

Planning for end of life care within lay-led chronic illness self-management training: The significance of ‘death awareness’ and biographical context in participant accounts[☆]

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Abstract

UK health policy dictates that Advance Care Planning (ACP), including the use of living wills, promotes choice and quality regarding end of life care for those with chronic and life-threatening conditions and it has been incorporated in self-management training. This paper reports a qualitative evaluation based on in-depth interviews with 31 respondents who had completed a UK-based lay-led self-management course (The Expert Patients Programme), and 12 respondents who had completed the same course adapted for people who are HIV positive. We draw upon previous social research on ‘death awareness’ and the biographical context of illness experience and management in examining the impact of incorporating this subject within a self-management intervention. The analysis demonstrates that many participants were unprepared to face issues raised in the session with material represented as disrupting some aspects of illness adaptation and existing views about death and dying. Positioning educational material on death and dying alongside that on ‘positive’ self-management of illness highlights the complexities and sensitivities of planning for end of life care with implications for future educational interventions of this type.

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Introduction

Planning for end of life care (often referred to as Advance Care Planning - ACP) is presented as a means of

promoting choice and improving quality of such care (Singer et al., 2002), particularly for those living with chronic and life-threatening conditions. Recently, a policy commitment to ACP is evident by inclusion of the subject

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in national state sponsored self-management training programmes.¹ This growing focus on ACP seems consistent with two societal trends discussed within social science literature. First is the promotion of ‘open awareness’ around the subject of death and dying where palliative care has come to be framed as a public health concern rather than a social taboo (Kellehear, 1999). Secondly, ACP can be viewed as a form of ‘risk’ management where we are all expected to take part in the monitoring of various forms of risk by accepting responsibility for all aspects of our lives, including current and future health states (Beck, 1992).

Living Wills (sometimes known as Advance Directives or Statements) are one means of documenting preferences and plans for end of life care because they allow people to outline specific treatments (e.g. mechanical ventilation) that they would want or reject in event of future incapacity. An additional component of ACP (known as the granting of Lasting Power of Attorney; LPA) is the appointment of a person granted power to make health care decisions on behalf of another. Both these components of ACP have been incorporated into the UK Expert Patients Programme (EPP) which provides self-management training for those with long-term conditions (NHS Expert Patients Programme, 2002).

There has been an increasing trend towards the formalisation of self-management via policy initiatives. In the UK, the EPP has been adapted from the Chronic Disease Self Management Programme (CDSMP; Sobel, Lorig, & Hobbs, 2002) developed in the United States. The underlying philosophy of both courses is that patients with different chronic diseases face similar self-management problems and disease-related tasks; and that they can be educated to manage their conditions better, thus using fewer health care resources. In adopting a generic approach, the courses target those with a wide variety of conditions ranging from common ones such as diabetes, asthma, and arthritis, to those with rare and sometimes medically contentious conditions such as Myalgic Encephalopathy (ME) and Chronic Fatigue Syndrome (CFS). The EPP is very similar to the CDSMP and comprises six 2.5 h sessions giving attention to a number of topics including: exercise; cognitive management techniques; nutrition; sleep; medications; emotion management; communication

with health professionals; problem-solving; and decision-making. The subject of ACP is slotted into one of the six sessions. Information provided for potential participants on the EPP website offers little detail of the course content and no mention about the inclusion of material on planning for end of life care. The website states: “Over the six weeks you will find out about easy to learn ways of dealing with symptoms such as fatigue and pain, as well as ways to improve your general health and well-being” (http://www.expertpatients.nhs.uk/course_details.shtml).

The UK has been influenced by developments in the United States where there has been a proliferation of educational interventions on ACP but a failure to improve completion rates of advance directives (Brown, 2003). This has prompted some to advocate alternative documentation and conceptualising ACP as a process of discussion (Doukas & Hardwig, 2003; Emanuel, Danis, Pearlman, & Singer, 1995). In the UK, the development of educational materials on ACP has recently gathered impetus with a number of resources now available (e.g. Kendrick & Robinson, 2002; Seymour et al., 2007; The Patients Association, 2003), and several educational projects reported (e.g. Carrese, Mullaney, Faden, & Finucane, 2002; Sanders, Seymour, Clarke, Gott, & Welton, 2006).

Placing material on the sensitive subject of death and dying within the context of a programme geared to ‘positive’ self-management of illness draws attention to ambiguities of cultural ideas in relation to health, illness and death. However, whilst contemporary cultural ideas surrounding death and dying have been widely discussed, we know little about what impact notions of ‘planning for death’ may have when these ideas are deliberately introduced into peoples’ lives through educational interventions.

The aim of this paper is to examine the impact of incorporating this subject within a self-management intervention. We analyse data taken from a qualitative study embedded within a randomised controlled trial (RCT) designed to evaluate the effectiveness of the generic EPP course (Kennedy et al., 2007), and qualitative interview data from respondents who completed a course adapted from the generic version of EPP specifically for people who are HIV positive and run by a voluntary organisation. These studies were closely related and conducted as part of a larger programme of work to evaluate EPP within the UK. The aim was to explore the context and response to the programme in a way that would not be possible within a randomised controlled trial (RCT) evaluation design. The two studies are closely related because HIV has come to be

¹ The term self-management is related specifically to living with a long-term condition and has been defined as: “The individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a long term disorder.” (Tomkins & Collins, 2005: 6).

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