

Working definition

- “ACP is a process of discussion between an individual and their care providers irrespective of discipline. If the individual wishes, their family and friends may be included. With the individual’s agreement, this discussion should be documented, regularly reviewed and communicated to key persons involved in their care...” (NHS, 2007)

Background

- Death institutionalised - most patients prefer to die at home yet most die in hospital
- Policy & Legal drivers
 - Choice as the cornerstone of NHS reform
 - Mental Capacity Act
- Consumerism
- Paternalism and beneficence versus self-management and autonomy
- Euthanasia/Bill for Assisted Dying

Preliminary study

- Small qualitative interview study in South Yorkshire
- Developed, tested and evaluated ACP protocol
- Sample: 15 patients, 3 lung cancer nurses
- Patient findings:
 - Nurses' attributes supported discussion
 - Content of discussion
 - Wanting choices carried out
 - Recording of discussion
 - Various reactions and outcomes
 - Talking with family about choices
- Staff findings: 'window of opportunity', nurses own needs, consultant communication, writing it down.

Literature review

- No UK evidence
- ACP is described using a variety of terms
- Differing underpinning principles
- Little evidence of patients and family experiences
- Varied complexity and levels of interventions reported.
- Inconclusive if ACP should be a stand-alone intervention or part of an integrated approach
- ACP is more than documentation!
- Lack of evidence on who should initiate, timing and training required

Aim

- To explore the experiences of patients in discussing end-of-life issues related to preferences and decision-making about future care and treatment, to determine the care components required to develop an ACP intervention.

Method

- A cross-sectional qualitative study using mixed methods.
- Sample
 - 1) 25 patients with advanced lung cancer who had completed 'active treatment' (18 men, 7 women)
 - Most from lower socio-economic backgrounds
 - 27 face to face interviews
 - 2) 15 family carers (9 current and 6 bereaved)
 - 2 focus groups and 6 individual interviews
- Analysis: Grounded theory approach

Emerging findings – a work in progress

- Substantive categories:
 - Prognostication
 - Living in the present - coping with a shortened life
 - Patients feel the doctor knows what's best
 - Planning for death - but not dying
 - Doctors and nurses communication about the future
 - Patients knowledge of cancer and its treatments

Prognostication

- Patients talked about their doctors discussing prognosis with them and the emotional impact
- Prognosis was given in months to live or hinted at using words such as 'terminal', 'serious', 'incurable'.
- Doctors need to provide prognoses to develop a management plan, but patients may not want to receive this information or prefer to trust their doctor
- Giving and receiving or non-disclosure of prognosis had different meanings for patients.
- Knowing sometimes reduces ability to cope with future
- Importance of feelings in relation to patients acceptance of dying

Living in the present - coping with a shortened life

- Not discussing the future – not feeling ill
- Finality, not near enough to death to decide
- Living a ‘day at a time’
- Don’t want doom and gloom
 - “I think it’s a bit morbid isn’t it, planning that.” Henry, aged 60
- Hanging onto life as ‘normal’ – living for now
 - “Well there’s nothing to discuss at the moment. To me there’s nothing to discuss. I want my whole family to carry on normally. In other words, those that are working to go to work. I know if I need them I’ve got a phone.” Andy, aged 73

Patients feel doctor knows best

- “Well I always this; they, they know what they’re talking about, so I listen and I try whatever they wanted”. Dennis, aged 73
- Patients talked about trusting their doctors to make the right treatment decisions.
- Patients talked about not being qualified to make decisions and struggled with notion or possibility of different options.
- Refusing generally was not an option.
 - “...if doctor says jump I will say how high. Whatever he said I’d go by. No matter what he said I’d go by. If he said what we’ll do will make you bad for a month I’d carry on. I’d do it. Yeah...”
Burt, aged 64

Planning for death – but not dying

- Although many discussed not planning for the future some had made preparations for their death
- For some, plans related to concerns for family
- Will , letter of wishes, finances
- Funeral
- Little understanding of living wills/advance decisions
- Preferred place of care

Health professionals communication about the future

- Doctors don't discuss future options/choice
 - ...'you're just a number to them aren't you, you're a bed. They've got your notes, you know, they don't ask your wishes, they just look at your notes..''
 - Colin, aged 54, Married.
- For others they felt the doctors just told them a 'step at a time'
- Health professionals don't have 'deep discussions'
- Support and reinforcement of an optimistic attitude
- Loss of faith/trust in some doctors led to non-disclosure of concerns.
- Lack of explanation about disease progression and what to expect
- Having to or expecting to ask
- Lung cancer nurse – someone 'who's there for us'

Summary

- Giving and receiving or non-disclosure of prognosis had different meanings for patients.
- Importance of patients feelings, time since prognosis in relation to acceptance of dying and discussions about the future
- Patients talked about not being qualified to make decisions
- Choices or options were not discussed
- Doctors and nurses communication and attitudes about the future affect patients experiences

Future research

- Who is the disclosure of a prognosis for ?
- If some patients prefer not to discuss the future, how can they be supported to realise their preferred place of care and other wishes?
- Are there real choices for future care/treatment?
- When, if at all, should ACP be initiated? Or should we be considering a model which is self-directed rather than medically-led?
- Should the focus be on supporting ACP with the family?
- What can be learnt from women's experiences of developing birth-plans?
- What skills do health professionals need for engaging in sensitive discussions and to reduce the risk of harm to patients and/or their families?

Thank you

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