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EDITORIAL

Revd Dr Steve Nolan

For those who take these things seriously, the scoping review of recent research published by Mowat at the beginning of the year has added a new layer of imperative to the chaplain experience. Now, not only do chaplains need to be expert in the scriptural interpretations and liturgical practices of our particular faith community (including a working understanding of the beliefs and practices of others); *and* be skilled in a broad range of pastoral situations (equipped with ethical insight), which we can respond to with little or no forewarning (and sometimes in the middle of the night); *and* be competent in the political machinations and management complexities of our given health care specialty; *and* be able to teach across a range of abilities to a spread of professional disciplines; we now have to be able to write up and publish our experience/practice, have it blind peer-reviewed and call it research.

For anyone who has always wanted to be a writer, this might be a godsend – a bona fide endorsement for a talent waiting to flourish. But for those otherwise inspired, this is not what they signed up for – just one more in an expanding set of increasingly professional demands that conspire to take them away from the real work, which is being *with* patients.

This was brought home to me at a recent London Regional meeting of CHCC colleagues, at which Simon Harrison, the previous editor of this journal, was speaking about writing for publication. Towards the end of the discussion one senior chaplain expressed the thought that, while he might like to write, it wasn't really his strong point and, in any case, it was not what motivated him into ministry – he was a pastor, a people person. A number of others shared his view, including one person who offered a powerful defence of her conviction that research and publication were part of an agenda that was taking chaplaincy away from its true calling: to be (as she put it) the hands and face of Christ.

If, given the spread of faiths represented within chaplaincy, we factor out the specificity of this particular comment, this colleague perhaps reflects something of the tension that exists among chaplains: we want to be practitioners, but we are increasingly expected to be managers and now researchers.

The tension is real, and it was certainly palpable in the London meeting, but it is a real-world tension that we have to face and learn to work with. Real-world chaplaincy

can no longer assume its once privileged seat at the health care table, and if we believe in its value (which we do) then it is up to us to demonstrate its worth. As Simon wrote in a recent editorial: 'the days of justifying our role on the basis of anecdote or personality are over'. There is need for empirical research and theory construction regarding what we do and why and how it is effective with patients.

For this reason, the first part of this double edition offers four articles intended to help chaplains attend to 'the research issue'.

Mark Cobb opens this focus on research with an invitation to grow the skills needed for research within the resources and budgets of our existing departments. He identifies the reason that, to this point, we have as a profession lacked a presence within health care research and explores a strategy for increasing our research capability and capacity.

Peter Speck, a pioneer and long-standing advocate of chaplaincy research, looks at some of the issues and challenges facing chaplains as we undertake research – perhaps for the first time. He shares some of his experience and offers guidance to those thinking about beginning research.

My own contribution is a practical guide to help first-time authors navigate through the process of writing for publication. I suggest reasons for writing, I look at how to approach a journal, how to prepare your typescript, how to go about writing, and I offer comments on the technical apparatus that many of us find so off-putting.

Finding good literature is a perennial issue, and the NHS Library is an important resource for that task. Jan Brooman's guide should provide an invaluable easy introduction to using the new web-based database.

The three articles that follow are all examples of research in practice. Faye Witton describes how implementing the Liverpool Care Pathway has enhanced spiritual care in an acute hospital setting (Doncaster and Bassetlaw); John Watts outlines the experience of delivering spiritual care with chronic illness (renal patients at Guy's and St Thomas'); and Peter Collins details an innovative experience combining spirituality and art, and its reception at five different hospitals (three in London and two in the Midlands).

However, before we rush headlong to the wholesale embrace of Evidence-based Practice, we may want to pause at least long enough to take seriously the comments of colleagues anxious about how the values of the Professional Agenda are impacting what have been the established values of chaplaincy, as we have known it; we may want to ask whether we might not be risking the loss of something important, something that is about the intuitive pastoral response that connects people with people. Is it possible that we might have something to learn by listening to the intuitive sense some colleagues have that they are increasingly isolated by the emphasis on the Professional Agenda and alienated from the practice of chaplaincy?

If this journal is to do its job properly, then it has to be as a vehicle for chaplains' academic and professional interests and the development of effective practice; it has to include room for those who can to develop their research and encourage other colleagues to join them in research, but it also has to allow room for reflection and creativity, and yes, even a bit of theology and philosophy. This is the direction the journal has been taking, and it will be important to resist becoming, by accident or design, in any way exclusive.

The remaining articles supply some of that reflective ballast. All meeting has an implicit spiritual quality, and for chaplains that spiritual quality is more likely to become explicit. In a very reflective piece, Stephen Bushell explores what it is that we bring to spiritual encounter and how we as spiritual carers are with the material of encounter.

The final article comes from Maureen Turner who offers an interview with Dame Cicely Saunders when she was aged 82. In the article, Dame Cicely reflects on her life, work and the major developments of the so-called 'Modern Hospice Movement'.

I think this makes for an interesting mix of articles relating to the professional and academic development of chaplains. But it has been difficult to pull together. At the beginning of the year, when the Editorial Team met to plan the Spring/Summer edition (9.1), the fact that there was very little in the store of articles to draw on was real-world evidence that chaplains do tend to make reluctant writers! Through the year, the Team has continued to encourage people to write and I want to underline that support is on offer to anyone who is considering writing, perhaps for the first time – you are welcome to make contact and discuss your ideas, even at a very preliminary stage.

Steve Nolan Esher

GROWING RESEARCH IN THE PRACTICE OF CHAPLAINS

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Abstract

Research into subjects that relate to health care chaplaincy, such as prayer or religious practice, is a growing field but one that rarely involves chaplains. This is not surprising given that research skills are seldom recognized to be a prerequisite of a chaplain's appointment, and research activity may not be included in development objectives of individual chaplains or departments. In addition, the pastoral practice of chaplains may privilege experiential knowledge over knowledge derived from research. Despite these barriers, the health care context provides a wealth of opportunities and resources to grow the research capability and capacity of chaplains, which are explored in this article.

Key Words

Chaplain, Chaplaincy Service, research, evidence base, knowledge

Main Article

Introduction: the growth of research in religion, spirituality and health

Caring for people who are sick presents many challenges to those who profess to engage in this work, not least of which is the moral demand of pursuing the good of the patient. For this reason, the theories, techniques and practices used by many health care disciplines are derived from and refined by systematic inquiries in an attempt to understand the most effective treatment and care possible, to avoid harm and to demonstrate benefit. Consequently, health care is a seedbed of research, substantially in the physical sciences related to the immediacy of problematic human bodies, and to a much lesser extent in the social and behavioural sciences related to the lived experience and social environment of being human.

There are a few research shoots appearing in the small world of chaplaincy, but if chaplains rarely explore or explain their experiences, observations and ideas through research, then other disciplines have been less reticent to examine phenomena that intersect with chaplaincy knowledge and practice, such as the relationship between religion and health (Koenig 2000) and the therapeutic effectiveness of prayer (Roberts et al. 2007). The aim of many of these studies is to provide evidence of a hypothetical causal relationship or process from which can be derived an abstract account of, say, the role of religious beliefs in depression. Leaving aside the inherent problems of applying reductionist techniques to the complex open systems in which real people live and practise religion, there appears to be no shortage of natural scientists pursuing such inquiries. Similarly, though less often, social scientists make inquiries in order to describe, say, the health beliefs of patients from a particular faith community and provide a causal analysis of the social mechanisms involved in order to explain why such beliefs persist in the modern world. An insight into the academic research world and its growing interest in chaplaincy-related subjects can be found by looking at the content of journals. For example, the Journal of Religion and Health 'presents articles that deal with mental – and physical – health in relation to religion and spirituality of all kinds. It provides a scholarly forum for the discussion of topical themes on both a theoretical and practical level' (www.springer.com/public+health/journal/10943). However, the interest is also evident beyond subject-specific research journals, for example, the leading British Medical Journal indexes 108 articles under the subject of 'spirituality' and 70 under the subject of 'chaplains' (www.bmj.com).

The proposition of this paper is that research provides intelligible, rigorous and systematic methods to investigate and describe claims about the world; that health care chaplains and those in their care have the potential to benefit from research; and therefore, that health care chaplaincy as a discipline should be actively engaged in research projects and in interpreting, questioning and implementing research findings to improve its practice.

What are the barriers to research for chaplains?

However compelling the logic of the argument, or the aspiration of the discipline to be research active, in reality research remains outside of the norm for most chaplains in the UK.

Chaplains in the health care context are predominantly formed by theological education, pastoral care training and the humanities, which may have some underpinnings in research-related subjects including biblical studies, history, ecclesiology, psychology and sociology. However, most chaplains are not trained in research methods and, while they may practise forms of theological reflection, few apply recognized methods of critical inquiry and analysis. This is evident in the paucity of research published by chaplains and their limited engagement (in print or at conference) with the research of other disciplines into relevant subjects such as prayer and beliefs. Exceptions to this are descriptive and sociological studies in which chaplains are the participants (Orchard 2000; Mowat & Swinton 2005).

