COMPASSION
IN DYING

SUPPORTING YOUR CHOICES
AT THE END OF LIFE

SUMMARY REPORT

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HOW DO PEOPLE APPROACH DECISION MAKING AT END OF LIFE?

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A SECONDARY ANALYSIS OF NARRATIVE INTERVIEWS WITH PATIENTS ABOUT EXPERIENCES OF LIVING WITH TERMINAL ILLNESS

SUMMARY.

In order to further understand how people approach decision making at the end of life, interviews of people living with terminal illness were examined.

Seven themes emerged from the data: 1) accepting the curtailment of life; 2) information seeking and treatment decisions; 3) expectations of the dying process; 4) anticipating decisions and getting advice; 5) the importance of familial practices and processes; 6) knowledge and the use of preference tools; 7) perception and experience of iatrogenic (medical) harm.

THE SAMPLE.

This secondary analysis was based primarily on interviews drawn for a study of people living with terminal illness, and published on the www.healthtalkonline.org site as 'Living with Dying'.*

That study comprises a total of 42 interviews with participants who identified themselves as having a condition considered terminal. In some cases, participants were close to the end of their life and were anticipating death in the near future (within a matter of weeks). Other participants anticipated living longer. Carried out in 2004, it should be noted that these interviews were conducted prior to implementation of the Mental Capacity Act 2005. That Act formalised provision for Advance Decisions and introduced new Lasting Powers of Attorney for healthcare matters.

In addition, interviews carried out for other sections of www.healthtalkonline were appraised by either a keyword search or through review of the thematic analyses already published. Research for seven out of eleven of these sections was carried out after the Mental Capacity Act had been implemented.

The other sections used were: Breast cancer (2001), Bowel cancer (2007), Heart failure (2004), Leukaemia (2010), Lung cancer (2003), Lymphoma (2007), Motor Neurone Disease (2008), Ovarian cancer (2004), Pancreatic cancer (2011), Parkinsons Disease (2008), Caring for someone with a terminal illness (2011).

THE INTERVIEWS.

The interviews are a combination of narrative and semi-structured method. In the first part of the interview participants are encouraged to start telling their story in their own words. Whilst participants probably shape their narrative so as to manage impressions and put themselves in a positive light, they are free to choose what to divulge. These data provided opportunities to extrapolate theoretical or thematic constructs from patient accounts of their experiences.

Later sections of the interviews are semi-structured. Here the interviewer has invited comment on specific issues identified in the literature; or issues which have become apparent in interviews conducted earlier in the project and which merit further exploration.

ANALYSIS.

The full transcripts were re-analysed with a focus on how participants conceptualised decision making and the challenges that faced them at the end of life.

It was originally thought that secondary analysis of the data might yield insight into the following questions (among others):

- How consistent with principles of medical ethics and law are patients' and families' experiences of decision making at end of life, Advance Decisions, and decision making on behalf of others?
- What are patients' and families' perceived barriers to Advance Care Planning?
- What are patients' and families' perceived barriers to shared care and shared decision making where these are desired?
- What are patients' and families' perspectives on taking responsibility for 'difficult decisions'?

The data supply some indicative answers to these questions. They also raise important questions about the implications of the recently published (2012) National Bereavement Survey (VOICES).[1]

Seven themes emerged and are discussed in brief in the summary below. The full report, which is available from Compassion in Dying, explores the first six of the seven themes in depth. Research is continuing on the final theme, iatrogenic harm, and this is not discussed further in the full report.

THEME ONE:
AVOIDING, RESISTING, RECOGNISING AND ACCEPTING THE CURTAILMENT OF LIFE.

Although all of the participants had volunteered to be interviewed about their experience of having a 'terminal' condition, the majority of interviewees evidenced strong psychological aversion to such a label. Determined optimism, refusal to entertain negative thoughts or emotions, and living day-to-day without thinking about the future, were frequently cited as key coping mechanisms. Several interviewees discussed a point at which they had had to face up to their prognosis, for example when applying for benefits only available to terminally ill.

- These data illustrate the well-known difficulties that surround promoting advance planning for care and decision making at end of life. They are also suggestive of where targeted information about end-of-life rights and decisions might have most (and least) impact.

THEME TWO:
INFORMATION SEEKING AND TREATMENT DECISIONS

There was marked variation in patients' desire for information about prognosis, and their information-seeking behaviour. Some sought to avoid negative information while others were frustrated that clinicians avoided giving them the 'bottom line'. Some were critical of professionals for initiating information-giving while others were critical that information was not freely volunteered. Some had sought information about their condition on the internet, but none spoke of using the web to locate information about their rights or the dying process.

- These strongly divergent data are indicative of the difficulties of tailoring appropriate information for this audience, both for health providers and advisory organisations. What some patients welcome, others resent. It should be noted that while internet use for health advice has greatly increased, there remains very little sensitively written and balanced information about the physiological and social processes involved in dying.

THEME THREE:
EXPECTATIONS OF THE DYING PROCESS AND WHAT IT MIGHT ENTAIL

Interviewees' understanding of the dying process and thus what decisions or choices might arise was derived from three main sources: advice from health professionals, discussions with friends, and experience of the death of family members, friends or other patients. Interviewees' recall of the information supplied by health professionals suggests that they either receive or choose to remember a comforting account of pain-free 'fading away'. Expectations based in the experience of the death of another were more divergent, so that some interviewees anticipated a dignified exit with well-managed pain whilst others feared inevitable indignity and/or pain at the end of life.

