

participate. This mirrors our experience in Bradford.⁵ Although a few people had negotiated advance statements individually with their consultants, two years of extensive development work with service users and mental health professionals generated a disappointingly low uptake of advance statements. Of 70 service users who attended presentations on advance statements only one took up the opportunity. This is puzzling. Attempts to reduce compulsion and increase the involvement of users in their care are noble objectives. Why are service users reluctant to get involved?

There are many possible reasons for this. Most people dislike making wills because to do so acknowledges the reality of death. Similarly service users may be reluctant to plan ahead because they prefer to deny the possibility of readmission. We want to focus on two ways of understanding this reluctance. The first concerns the appropriateness of using randomised controlled trials to evaluate complex interventions where it may be difficult to specify the active components, making replication difficult.⁶ The outcome of such interventions depends on contextual factors and how the participants interpret these. Joint care plans and advance statements are complex social interventions that occur in an intricate web of personal and professional relationships that are characterised by contested and competing values. Who had control of the processes of selection and initiation of joint care plans—service users or research staff? What training, preparation, and development work took place with users and staff? Meyer points out that action research is a more suitable method in such situations.⁷ The participatory nature of action research engages research subjects actively in the research processes of deciding the research questions, design, and implementation. It is more “democratic” than positivistic research and thus capable of taking different interests into account. The Bradford project used action research but still failed to enthuse service users. This implies a more fundamental problem relating to power and powerlessness.

Psychiatry, unlike any other branch of medicine, is the only specialty in which treatment is regularly given for extended periods against the person's wishes. Many service users do not consider themselves ill, yet find themselves forced to take medication. Another way of understanding the reluctance of service users to plan

ahead is that they feel demoralised, disempowered, and oppressed by years of compulsion in the mental health system. We must be circumspect in hoping that interventions such as advance statements will change the situation. Psychiatrists are not the only oppressors; we include here the panoply of state control of deviance, stigmatisation by society, and our collective social intolerance of difference. As psychiatrists we have a duty to engage with our patients' painful social realities while grasping positive opportunities, as Henderson et al have done, for more collaborative ways of working.³

Against the wider political context psychiatrists and mental health professionals are right to fear the effect that increased compulsion will have on their relationships with service users, but the idea that we can soothe the pain of greater compulsion with the balm of advance statements is simplistic. Liberation, as Paulo Freire put it, cannot be handed to the oppressed by the oppressor,⁸ but we must continue to work with service users to make greater freedom a possibility for them. This is why advance statements and joint care plans are so important.

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Spiritual needs in health care

May be distinct from religious ones and are integral to palliative care

Spiritual needs change with time and circumstances. The National Institute for Clinical Excellence guidance, *Supportive and Palliative Care for Adults with Cancer*, published in March 2004, acknowledges this and recommends that healthcare teams ensure accurate and timely evaluation of spiritual issues through regular assessment. This reflects the increasing emphasis on spirituality as a factor contributing to wellbeing and coping strategies.¹⁻⁴ A proliferation of textbooks and book chapters with titles containing the word “spirituality” seek to elucidate

what spiritual care is, how it might be assessed, and how needs might be met.⁵ However, a lack of consensus remains as to what spirituality actually is.⁶

Some key words occur quite regularly in the various descriptions of spirituality in journals and textbooks (box). In health research we should differentiate between the terms spiritual and religious since, if they are used interchangeably, reports of spirituality may be describing religious practice and affiliation.^{7,8} These can be interrelated. Spiritual belief may or may not be religious, but most religious people will be spiritual. A

non-religious person may still therefore have a deep spirituality and spiritual needs. Spiritual care is not just the facilitation of an appropriate ritual but engaging with an individual's search for existential meaning, as reflected in the existential domain of the McGill quality of life questionnaire.⁹

Variables such as religious practice often seem easier to measure. Where participants for research have drawn from communities where religious practice is at high levels, these studies have shown that participating actively in the life of the faith community seems to lead to better health profiles. Religion also strengthens people's ability to cope with life threatening disease,^{3 6 10} and its importance in predicting aspects of psychosocial need in patients with cancer has been reported.¹ These studies are examining religious affiliation and behaviour even though some of them talk about spirituality.

Recently researchers have begun to look at populations that may not be religious but claim to have a clear spiritual belief. King et al reported that 71% of people who entered their acute hospital study had an important spiritual belief, even though many did not express that in a religious way.⁸ Other studies confirm this proportion and are beginning to show the importance of spiritual belief in predicting clinical outcome,⁸ the management of death distress,¹¹ end of life despair,² and assessing quality of life in oncology patients.^{9 12}

Evidence is growing that spiritual belief and religious practice are important predictive factors for a larger proportion of people entering health care than previously thought. Many may benefit from support for this aspect of their life. A need exists for user friendly and brief measures to assess spiritual need in the absence of religious faith, so that it may be addressed properly rather than as some general panacea which is assumed to be good but is not individually tailored. Only in this way may we "ensure that the spiritual elements of disease are taken into account," as recommended in the guidance from NICE.

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Key words and phrases in spirituality literature

Meaning—making sense of life situations; deriving purpose from existence

Existential—searching for personal meaning within one's life, death, and concerns about freedom and isolation

Value—cherished beliefs and standards of, for example, truth, beauty, behaviour, or thoughts

Transcendence—appreciation of dimension beyond self; creating ability to rise above "here and now" experience

Connecting—relationships and communication with self, others, environment, higher power, the sacred

Becoming—links to identity, personal growth, through reflection on life experience

Coping—means of using or developing strategies in critical life events; achieving inner peace

Spirituality—the search for existential or ultimate meaning within a life experience, such as illness. (This belief usually refers to a power other than the self, which people may or may not describe as God, higher power, or forces within nature, and with which they communicate. The power helps the person to transcend the here and now, re-establish hope and the ability to cope)

Religion—is an expression of spiritual belief through a framework of rituals, codes, and practices; the sense of otherness or a power being a deity or supreme being

Philosophical—relates to the same searching, but with a rejection of any influential power external to the self

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New treatments for colon cancer

Though experimental, they may herald a new era of cancer therapy

Until the early 1990s the medical treatment of colorectal cancer represented a therapeutic desert with little or no progress. Since then we have witnessed the establishment of effective adjuvant chemotherapy and the treatment of advanced disease has improved substantially. In the past year colorectal cancer has been at the cutting edge of new developments in medical oncology. Although some of these new treatments are still experimental and not yet standard practice, they are worth flagging up at this

preliminary stage because the proof of principle they have established may herald a change in the way all cancer is treated in future.

Fluorouracil has represented the cornerstone of medical treatment of colorectal cancer for nearly 40 years, but it took until 1990 to show that adjuvant

See also p 133



Additional references w1-w4 are on bmj.com

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