Research skills are not recognized as a qualifying competency at entry level, and appointment panels may lack the understanding and knowledge of the relevance of research to chaplaincy to be able to ask necessary questions. All chaplains under Agenda for Change will be subject to an annual review against the Knowledge and Skills Framework, which includes Service Improvement as a Core Dimension. However, it is only an example and not a requirement, at level 2 and above, for chaplains to evaluate their own and others' work 'through appraising own and team practice in the light of research findings' (Department of Health 2004). In contrast, the chaplaincy-specific capabilities and competencies framework produced by NHS Education for Scotland contains explicit statements about research awareness, the use of research evidence, and participation in research projects to support best practice (NHS Scotland 2007). For example: 'evaluate and apply relevant research findings and, in collaboration with other members of the chaplaincy and health care teams, incorporate them into practice.' The Scottish framework is a significant achievement and a major step forward in articulating the knowledge, skills and behaviours specific to chaplaincy, but it will require the commitment of both chaplains and their managers to realize the aims of the framework, and outside of Scotland the document has no official status in the NHS.

Chaplains often work in small teams and many chaplains are part-time. This can limit the momentum and capacity that a Chaplaincy Service requires to pursue engagement in research. A journal club is one means of supporting critical engagement and learning from articles on research relevant to chaplaincy (for an example of the type of article that could be discussed see Piderman *et al.* 2008), but time has to be found when chaplains can attend, and they need to develop skills of critical engagement and knowledge of research methods to understand how the research was carried out and the results derived. This can be compounded by a lack of understanding of the role of research in chaplaincy by team leaders and managers, which results in research activity being given a low priority, few if any resources and no clear objectives.

Finally, there may be epistemological and theological barriers to developing research that result from the way some chaplains understand the validity of research-generated knowledge in relation to their faith-based beliefs, practices and interpretations of experience. Empirical and theoretical forms of knowledge can, from a pastoral perspective, appear less important or relevant to the immediacy of experiential knowledge, but such privileging may obscure important alternative narratives and insights that can provide a fuller picture beyond the limited view of an individual or a faith perspective. Chaplains may also encounter health care researchers who make disproportionate claims against what they think chaplains represent and invoke a questionable antithesis between science and religion as a reason to keep their distance. However, the experience of chaplains active in research suggests that other disciplines are generally more than hospitable towards curious chaplains wanting to engage in interdisciplinary approaches to research.

What might enable research for chaplains?

There are practical and strategic steps to be taken that can support the development of research in chaplaincy, but before we take these it may be helpful to gain the commitment of chaplains to the benefits of research; this commitment will in turn provide a momentum and aim to the endeavour. Research has the potential to:

- enhance the ways in which chaplains understand and care for patients;
- open up unexamined areas of chaplaincy practice and provide fresh insights, interpretations and explanations;
- critically and creatively question the tacit assumptions, knowledge and beliefs of chaplains;
- inform the training of chaplains and other health care professionals;
- enrich debates and stimulate dialogue and reflection;
- provide a descriptive language and process of engagement that enables multidisciplinary communication and interaction; and
- generate a body of knowledge that may contribute to the evidence base for chaplaincy and demonstrate its value to health care.

Chaplains cannot claim any privileged position when it comes to research practice, nor are they Cinderellas at the research ball, for they can bring theologically derived descriptions of the world, pastoral experience of caring for people in the context of health care and critical reflections on the interplay between the two. If the claim that chaplains are practical theologians is valid, then to some extent they are already implicated in action research (Swinton & Mowat 2006). This is a unique disciplinary perspective because chaplains constitute a community of practice and learning that is committed to promote the spiritual good of the patient. Consequently, while health care chaplains can be included within generic chaplaincy or health care spirituality studies, there is a legitimate field of inquiry called *health care chaplaincy research* that may be distinguished from other areas of study in as much as (1) it focuses on the beliefs, knowledge, concepts, experience and practices that are particular to health care chaplains and (2) it is grounded in the pastoral/clinical relationship between chaplains and those they care for. This suggests two basic conceptual questions that may provide a foundation for an emerging agenda: first, what is the good of the patient that the chaplain is concerned with? and second, what knowledge, beliefs, methods and practices do chaplains apply to achieve this good?

A commitment to the potential benefits of research, with an understanding of what chaplains can contribute to research should provide some of the necessary conditions to begin the task of developing research in practical ways. Research will never become more than exceptional unless it is integrated into the regular practice of chaplains and this means embedding research activities and resources into Chaplaincy Services, job descriptions and development objectives. Health care organizations usually offer a wealth of resources that can support chaplains in this aim including: specialist librarians who can assist in literature searches; research departments who can provide guidance, training and sometimes small grants; and colleagues in a wide range of other disciplines who are happy to welcome chaplains to attend in-house seminars and to discuss research findings, ideas and projects. Most of this can be obtained without financial cost and from it learning, confidence and mutually beneficial relationships can be developed. This provides the grounds to develop chaplaincy research events.

It is unrealistic at this stage to think that all chaplains are in a position to take these steps, but should we not at least expect that more senior chaplains should be research-aware and understand how relevant research findings may inform practice? Equally, chaplains undertake higher degrees that, at master's level, often include research modules and, at doctoral level, include primary research. Is it not reasonable to expect that they will disseminate their findings in some form as part of the research process? This is one of the purposes of the Chaplaincy Research Network which meets twice a year and is supported as a specialist interest group by the College of Health Care Chaplains. A virtual support is provided through a national academic mailing list service known as 'JISCmail', which hosts an electronic discussion list via email for chaplains, educationalists and researchers to share information, announce news, conferences and similar events (including the Chaplaincy Research Network) and discuss common issues. Chaplains can become members of the 'CHAPLAINCY-SPIRITUALITY-HEALTH' list for free and can join in the talk, start a discussion, or simply listen (www.jiscmail.ac.uk/cgibin/webadmin?A0=CHAPLAINCY-SPIRITUALITY-HEALTH).

There is much that individual chaplains and departments can accomplish, but we also need to think more widely and strategically because of the limited size of the profession. Chaplains should be well placed to identify clinical colleagues who can encourage, inspire and support them, but we also need to build links with academics in university departments who may be potential collaborators and find mutual benefit in a relationship with practising chaplains. Beyond these groups the chaplaincy profession may be more ambitious and seek collaboration with other professional and research bodies, for example the Spirituality and Psychiatry special interest group of the Royal College of Psychiatry

(www.rcpsych.ac.uk/college/specialinterestgroups/spirituality.aspx), or the Sociology of Religion Study Group of the British Sociological Association (www.socrel.org.uk). A developing research network of this nature would provide a creative and critical forum in which to develop a consensus about key research questions, develop study protocols and methodologies, and identify and add weight to applications to funding bodies.

Conclusion

Research is a challenge to chaplains as a small profession and to a culture of implicit and experiential knowledge, but the growing field of research into subjects that relate to the interests and practices of chaplains by other disciplines offers some insights into the possibilities and problems of research. At its best research can contribute to new ways of understanding the world and interpreting experience that are liberating, helpful and inspiring, all of which should have some resonance with the aims of chaplaincy. But whilst it is evident that we are in the early stages of developing research capacity, we must also recognize that health care chaplains operate in a context that is hospitable to research activity and that offers many accessible resources. This provides the conditions to grow research in the practice of chaplains and to develop a collaborative base from which we can establish more generative, supportive and sustainable developments for research in the future.

Acknowledgements

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CHAPLAINS AS RESEARCHERS: OUTLINING THE PROCESS AND THE CHALLENGES

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Abstract

Many chaplains find the prospect of conducting any form of research quite daunting. This article guides the reader through the key components of the research process, from defining the research question/hypothesis to the presentation of the findings to the funding body or as a published paper.

Key Words

Research methodology; Mowat; research process; chaplaincy; spirituality; ethics

Main Article

Introduction

The publication of the Mowat Scoping Review of Recent Research in January 2008 has provided a valuable review of current research into health care chaplaincy and spirituality within the NHS and set out a clear picture of those aspects which have not already been studied and which are closely related to practice. It is hoped that the report will guide chaplains undertaking higher degrees, or beginning to consider a research project, to put their energies into addressing some of the gaps rather than revisiting areas already examined. I have argued elsewhere about the importance of developing a research base for what we do (Speck 2005) and I am aware that some chaplains find this daunting; some might argue that we should not align ourselves with the 'measure everything' culture of the NHS. However, if some chaplains do not engage in this work other professionals will continue to examine this aspect of care, and may not be as conversant as healthcare chaplains are with the intricacies and sensitivities required in providing good, effective pastoral care. Whether or not we actively engage in research, we should be conversant with what has already been undertaken, much of which has been captured in the Mowat review (2008).

In this paper I wish to look at some of the issues and challenges that chaplains may face in undertaking research in the hope that more may be encouraged to engage in this activity.

It is interesting that when, nearly 15 years ago, Professor Michael King (an academic psychiatrist) and I started researching the possible relevance of belief on clinical outcome for patients with heart disease (King *et al.* 1994), we had enormous difficulty in getting funding, obtaining ethical approval and subsequently getting our results published. We were experiencing the 'anti-tenure factor' (Sherrill & Larson 1994). This meant that researchers were perceived as entering an academic cul-de-sac for trying to study and research religion and health, and were in danger of committing professional suicide. Certainly, some of the referees' reports on papers describing our research findings showed that editors and referees were at a loss to know how to respond.