- These data supply an informative qualitative commentary on, and counterpoint to, quantitative data created in the first National Bereavement Survey (VOICES) published in July 2012.[1]

THEME FOUR:
ANTICIPATING DECISIONS AND GETTING ADVICE

Interviewees were prompted to describe the sorts of decisions they thought might need to be made as their illness progressed. Reflecting the themes above, few identified medical decisions. Many referred to making provision for family and had consulted legal or financial advisors. None of the advisors were reported to have raised end-of-life decisions, and by and large were reported to be ignorant of the scope for making Advance Decisions at that time.

- The frequency with which legal and financial advice was sought, and the limited knowledge of these advisors about end-of-life rights, suggests that considerable progress in informing people about their rights could be made if professional advisors were better informed.

THEME FIVE:
THE IMPORTANCE OF FAMILIAL PRACTICES AND PROCESSES

From the perspective of medical law and ethics, one of the most notable features of the data is interviewees' concern for familial practices, relationships and responsibilities. Family and familial practices entered participant narratives generally without prompting, and in many interviews were a main pre-occupation. Protecting intimates from distress constituted a major source of anxiety, and the data are revealing in how interviewees construed the notion of becoming a 'burden' on family and others close to them.

These data point to how concerns for significant others are a core part of the experience of terminal illness, but are a neglected part of the discussion in medical law and ethics. Published research in this field tends to focus on the legitimacy and capability of family members as decision makers on behalf of incapacitated patients. Our data illustrate how thin a conception of carer involvement in the life of dying persons this represents. They pose questions about how patients' decision-making processes should be understood, theorised, and supported.

- Greater consideration should be given to how to support carer involvement in shared decision processes. Concern for family and friends could supply a valuable focus for information and campaign work. Information aimed at family members might also be a means of enhancing the current provision of information by advisory services.

THEME SIX:
KNOWLEDGE AND USE OF PREFERENCE TOOLS

It has already been noted that the core data set was created prior to the Mental Capacity Act 2005 and the introduction of new decision tools. A prompt to talk about 'living wills' (now known as Advance Decisions) was, however, included in all interviews. As might be expected, there was widespread ignorance and misunderstanding about their aims and legal validity. Refusal of CPR (cardiopulmonary resuscitation) tended to be conflated with refusal of all life sustaining procedures. Among those who regarded Advance Decisions as valuable, the most frequently cited reason for not having made one was that it was 'too early' in the course of their terminal illness, even though being in receipt of benefits (Disability Living Allowance or Attendance Allowance) meant many had a prognosis of less than six months to live. This attitude towards Advance Decisions strongly echoes Theme One. Some data also suggested that for participants, simply not knowing what their preferences were was an inhibiting factor, particularly when seeking to make plans independently of medical advice.

- These data powerfully reinforce existing understanding of impediments to using preference tools. They also serve as a commentary on the National Bereavement Survey (VOICES) findings relating to patient preferences. It is clear from our data that many patients will not have considered their preferences in detail or discussed them with family, so data in the National Bereavement Survey (VOICES) relating to care organisations' compliance with patient preferences may be unreliable.

THEME SEVEN:
INCIDENTAL DATA CONCERNING PERCEPTION AND EXPERIENCE OF IATROGENIC HARM

The secondary analysis yielded an unexpected finding, which was a strikingly high rate of perceived medical harm among those interviewed. Interviewees identified misdiagnosis, delayed referral and serious medication side-effects in a little over one third of the interviews. Some also ascribed their illness to iatrogenic harm, although these ascriptions might be misleading (e.g. referring to the coil as a source of breast cancer, which might apply to the Mirena but not non-hormonal contraceptive coils). In biomedical research terms these data are of limited evidentiary status because they are retrospective reports. However, they are of ethical and psycho-social significance.

- These data are undergoing further analysis.

RESEARCH CREDITS.

Conducted by Suzanne Shale.

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The Health Experiences Research Group provides content for www.healthtalkonline.org by gathering and analysing patients' accounts of experiences of health and illness. These data are collected in accordance with a highly regarded qualitative research protocol, recognised by the National Institute of Health Research as the 'gold standard' for qualitative research in health experience. The research has been approved by a National Research Ethics Service Committee, and all data gathering and data processing is carried out in compliance with the terms of this approval. Data are copyrighted to the University of Oxford for use in broadcasting, teaching, research and publication.

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References
The full report cites the following literature:

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Johnson JO, Sulmasy DP, Nolan M (2007) Patients' experiences of being a burden on family in terminal illness *Journal of Hospice and Palliative Nursing* 9(5) 264-269

McPherson CJ, Wilson KG, Murray MA (2007) Feeling like a burden to others: a systematic review focusing on the end of life *Palliative Medicine* 21: 115-128

*** Original research for Living with Dying was carried out by Alison Chapple and Audrey Chamberlain**

ENDNOTE

1. NATIONAL VOICES survey key findings report (2012) Department of Health

healthtalkonline.org
youthhealthtalk.org