We, and others, have now published many papers, and it is easier now to obtain funding and ethical approval, and to get the results published; also, more people are entering this field of study. Interestingly, apart from a small group of people, most of the research on spirituality has been undertaken by non-chaplains, and it is noticeable that very few chaplains have sought to collaborate with other professionals who are already actively researching areas that could easily include a spiritual dimension to their study.

Before going on to think about the challenges that face chaplains and others, it is important to understand that 'research' means different things to different people. To the professional academic researcher it can mean large-scale studies lasting for several years with a team of full-time purposefully appointed staff and technological backup. For others, it can simply be 'I did a bit of research into that a few years ago' or 'I *googled* the topic and found an interesting review article'. Whatever the scale of the project, the word 'research' implies a process characterized by a logical approach to solving a defined problem, or obtaining and analysing information.

The research process

There are a number of distinct stages in the research process. These may overlap, but each needs to be addressed whatever the topic studied.

- selection and formulation of a research question or hypothesis including clarification of concepts and terms used
- clear statement of aims and objectives

- literature review to see what is already published
- design of study and choice of methods
- funding what resources will be needed \pounds + skills + personnel
- ethical considerations
- construction of instruments questionnaires, interview schedules, etc.
- pilot study to test methodology, acceptability of approach, questionnaires, etc.
- data collection
- analysis
- recognition of limitations of study
- communications who needs to be informed, agreement sought
- preparation of report, presentation of findings and paper for publication

In thinking about spirituality there are challenges associated with each of the above steps, but these are not insurmountable, especially if the study collaborates with an established researcher or team.

The research question

It is important to clarify the research question or formulate a hypothesis. It helps to seek out appropriate people to comment on your chosen topic and to help review/revise your hypothesis or research question. As an example: you might wish to see whether the attitudes of clergy to personal ageing influence their pastoral care of elderly people. In this case, the null hypothesis would be that attitudes do not influence the provision of pastoral care, and this is what you would set out to prove or disprove.

Null hypothesis – taken from statistics, a null hypothesis (H_0) is a hypothesis set up in order to be tested and refuted (nullified), the aim being to support an alternative hypothesis (H_1). The null hypothesis is presumed true until the researcher finds enough statistical evidence to prove otherwise.

Aims and objectives

Having well-formulated aims and objectives helps to clarify the hypothesis and to take the statement of the study further.

Aims – are statements that give the general overview of what you expect of your research project.

Objectives – are statements that give the detail about what you expect to achieve.

The aims and objectives for the example given above might be:

Aims:

- to describe the attitudes of parochial clergy towards their own ageing;
- to test the null hypothesis that attitudes to personal ageing do not influence pastoral care for elderly people;
- to examine the training received by clergy and identify any further training needs regarding elderly care and psychology, and knowledge of the ageing process.

Objectives:

- to review the published literature relating to clergy, ageing and attitudes;
- to select a sample of clergy and obtain information on attitudes to personal ageing, towards elderly people, and knowledge of the ageing process;
- to analyse the data received and use it to test the hypothesis;
- to make recommendations about any factors identified which influence the pastoral care of elderly people within the churches.

Literature review

It is not appropriate here to go into detail about how to undertake a literature review. There are many books that can help with this task (e.g. Hart 2001), and other help is available. Postgraduate students will be able to seek help from a tutor; others might find experienced researchers a good source of help and advice. Hospice and NHS Trust librarians are very skilled in doing searches and may offer training days for staff. They may also be willing to undertake a search for you (possibly for an agreed fee) and may even obtain reprints of relevant papers. Recent changes to the National Library for Health website have improved the service and it now offers one-stop access to Medline, PsychoINFO, and other important databases (<u>www.library.nhs.uk</u>).

To get an initial feel for your subject you might look at 'PubMed' (<u>www.ncbi.nlm.nih.gov/pubmed/</u>). This is a service of the US National Library of Medicine that includes over 16 million citations from Medline and other life science journals, and it also gives general guidance, for example, on how to refine your search. Clarify whether you are looking for academic, peer-reviewed journals only, English only, unpublished research theses, or chapters in books. This may also lead you to handsearching along library shelves. Remember, each article will include references at the end that will lead you onwards – so seek help before you drown!

If you are to refine your search and bring a possible 6,966 references down to a more manageable number, it is important to be clear about the key words for your search. A

helpful trick is to use 'wildcards'. One of the most common is the asterisk (*) character to stand for other characters. So, searching 'spiritual*' will also give results for 'spirituality' and 'spiritualism'. But be cautious, searching for 'h*s' will also give results for anything from 'his' and 'homes' to 'herbaceous' and 'horticulturalists'! Offer 'descriptions' of how you are using the key terms (Speck 2004).

Methodology

Your choice of research method will depend on what you wish to examine and the availability of suitable tools that already exist, or that may need to be developed. Where possible, use an existing tool since developing new tools or scales is very time-consuming and requires experience. There are essentially two main approaches to research method: quantitative research – effectively the realm of statisticians who are happy to number-crunch – and qualitative research – about which statisticians are less happy and have more reservations, unless they are experienced with qualitative work.

Quantitative research – aims to remove subjectivity and usually works with large groups answering structured questions to produce numerical data that can be analysed statistically.

Qualitative research – is more accepting of the subjective and usually works with smaller groups (or individuals) to analyse meanings, concepts and descriptions.

A mixed methodology can be helpful in researching healthcare chaplaincy and spirituality, for example, scales to measure strength of belief, attitudes or level of knowledge (giving quantitative data) supplemented by focus groups or interviews (providing qualitative data) (Jones *et al.* 2005).

A useful resource which reviews a variety of scales and measures is Hill & Hood (1999). Recent articles and your literature search will also help identify scales, instruments to measure attitudes, spiritual wellbeing, etc., as well as a critical evaluation of such measures.

Funding and ethics

The nature of your study will determine whether funding is necessary and, if so, where you might to go to find it. If collaborating with others, you can discuss this with other researchers, but the *Charities Digest* is a useful resource, readily available in most libraries.

Ethics approval is essential before you start collecting data, including data for pilot studies. If you are doing a degree, you will need to obtain ethical approval through your university, otherwise via the local area NHS Research Ethics Committee (REC) where the study will take place. The National Research Ethics Service has a useful website (<u>www.nres.npsa.nhs.uk</u>).

If your research subject might be thought to be emotive, intrusive or potentially distressing for participants, you will need to be aware of sensitivities, particularly around interviews. You will need to give the Participant Information Sheet careful preparation, and make sure you use 'user-friendly' language (Speck 2007). Also, consider possible objections before completing the required forms, and allow plenty of time for processing.

Before completing the Ethics Application there are several issues you need to have decided and planned:

- Who needs to be informed, what permissions need to be sought? Even with a simple audit, it will be important to obtain permission and consent in writing from the relevant people accountable for access to patients, staff, volunteers, etc.
- Data Protection: If you intend to process non-anonymous data relating to other people, you may need to register for Data Protection (the Data Protection Controller for your Trust or university will be able to advise you). You will need to ensure you retain tapes and transcripts, which need to be kept in a safe place.

It can be helpful to include an exit survey – 'How was it for you?' – which can be forwarded to the Chair of the REC to deal with any concerns there may be about participant distress.

Budget development

Think about all the costs you might incur: travel, postage, stationery, printing/photocopying, literature search, transcribing, salaries, fees for use of scales, statistical advice, software, etc.

Data collection

Plan your work. Create a time chart to show how your study will progress and how you will complete it within the timeframe available. If you need to train interviewers, allow time for support of the data collectors, and organize your data as it comes in. Ensure

each sheet is coded and identified to prevent mistakes later. Keep *all* data and keep a process log/diary.

Construction of instruments

Questionnaires need careful construction and you should test and re-test yours to check reliability and validity. You might need to consult a statistical advisor to ensure that responses can be analysed and that they answer your research question.

Reliable – is the test reliable? Can it be repeated? If you measured the same person with the same test, would the result be the same? **Valid** – does your test measure what you intended it to measure?

Choose established and published scales or measures when possible, and make sure you obtain permission to use them – especially if you decide to make changes to any aspect of the scale.

Pilot study

Before your invest too much time and resources in your project, you need to know that your methodology works, that your approach is acceptable, that your questionnaires are capturing the data you want, and that it will be analysable. A pilot study is a good way to test your method. Identify a small group of people that you can match to your intended sample, but that is separate from your main study.

Focus groups

If you plan to use focus groups, think about creating a framework for the topics you want the group to discuss. The framework can be structured, semi-structured or unstructured, but it can help novice researchers to get the group working effectively.

Analysis

Having decided at the design stage how you will collect your data, the form of your analysis will depend on the type of data. For example, analysing material from focus group interviews is a very different form of analysis from the kinds of statistical analysis needed for answers to questionnaires and scales.

You will need to transcribe and format recorded interviews in order to analyse themes, etc. It is helpful if you can get someone else to check themes that are emerging to protect against bias. Keep a log of your thoughts as you do your analysis, or you risk forgetting the impressions and ideas that emerge. Also, note at this stage any limitations of the study that become obvious and any things you realize that you might have done differently.

Recognition of limitations of study

It is important to acknowledge any potential for bias. For example, are you setting out to develop evidence to prove the value of your service in order to remain employed? How will you demonstrate impartiality and objectivity? Have you sought an external review of the scientific merit of the study? Is there collaboration with people who have different beliefs to your own – people from another faith, humanists or atheists? When writing up the study at the end, remember to acknowledge any possible bias.

Preparation of report and presentation of findings

Be clear who needs to know the findings and target that audience. Prepare an abstract for possible submission to conference, either as a poster or oral presentation. Consider if, and where, to publish your results. Pay attention to peer-review comments when submitting an article to a journal and ensure you address any comments before resubmitting. Most importantly, don't get discouraged!

Some specific challenges for chaplains

Motivation and perceptions about the importance of research activity can influence chaplains' willingness to engage. Many chaplains may also feel they lack time, skills or knowledge, so why not consider collaborating with a more experienced researcher? It is important to increase awareness of what already exists (through journals, clubs, etc.), but it is also helpful to identify and network with other research teams. For example, researchers looking at breathlessness in COPD/cancer and coping strategies might be willing to include spirituality/strength of belief as an additional factor to explore.

Where do we go from here?

In *Alice's Adventures in Wonderland* there is an interesting meeting between Alice and the Cheshire Cat:

'Which way should I go from here?' said Alice.
'It depends where you want to get to,' said the Cat.
'I don't much mind,' said Alice.
'Then it doesn't matter which way you go,' replied the Cat.
'So long as I get SOMEWHERE,' said Alice.
'Oh, but you're sure to do that', said the Cat, 'if you only walk long enough.'
(Carroll 1994)

For health care chaplains the direction of future research does matter, as is made clear by the Mowat review (2008). While we have a certain amount of research into what chaplains do, and a number of studies which illustrate a relationship between spiritual belief and a variety of health outcomes, we have very little information as to what form of intervention is most helpful to patients and families. In many ways this represents a great challenge for current and future chaplains to address, and it would primarily inform chaplains as to what is best practice in the variety of pastoral encounters they have.

This paper is based on a presentation given to 'Chaplains as Researchers of Spiritual Care' study day, St Christopher's Hospice, London, 30 November 2007.

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WRITING FOR PUBLICATION: A ROUGH GUIDE FOR FIRST-TIME CHAPLAIN AUTHORS

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Abstract

Chaplains are encouraged to publish articles relating to research they have completed or reflecting on good practice. However, many chaplains suffer with what Heyman & Cronin call a 'low sense of research esteem' and what Heinrich *et al.* term the 'impostor syndrome'. This paper offers chaplains help to become first-time authors. It encourages chaplains in writing for publication and in submitting to academic and professional journals such as the *Journal of Health Care Chaplaincy*. The paper attempts to demystify the process of writing for publication: it suggests five good reasons for writing; explains how to approach academic journals with an idea for an article; offers advice on writing up a project; and looks at the sometimes confusing technical apparatus of references and abstracts.

Key Words

First-time author; writing for publication; *The Journal of Health Care Chaplaincy*; references; abstracts

Main Article

`... and when you've finished your project, you should think about publishing your results.'

I didn't think my suggestion was particularly outrageous, given that we were students together discussing our final year Master's work. But by her look of incredulity, anyone might have thought I'd said something deliberately offensive. As far as she was concerned, publication was what other, *clever* people did; she didn't think of herself as one of *those* people. Why would I even suggest such a thing?

My fellow student is not alone: from what I observe, many, if not most, postgraduate students seem content to get their research out of the way: pass their module, move on and leave their hard-won insights as so many words on paper stuffing a file lost in a cupboard. For many, 'doing research' is simply a course requirement, a means to an end and, having achieved their end, they plan never to engage with the research process again. But in reality, passing the module and attaining the degree is only half the job; sharing what has been learnt with others who are professionally interested in what you have discovered, is an equally important part of the research process.

Perhaps my fellow student felt similarly that research was a hurdle she had to get over. But I think there was something else going on for her; I think the idea of publishing, putting her work into the public domain, intimidated her. I think she felt her ideas and her work too unworthy to stand alongside other – in her view – 'better' writers. And I suspect that she was suffering from what Heyman & Cronin call a 'low sense of research esteem' (2005: 401) what others term the 'impostor syndrome' (Heinrich *et al.* 2004).

In part, there is an institutional problem in that few colleges or universities routinely offer specific training in writing for publication, and few tutors encourage students to publish. While there is help for students needing support with academic writing for assignments, specific modules on writing for publication are far from mainstreamed, which is odd given that there is so much pressure on academic staff to publish.

This paper is an attempt to help chaplains who have something to say to get work out of the cupboard and on to the printed page – perhaps in this journal. I want to try to take some of the mystique out of the process of getting published. I'll explain how to approach an academic journal with an idea for an article, how to write up your project, and I'll look at some of the 'technical stuff' like references and abstracts. First, I want to suggest five good reasons for writing.

Five good reasons for writing

1. Seeing your own work in print

It may seem frivolous, but one important reason for writing is the buzz that comes from seeing your work in print. I still remember the excitement of seeing my first published article, and the pleasure hasn't lessened with subsequent publications. This may be more an admission of my own narcissistic neuroses than a genuinely objective reason for writing, but as Freud and the Dalai Lama have observed, pleasure is a great motivator, and a deserved pleasure awaits beyond the hard work of writing and rewriting. Publishing an article is a real achievement that you can, and should, enjoy.

2. Shaping your ideas

Writing is a form of communication between you, the author, and the person who reads your work. As a piece of communication, it requires you to know what you want to communicate. Unlike conversation, where there is little time to reflect and think about what is said, the craft of writing offers the relative luxury of laying out your ideas on paper and questioning yourself about what you have written: Do these words express what you really mean to say? In the process of putting words on the page, writers are articulating their own ideas to themselves, often for the first time; in the act of critically reflecting on what they have written, they begin to see (literally) that what they thought they thought didn't actually represent what they now realize (having read it) that they really do think. This is why writing can be such an exciting and creative process in which new ideas form themselves, at times almost despite the writer's original intention.

3. Continuing professional development

Continuing professional development (CPD) is a fact of professional life for chaplains in a way it has never been in church, synagogue, mosque or temple. As long as 'pastoral' clergy know their scriptures and practise their craft, everyone is (more or less) happy. But chaplains, like other health care professionals, have to keep up to date, which means continually developing and evidencing their development. Publishing an article is a clear demonstration of CPD, not just to your line manager but also to the whole profession.

4. Sharing insights/practice/knowledge

Publication is not the only means of disseminating the results of your research: local teaching sessions and conference presentations (oral and visual, in the form of posters) are other good vehicles for your discoveries. However, publishing an article in an academic or professional journal is an effective way of communicating with a wide audience of chaplains and other health care professional colleagues. Dixon suggests four reasons for publishing your insights/practice/knowledge:

- i. Any lessons learned about improving practice will be useful to people working in other organizations or in other countries.
- ii. Others can review the work and provide helpful feedback or suggestions to the author.
- iii. The work may result in changing others' practice or at least suggesting areas for further development or debate.
- iv. A network of people who are interested in the same subjects or methods or who are doing similar work can be established. (2001: 417)
- 5. Staking our claim

Chaplains are the specialists in spiritual care. Our clergy formation, normally over many years, has been geared towards our own spiritual development and in such a way that we are now able to help and direct the spiritual development of others. It is quite right that people so trained and formed have an important contribution to make to spiritual care; for us it has more than a professional interest – for us spirituality is an existential concern. So this is an exciting moment for chaplains in health care, where spirituality is on the agenda as never before – in particular, the nursing literature is full of articles on spirituality and the book-length literature is growing. As such, many non-specialists are researching, writing and publishing on spirituality, and much of what is written has value. However, due to a lack of training, the non-specialists are often limited in the depth of their knowledge and understanding, and this is often evident. McSherry (2006), for example, writes about the 'Dark Night of the Soul', an idea he draws from the Spanish mystic, St John of the Cross. But, lacking the depth of understanding properly to comprehend St John, he fails to grasp the concept and misapplies it in a way that damages the idea of spiritual distress and possibly distorts the practice of spiritual care in a health care context (2006: 59–60). Frankl (2004), existential psychotherapist author of Man's Search for Meaning, is similarly often misunderstood and misrepresented. The point is that if we, as spiritual care specialists, don't research, write and publish, instead of being leaders in spiritual care, we will abandon the field to non-specialists and concede our right to object when others misunderstand the spiritual wisdoms they appropriate.

Approaching a journal

Journals have a mission. Usually, this will be stated somewhere in each issue, often on the page listing the team of editors and the editorial board, or with the advice on how to submit an article (typically, on or near the front or back covers). Occasionally, the statement is only available on the website. Mission statements can be very succinct or quite detailed – the American liturgical journal, *Worship*, states its mission in six words: 'A review concerned with liturgical renewal', while *Practical Theology* (formerly *Contact*) (www.equinoxjournals.com/ojs/index.php/prth) gives a much fuller account. But, short or long, the mission statement is a statement about the kind of articles editors will consider.

It would be a very obvious and basic mistake, then, to offer a research report on nurses' attitudes to chaplains in A&E to a journal like the *International Journal of Public Theology*, which 'seeks to engage in dialogue with different academic disciplines such as politics, economics, cultural studies, religious studies' on 'public issues of contemporary society' (www.brill.nl/ijpt). This will guarantee rejection.

The mission statement of *The Journal of Health Care Chaplaincy* is: 'to include a balance of subject areas (e.g. palliative care, mental health, professional practice, etc.), as well as a range of styles, from academic/evidence-based work to reflective/experiential articles'. This is a broad statement and, as long as articles are within the area, it gives an open door to a wide variety of health care chaplaincy-related articles.

Directed by their mission statement, editors are motivated by professional interest in their discipline; they want to produce a journal that contains articles of the highest quality, that will be read widely and that will develop debate in the field. Editors need good material to publish and they actively look for it; so when your article lands on their desk, they will be open to the possibility of publishing it.

But you don't have to 'cold call'. Journal editors are not remote, Olympian figures; they are usually hard-working, fellow professionals – whether academics or practitioners – whose editing role is in addition to the rest of their busy professional workload. Many will be very willing to receive an email in which you put forward your initial thoughts. And if you are a first-time author, be 'up front'. Having identified the journal you think the most appropriate, email the editor, explain this is your first article and outline your idea.

Heinrich *et al.* (2004) propose writing a 'query letter', by which they mean a formal letter or informal email that focuses on a topic, identifies a slant and provides a working title for an article. They suggest that writing a 'query letter', which includes stating the central idea in a single sentence, can be a good way to clarify your writing project.

Because editors are hard-working fellow professionals, you should take seriously the 'Guide ...', 'Instructions ...' or 'Resources ...' for Authors that journals provide. Again, these are usually to be found in some form in each issue of the particular journal – although the journal website will often have more detailed guidance. (See the 'Instructions for the submission of articles' in the end pages of this journal.) These instructions give advice on the particular house-style of the journal you are targeting: how to reference (Harvard or Vancouver?), peculiarities of spelling (-ize instead of -ise), layout, abstract/key words and how to submit (hard copy, disk, email). By following the instructions you do two things: first, you show that you have done your homework and are serious about being published; second, you save the editor *a lot of time* which, as Unruh (2007) notes, can be an important factor in how your work is received:

Manuscripts that are inconsistent with the guidelines frustrate reviewers and may increase reviewers' scrutiny of other mistakes and potential problems with the manuscript. A paper that is written according to the guidelines will be reviewed much more favorably. (2007: 64)

Having received your article, and having made an initial decision about suitability for publication *in their particular journal* – does it fit their mission statement? – the editor will put your work out for review. If it goes for 'blind review', anything that can identify you will be removed: your name from the title page and footer and, if you have included reference to other work you have published, from the reference list. If you know your work will be blind reviewed, then you should remove these references yourself (insert 'Author' for your name in the reference list); and you should also remove the author identification from the properties for the file of your Microsoft Office document. To do this, use the following procedure:

Tools>Options>Security>Remove personal information from the file properties on save>Save.

The reviewer will have been chosen because s/he has expert knowledge and/or experience in the particular area of your article, and will be looking for things like originality, value in advancing the field and generating new ideas; accuracy and factual errors; dependence on outdated research; and relevance to the readership. Whether the reviewer agrees or disagrees with your argument will not be a factor in whether your work is accepted or rejected. The reviewer's role is advisory, and it is the editor who is ultimately responsible for the final decision to accept or reject your submission.

Writing your article

If you are a first-time author it may seem like a big enough achievement just to get your work published. But there is a view that anyone can get anything published. All you need to do is make a list of possible journals and work down the list – some editor somewhere will eventually take it! But what is important for all authors, and particularly first-time authors, is that your work gets *read*, and by the right readers – those you want to influence. So, rather than seeing your article as a work of literary art, think of it as a piece of communication from you to your professional peers. In this sense, there are a number of questions you can ask yourself before you write.

Who to communicate to?

As you begin to write, it can be useful to imagine an 'ideal reader' and keep this reader in mind as you write: What does your reader need to know? How should you write for your reader? What do you have to say that your reader will find new and interesting? ('New', here, doesn't mean something that no one else has ever written about before, but 'new' in the sense of fresh or different, what Heinrich *et al.* [2004] refer to as 'slant' and Heyman & Cronin call 'storyline' [2005: 402].) One helpful approach is to personalize your ideal reader in terms of someone you know and then write for that person.

Dixon (2001) is helpful in distinguishing writers according to two types of writing behaviour. On the one hand, gathering-type writers collect all the material they think might be relevant to their paper, they then read all they have gathered and sift the material in order to organize their ideas before they begin to write. Dixon notes that this 'is the behaviour that students learn as part of their formal education' (2001: 419), but when it comes to publishing, she warns that gathering-types are prone to serious mistakes: they can be vague about their target readers, unclear about their purpose and their key messages, and they may therefore organize their work poorly.

By contrast, hunting-types are more focused and more efficient. Hunting-types:

- decide why the paper is needed;
- are clear about whom they are writing for;
- know the specifications their writing has to meet;
- devise a strategy to respond to the specifications in the form of a brief outline;
- gather only the material needed according to the outline;
- get their ideas down quickly and test them for clarity;
- organize their ideas logically to get across key messages to the readers;
- edit their own writing. (Dixon 2001: 419)

When it comes to locating your ideal reader, successfully published authors in Unruh's (2007) research emphasize the importance of choosing the appropriate journal. Unruh suggests thinking about journals that are cited frequently in your research area and reading several issues looking for style, format, nature of discussion and ideological positions. Good sources of information about journals are the websites Journal Info (http://jinfo.lub.lu.se) and JournalSeek (http://journalseek.net). Obviously, as a chaplain you should consider submission to this journal, *The Journal of Heath Care Chaplaincy* – but there are others, for example, *Australian Journal of Pastoral Care and Health* (www.pastoraljournal.findaus.com), *PlainViews* (www.plainviews.org), *Practical*

Theology (formerly Contact) (www.equinoxjournals.com/ojs/index.php/prth), Scottish Journal of Healthcare Chaplaincy (www.sach.org.uk/journal.htm), or any of the 150 nursing journals (Mee 2003).

What to communicate

If you have produced a piece of written work, for a degree or study course, this will be an obvious thing to think about publishing. But Davis & Tschudin offer a caution:

A regular disappointment for an editor is to receive a manuscript from an author who states that a tutor has told the person it should be published. Essays written for courses of study almost never make good journal articles. For a course of study it is necessary to demonstrate knowledge of the subject; a journal article or essay has to take the subject forward by adding to the knowledge base. (2007: 427)

Their advice is intended not to dissuade you from trying to publish your work, but to help you avoid an unnecessary rejection, and to point out that, however good it is academically, your essay will need to be reworked.

Academic dissertations or research reports are often complex pieces, and to work as articles they need to be streamlined and given a particular focus or 'slant' (Heinrich *et al.* 2004). Heyman & Cronin advise that a 'single paper should tell one story to one audience' (2005: 402). By way of example, they suggest:

a paper that focuses on theoretical or methodological issues designed to generate discussion may be more appropriately placed in an academic journal. A paper which aims to inform practitioners of potentially useful findings for practice might be best suited to a journal whose target audience is practitioners and clinicians. (2005: 402)

But it is not only those following a formal academic programme who have interesting and relevant things to write about. Small-scale, locally embedded research projects and clinically focused reviews and conceptual analyses can be productive sources for future research and stimulating discussion (Heyman & Cronin 2005: 401). A good example of one such project, recently published in this journal, is Hancocks & Lardner (2007).

How to communicate

Writing style is an important feature of a successful submission (Mulhall 1996) – though not perhaps the most important (Davis & Tschudin 2007) – and it does require attention to those currently unfashionable subjects: spelling, grammar, syntax and punctuation. Word processing has removed all excuses for poor presentation.

What advertising copywriters call 'tone of voice' is also important in producing good academic writing. But don't confuse 'good academic writing' with a style of writing that pretends at academic objectivity but that ends up being forced and laboured prose, for example, when the person writing refers to 'the author' and 'the author's opinion'. There is no 'correct' style for academic writing, there is only good writing (which will be clear and fluent) and bad writing. Dixon perhaps overstates her point to make her case: 'A paper is well written if a reader who is not involved in the work can understand every single sentence in the paper' (2001: 418).

The only sure way to develop your writing skill is to write and then listen to the opinions of intelligent, trustworthy critics. However, here are some helpful strategies for improving style:

- Write rough: don't be afraid to make a first draft that is rough and unpolished you can go back and rework ideas once you have them down on paper.
- Structure: make sure that what you want to say has a structure that is clear and logical, each point following naturally from the last too many potentially good essays fail because they are poorly structured.
- Distance: when you've written your article, put it away for a period when you come back to it you will approach it with a fresh mind and see it very differently.
- Read aloud: listen to the sounds of your written words if it doesn't flow and make sense, rewrite it.
- Edit and rewrite: don't be afraid to cut out words, sentences, even paragraphs if they don't help what you are trying to say – be brutal, especially when you think it is your best prose!

The technical apparatus

All good journals will provide guidelines for authors detailing what the editors expect in terms of references, abstract, key words, etc. These guidelines should be fairly clear and should be followed carefully. Here I will deal with two points that often trouble firsttime authors: references and abstracts.

References and citations

Referencing your work is important because it allows those who want to, to both check your sources and widen their own reading in the subject. Many first-time authors are particularly intimidated by referencing and the many variations of style in evidence. But actually, referencing is a simple and logical address system that provides the minimum information for locating a piece of work.

For a book reference, the information needed is:

Author/Editor (Year of publication) *Title of the Work: With Subtitle* Place of publication Publisher's name

For a journal:

Author (Year of publication) Title of the work *Name of the journal* **Volume** (Number/Part) Page range

The major variations depend on the chosen referencing system. The two systems commonly used in medical, nursing and scientific journals are Harvard and Vancouver.

The obvious feature of Harvard is that the date is placed by the author(s)' name(s) when the work is cited in the text, for example, `as Cobb (2005) says ...' References are then listed alphabetically by author at the end of the article:

Cobb M (2005). *The Hospital Chaplain's Handbook: A Guide for Good Practice*. Norwich: Canterbury.

 Vancouver differs from Harvard in that all citations are numbered sequentially as they appear in the text, for example 'as Cobb(23) says ...' At the end of the article, references are listed according to the order in which they occur in the text:

(23) Cobb M (2005). *The Hospital Chaplain's Handbook: A Guide for Good Practice*. Norwich: Canterbury.

(Detailed guidance is available at:

libweb.anglia.ac.uk/referencing/harvard.htm wwwlib.murdoch.edu.au/find/citation/vancouver.html)

Other variations, precise punctuation, capitalization of titles/subtitles, use of bold/italic, etc. tend to be a matter of the house-style of the particular journal.

Abstracts

The value of abstracts has changed with the use of electronic searches. Once upon a time, scholars passed laborious hours searching though paper indexes for titles relating to their research and then used the abstracts as summary guides to the articles' actual value. Abstracts are still useful as summary guides, but they are increasingly used by search engines to help researchers find relevant work. By constructing a good abstract, you will be helping readers find your articles and so increase the chance you will be read and possibly cited by other writers.

According to advice on the website of Blackwell Publishing

(www.blackwellpublishing.com/bauthor/seo.asp), search engines scan pages for keyword phrases, giving 'extra weight to phrases in headings and to repeated phrases'. It follows that clear, descriptive titles and repeated key phrases are more likely to be noticed. In formulating the name you give your article, it makes sense to think about what a researcher might be looking for and to get those words into the title.

In the days of print-only journals, it mattered far less if, for example, an author published an article on body dysmorphic disorder called The Broken Mirror in a psychology journal because the context was clear. On the web, people search on mirror when they want an item for their house.

(www.blackwellpublishing.com/bauthor/seo.asp).

It appears that the frequency of your key words and phrases influences the search, although overdoing it can lead to rejection by the search engine. So, having crafted your title, make sure you reiterate some key words/phrases within the abstract. The example offered on the Blackwell website concerns a search for papers on 'genocide' + 'holocaust consciousness' + 'Australia', but in a search for 'chaplain' + 'psychospiritual' + 'non-religious' an interesting, relevant example tops the list.

Waiting for the reply/dealing with rejection

The editorial process of considering a submitted article inevitably takes time. The editor will read it and (hopefully) send it for review. Like editors, reviewers fit their reviewing into the already busy workload. So be patient.

And don't be put off if your work is rejected. Learn from the experience. Maybe you sent it to the wrong journal: you may, for instance, have sent an academic piece to a professional journal, or perhaps you chose a journal whose ideological outlook was too different from your own. Maybe the reviewer misunderstood your argument, in which case you will probably still need to rework it; but maybe the reviewer has spotted things you were unable to see for yourself: maybe the focus of your writing needs to be clearer; maybe you have emphasized the wrong things and you need to rebalance the article; maybe you need to edit and restructure; maybe you need to do some additional research. A good review should highlight what is wrong and – at least implicitly – indicate what you need to do to put it right. Sometimes, the editor will invite you to resubmit; sometimes you will need to try somewhere else.

Conclusion

I'm not sure I was persuasive enough to raise my student colleague's low research esteem or to cure her impostor syndrome. But the fact is that, as a successful postgraduate student, she is already working at a standard suitable for publication in academic journals. Becoming a first-time author should be, for her and others like her, little more than putting that work into the right form and offering it for consideration to the editor of an appropriate journal. She is not alone in underestimating her ability, and she is not alone in being capable of producing publishable work.

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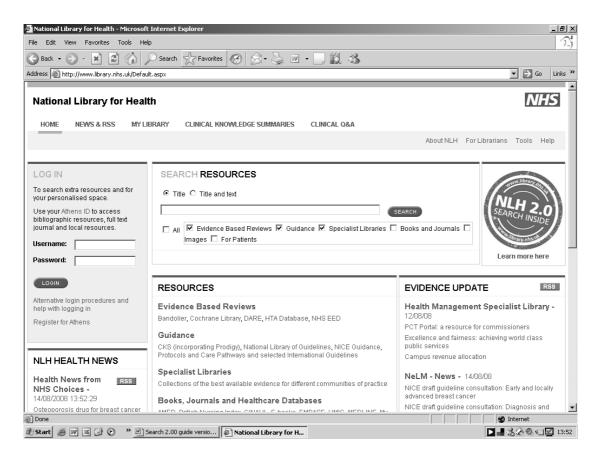
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SEARCHING THE HEALTHCARE DATABASES: EASY STEPS TO USING THE NATIONAL LIBRARY FOR HEALTH

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STEP 1

Go to the National Library for Health Homepage: http://www.library.nhs.uk

Enter your Athens username and password in the **LOGIN** box to search across all available healthcare databases. Click on **LOGIN**.

STEP 2

Accept the terms and conditions (this screen will only appear the first time that you log in). Click on **Continue**.

STEP 3

Books, Journals and Healthcare Databases is the best resource to use for accessing the key medical and nursing databases. Most of the databases contain abstracts and some have a link to the full text journal. This guide shows you how to use this resource.

Click on Books, Journals and Healthcare Databases.

It is possible to conduct a very quick basic search across one or more databases using this page, but you have a limited number of options. An Advanced Search gives you more options and is best for most searches.

Click on the link to the left of the screen for **Healthcare Databases Advanced Search page**.

STEP 4

Using this page will not give systematic results but is often adequate for many purposes. A quick **ADVANCED SEARCH** allows you to build up searches, save searches to re-run later, create limits and limit to date periods, it but does not use the full search functionality available.

Click on Select All, scroll down the page and click NEXT.

To perform a systematic search to support evidence-based clinical practice you need to use the extra limits and index features that are available in a **SINGLE DATABASE ADVANCED SEARCH**.

STEP 5

Think carefully about what you are trying to find out, and break down the topic into its key components. Try following this example through:

Chaplaincy in palliative care for the period 2003 to date

To formulate a search strategy, break the subject down into *palliative care* and *chaplaincy* and begin the search by entering the first term below. Click on **SEARCH**.

The default search field is *Title and Abstract*. If you want to search other fields, select from the drop-down menu to the right of the search box.

STEP 6

You will now see the number of articles that have been retrieved (**Hits**). A number (sometimes known as a set number) will appear in the box to the left of the search term alongside a note of which databases you are working in. This number can be used in

future as shorthand for whatever word or phrase it represents. The results are displayed in **Search history**.

STEP 7

Now enter the second term *chaplaincy* and click on **SEARCH**.

Note: You need to delete your previous search term before entering your second term.

STEP 8

You now need to combine the two terms using what is known as an operator.

AND is the most frequently used operator and will return results containing both of the terms you have searched on but will eliminate results containing only one of your search terms.

To find results which include a combination of both search terms simply click on the select box next to search lines 1 and 2 and click on the **COMBINE SELECTED SEARCHES** button, ensuring that combine with AND is chosen. (Alternatively, you could type **1 and 2** into the search box and achieve the same results.)

STEP 9

You are now ready to limit your search by date. If you were working in a single database, you would be able to limit by other options such as language or type of publication.

In the drop-down menus under **Date Limits** (at the bottom of the screen) add both 'from' and 'to' dates (if you require a single year just enter a date into the 'from' box and leave None in the 'to' box) *and indicate in the search box which search you want to limit* (in this case, 3). Click on **SEARCH**.

You will see that the number of results retrieved is reduced from 77 to 54.

STEP 10

As you have been searching all of the databases, some of the results will be duplicated. It is now time to remove these duplicates. This should be your very last step as you cannot continue to work with a deduplicated set.

Tick the search that you want to de-duplicate and click on the **REMOVE DUPLICATES** button (this may take some time!). You will see that 32 duplicate results have been found and removed, leaving 22 unique results.

STEP 11

You are now ready to show the records that your search has found, by clicking on the number of unique results in the **Hits** column (shown in blue, i.e. 22) to display a list of records on your topic in date order.

STEP 12

The number of titles displayed at a time can be selected by changing the drop-down menu in the **Items per page** box and if you prefer to view your results in a different order use the **SORT** button. You can also view abstracts (where there is one) at the same time as making a selection of results by clicking the **Show Abstracts** checkbox above the results.

Sufficient information is given on this screen to identify the source of any article.

STEP 13

If you want to see the full entry for any particular result, click on the title of the article at the top of the entry.

This option not only gives you the **Subject Headings** applied to the article by the indexer – if you did not find many articles of interest from your original search terms, displaying this entry for an article that looks relevant may suggest other subject headings that you could incorporate into your search – but also additional information not shown elsewhere such as the language of the article and the publication type.

To return to the list of titles, use the **Back** button on your browser.

STEP 14

If there is a link to the full text of the article, click on the supplier's link: 'Available from *ProQuest* in *ProQuest Medical Library'* (or similar). This will display the whole article, which can be saved or printed off free of charge. (You may be prompted to enter your

Athens details again so look for an Athens login if the content is not immediately evident.)

You will also see 'Available in *print* at *Princess Alice Hospice Library'* (or similar) against some of the entries, meaning that we have the original in the library here. **Check**.

STEP 15

You are now ready to select the citations that you want to keep. If you think the article is relevant to your enquiry, use the mouse to tick in the box to the left of the reference. Work your way down, selecting those you wish to keep.

If there are more citations in the set than appear on the page, click on the next number at the bottom of the page to move on to the next references, and so on until you have worked through the set.

STEP 16: PRINTING OFF YOUR SEARCH

When you have worked your way through the displayed references, scroll to the bottom of any page for your options. Select your options:

- The references you have selected are listed under **Results Selected**.
- Leave **Output Format** as it is unless you know better!
- Choose one of the 3 **Display Formats**.
 - **Short** (a brief citation) defaults to this.
 - **Medium** (includes the abstract).
 - Full (the whole record).
- Under Actions:
 - Use Export Results to display, print and save results follow on-screen instructions.
 - Use **Email Results** to send results to a specific email address follow onscreen instructions.

Note: Full text links and library holdings are exported when you print off or email your results, so you will be able to retrieve this information at a later date.

STEP 17: SAVING YOUR SEARCH

In Advanced Search you can save searches to run on a future occasion.

- Use **Delete Selected Searches** to edit your Search history so that only the search steps you wish repeated are displayed. The search will re-run exactly as saved. Once deleted they cannot be retrieved.
- Make sure that you leave all parts of the required search, i.e. do not delete Search number 1 if you later search 1 and 2.

To save the remaining *search strategy* (not the search itself), click **SAVE SELECTED ROWS**.

On the subsequent screen give your search a meaningful name and click **SAVE**.

To retrieve and re-run a saved search, select **My saved searches** from the login box on the left. A list of your saved searches will then be displayed.

Select the one you wish to re-run and click **RUN SEARCH**.

ADDITIONAL SEARCH TIPS

Searching for literature can occasionally lead to unsatisfactory results. There are generally two types of problems that may be encountered:

- too many irrelevant articles in the search results;
- too few relevant articles generated by the search.

In the worked example you only limited your search by restricting the date of publication, but three further solutions to the above problems are as follows:

1. Using phrases

Use quotation marks to search for a phrase e.g. "palliative care". Your results will only contain these terms next to each other, in the order entered.

2. Using alternative terms

The terms you used in the worked example were *palliative care* and *chaplain*. Either or both of these could be replaced with similar or alternative terms to improve the search. Also consider abbreviations and alternative spellings:

- Synonyms or alternative phrases, e.g. spiritual care.
- Terminology may change over time, e.g. terminal/palliative/supportive /end-of-life care.

- Commonly used abbreviations or acronyms, e.g. mdt or multidisciplinary team.
- Differences in UK and US terminology and spelling e.g. dyspnoea and dyspnea.

To search for alternative or similar terms check that the 'Combine with' button is set to 'OR' and click **Combine Selected Searches**. This will give results that include either term e.g. *palliative* or *terminal*.

3. Using wildcards

A wildcard is a symbol that takes the place of an unknown character or set of characters. As some words can appear in different forms, e.g. depressed, depression, depressive, you can use the asterisk * wildcard with word stems so that **depress*** will find **depress**ed and **depress**ive as well as **depress**ion, or **chaplain*** will find **chaplain**s as well as **chaplain**cy.

Phrase searching and wild cards can also be used together.

And finally ...

- Check the Subject headings for further ideas.
- Click on the names of authors to see other articles by this author.
- You can save results temporarily to the clipboard, within your session.
- You can print off your Search history when printing off your search by making sure the appropriate box is ticked (see Step 16).
- On-screen Help does not function yet (as at August 2008).
- Full text holdings are indicated with a link.
- Your librarian should be able to obtain articles from other libraries.
- Remember: librarians are there to help!

Correspondence

Jan is unable to respond to queries about using the National Library for Health.

USING THE LIVERPOOL CARE PATHWAY TO ENHANCE SPIRITUAL CARE IN AN ACUTE HOSPITAL SETTING

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Abstract

The Liverpool Care Pathway (LCP) was developed in the late 1990s in order to transfer best practice for care of the dying from the hospice setting to the acute hospital setting. A team at the Royal Liverpool University Hospital and Marie Curie Centre, led by Professor John Ellershaw, a consultant in palliative medicine, developed the LCP as an integrated pathway of care which provides an evidence-based framework and measurable outcomes of care for the last days of life. The project was awarded NHS Beacon Status in 2000 and was recommended in the 2004 NICE Guidance for Supportive and Palliative Care as a mechanism to be used in all settings to ensure that the needs of dying patients and their families are addressed. It has been incorporated into the National End of Life Care Programme, and the DoH White Paper of 2006, Our Health, Our Care, Our Say: A new direction for community services, which recommended its roll-out throughout the country. At the fifth National LCP Conference, 2007, it was announced that 1,233 organizations within England were registered as using the LCP, with a further 229 organizations registered outside the UK. Therefore, the LCP has been universally embraced as a tool to improve practice in care of the dying. This article will explore how the LCP has impacted on spiritual care in an acute hospital setting.

Key Words

Liverpool Care Pathway; spirituality; care of the dying; palliative care

Main Article

The Liverpool Care Pathway and spiritual care

Speck (2003) explains that the essential components of the Liverpool Care Pathway (LCP) are providing an agreed plan of care and using current research to establish good practice (Ellershaw & Ward 2003). As such, the LCP provides an effective means for ensuring that spiritual care is effectively taken into account. Kinder & Ellershaw (2003) state that the LCP highlights the need to deliver holistic care during the dying phase,

and particularly recognizes those aspects of care that present most difficulties during this phase. The LCP highlights spiritual and religious needs in the initial assessment and then prompts the reassessment of religious and spiritual needs every 12 hours. Marie Curie (2003) describe spirituality as including whatever gives a person meaning, value and worth in their life.

The experience of an acute Trust

Doncaster and Bassetlaw Hospitals NHS Foundation Trust commenced a three-year project in August 2005 to implement the LCP for all dying patients. Funded by Macmillan Cancer Support, the aim of this project was to improve standards of care for patients dying within the four hospitals in the Trust. A full-time project lead nurse and a parttime (one day a week) support nurse managed the project, and now, three years on, the LCP is used widely throughout the Trust. The LCP was introduced to each ward area individually, and the project nurses provided ward-based education regarding use of the LCP. It quickly became apparent that the nursing staff associated spiritual and religious needs purely with religion, and as such often felt uncomfortable about discussing this with patients and their families. This section of the LCP was often left blank.

Review of the literature reveals that it is not uncommon for nursing staff to feel uncomfortable discussing patients' spiritual and religious needs. Kuuppelomaki (2001) conducted a study of 328 nurses and found that almost half of them felt they were poorly equipped in terms of both knowledge and skills to provide spiritual support to patients. Baldacchino (2006) found a number of factors which inhibited the implementation of spiritual care. These included a perception that spiritual care is the domain of the chaplain, time constraints and lack of privacy. Milligan (2004) found that the factors affecting spiritual care were lack of time and inadequate training or experience. McSherry (2006) suggests that barriers influencing the provision of spiritual care are both extrinsic (within the environment) and intrinsic (within the individual). In a hospital environment extrinsic factors might include lack of privacy and a noisy, busy setting; intrinsic factors concern the individual's values and beliefs, and self-awareness of their own spirituality. Chung *et al.* (2007) found that nurses' own spirituality influences their delivery of spiritual care.

In my experience, nurses often confuse religion and spirituality and consider the two to be synonymous. However, I believe that nurses often provide spiritual care without realizing that this is what they are doing. An example of this is a patient who was dying in a side room of an acute medical ward. This patient supported a football club and was a fan of a pop group. Nurses alternated playing videos of his favourite matches and his favourite CDs. These were things that were important to the patient and brought him comfort. Looking through the LCP with a nurse, spiritual and religious care was not documented. When the nurse was asked why this section was blank, she explained that chaplaincy was not involved and the patient did not have any religious needs.

Florin *et al.* (2005) found that patients often identified problems regarding emotions/spirituality that were not identified by the nurses. Hermann (2007) explored the degree to which spiritual needs of patients near the end of life are met. This study found that patients reported unmet spiritual needs. Murray *et al.* (2004) also found that spiritual needs were important and often the source of unmet need for patients and carers. This study found that patients and carers were often reluctant to discuss spiritual needs, as they did not see this as part of a busy health care professional's role. However, when asked open questions or allowed to tell their story, they were able to explore spiritual needs. Stanworth (2004) also found storytelling to be an effective method of recognizing the spiritual needs of dying patients – listening to the patient's experience.

It is clear that patient's spiritual needs are sometimes not recognized as such by ward nurses. Education regarding the use of the LCP has included information about considering spiritual/religious needs more broadly, and exploring what is important to the patient and likely to bring comfort. Carroll (2001) found that the spiritual dimension of care infiltrates all aspects of nursing care. This study suggests that when spiritual care becomes an integral part of care-giving, lack of time is no longer a barrier, as spiritual care is entwined in every intervention. Grant (2004) found that the most common spiritual interventions used by nurses are those that are integrated into daily practice such as touch, listening, laughing, prayer and presence. NICE (2004) recommend four key areas in providing effective spiritual care:

- listening to the patient's experience;
- protecting the patient's dignity;
- affirming the patient's humanity;
- ensuring that spiritual care is offered as an integral part of a holistic approach to care.

At Doncaster and Bassetlaw Hospitals NHS Foundation Trust, during the education sessions regarding use of the LCP, information is provided about spirituality encompassing more than just religion, and this prompts nurses to consider other spiritual needs. Examples of spiritual care interventions are provided to enable staff to think more broadly, such as providing dignity/choice in care, touch, playing music, allowing pets to visit, having flowers from the garden, or photographs of grandchildren at the bedside. Nurses are encouraged to explore what is important to the patient and what brings value to the patient's life. In my experience, nurses feel uncomfortable beginning a conversation about spirituality and are unsure about what to say. Advice is provided about getting to know the patient and listening to the patient's story in order to establish what is important to the patient and what may bring comfort. Often assessing spiritual needs is about listening to the patient's story, and can be achieved by saying, for example, 'Tell me about your mum'. Other helpful questions for staff are: What is important in the patient's life? What brings the patient hope? What gives the patient strength?

The LCP enables more honest and open communication about dying with patients and families. An audit of the effectiveness of the LCP in improving care for dying patients has revealed that since its implementation within the local Trust, there has been a significant increase in the number of patients whose spiritual and religious needs were met during the dying phase. Prior to implementation of the LCP, a baseline review found that only 5% of patients in the dying phase had their spiritual/religious needs met. A recent audit of 388 patients who were cared for using the Pathway found that 63.6% of patients had their spiritual and religious needs met. Therefore, the LCP and the education surrounding it have improved the spiritual care provided for patients in the last days of life. It is recognized that there is room for improvement; indeed, the National Care of the Dying Audit: Hospitals, summary report 2006-2007 (Marie Curie 2007) found that a spiritual assessment took place in only around half of the cases submitted. This indicates that this is an area of care that remains challenging and may highlight a need for further education and training. Locally, the palliative care team continues to work to raise awareness and confidence in talking about spiritual needs. A self-directed learning package is also being developed by a multidisciplinary working group to enable health care professionals to explore the concept of spirituality.

Summary

Spiritual care at the end of life is often associated with religious needs, and as such can be a neglected area of care, as health care professionals find it a difficult subject to broach. Introducing the Liverpool Care Pathway, as a tool to guide best practice for dying patients in a hospital setting, has provided opportunities for education and discussion with health care professionals about what spiritual care is and how to assess spiritual needs. An audit regarding use of the Pathway has demonstrated significant improvements in spiritual care since its implementation; however, it is recognized that there is more work to be done in this area.

Correspondence

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QUALITY OF LIFE IN CHRONIC ILLNESS AND SPIRITUAL CARE: A CHALLENGE FOR CHAPLAINS

Revd John Watts is Team Chaplain at Guy's and St Thomas' Foundation Trust.

Abstract

Chronic illness affects quality of life in many ways. A 12-month pilot programme was devised to monitor physical, mental, social and spiritual aspects of lifestyle among kidney patients on dialysis. The 'Living Well Programme' aimed to see whether a coaching relationship coupled with self-care techniques might result in changes in quality of life. Wider implications for chaplains result if faith and spirituality can be linked positively to improving quality of living during long-term illness. The harsh conditions experienced by all dialysis patients seem to result in spiritual growth for those already belonging to faith groups. Spiritual care in chronic illness offers an exciting challenge to chaplains, but has been little explored. Typically, the request for spiritual care might come from committed faith group members or those who are anxious or distressed; however, chaplains have not typically been expected to offer advice and discuss with a patient how to improve their quality of life. This article looks at how spiritual care might be an important element in improving patient experience in chronic illness and, based on a pilot project at Guy's and St Thomas' Trust, it discusses the implications of chaplains getting involved in this field.

Key Words

Quality of life; chronic illness; pilot programme; coaching; harsh environment; new area for exploration

Main Article

Context: locating the 'Living Well Programme'

The Lifestyle Project began as part of a three-year programme sponsored by Modernization Initiative (part of Guy's and St Thomas' Charity) entitled 'Living Well with Kidney Disease', which included patient consultation and participation. Its aim was to address issues of quality of life and access to 'whole person' treatment across the illness trajectory. The spiritual care team's involvement began when the renal chaplain joined a task group entitled 'Emotional and psychological care for renal patients'. This led to six months of discussion around 'whole person' care and eventually to two work streams:

- a needs assessment of the psychological needs of kidney patients, and the kind of service needed to meet these needs;
- a Living Well Programme that would explore and develop innovative ways of assessing and improving quality of life/lifestyle, focusing initially on long-term haemodialysis patients, where evidence indicated the need was greatest.

The Living Well Programme (LWP) was centred on a 12-point Living Well Plan, a lifestyle assessment tool including physical, mental, social and spiritual dimensions. Spiritual care consisted of 3 out of 12 headings: 'Emotional wellbeing', 'Spiritual growth' and 'Joining a faith group'. Each heading had a time dimension (past, present, future) giving a narrative outline: how has this aspect changed and developed over time? The form was designed to be non-professional, that is, capable of being completed by patients alone, or with help from an LWP coach, a member of the 'Lifestyle' team (any discipline). In practice, as well as an overall lifestyle assessment and coaching tool, this offered a new way in to spiritual care.

Chronic illness: biographical and spiritual issues

Chronic illness affects the whole person. In the literature, Bury's (1982) definition of 'biographical disruption' as the key feature of chronic illness has been influential: it views chronic illness as a disruption to normal living. The problem with this standpoint is that disruption implies restoration: the implicit goal is that the life course must be returned to normal as soon as possible, something which, for many patients, is unrealistic. Charmaz (1991) offers a more realistic model, seeing chronic illness as a progression through adaptation to eventual immersion – illness simply takes over the whole of life.

From a sociology of healthcare standpoint, Frank (1995) offers a thorough survey of many of the published illness narratives and discerns within them three common themes or stages: chaos, quest and restitution. He describes the *chaos* of illness onset, where all predictability and control go out of the window and the patient is disoriented, not knowing what to expect; the *quest* stage is characterized by a searching for meaning: spiritual or biographical – the ongoing pain and resulting suffering needs to fit somehow into the patient's story in a coherent way; the *restitution* stage implies either a return to life as before or, more likely, that a new balance or equilibrium is struck and the illness is managed within a revised, adapted lifestyle and routine.

Many chronic conditions can be treated at home, but kidney dialysis patients offer a particular model of chronic illness that involves visits to hospital or dialysis centre three days a week – a heavy and disruptive treatment burden. Patients range from those working during the day and dialysing at night – a small but very determined minority – to those who are unable to work and have other concurrent disabilities.

At first sight, spiritual issues facing the chronically ill may be thought to be very similar to those in palliative care – loss and limitation; chronic pain; mortality; loss of freedom, lifestyle and social opportunities. But in practice, the climate of care is very different. Maintaining patients with chronic kidney disease is expensive. Renal replacement therapy offers two major options – dialysis and transplantation – but both these options involve long-term drug regimes and regular attendance at hospital. Therefore, the emphasis is on compliance, with patients urged to take an active part in their treatment regimes, medication, fluid intake, diet and so on. These patients are kept incredibly busy and have to devote much time and energy simply to staying alive.

In palliative care the turning point often comes when the goal of clinical cure is replaced by a more holistic palliative regime. Suddenly the patient can relax, priorities change, the focus moves on to quality of life, family involvement and creating opportunities for valued activities. Getting off the treatment treadmill allows a better quality of life. This culture change has not occurred for most chronic patients, who remain treatment- and task-centred, with little space for leisure and recreation. The limit for these patients is reached when the treatment burden becomes too great, and they decide they have had enough.

The Living Well Programme: a response

The Living Well Programme responds to this situation and asks the question: treatment for what? If staying alive is the only goal, then the system needs rebalancing in some way. The NHS spends huge sums on maintaining chronic patients, and in renal medicine these funds are devoted to very expensive clinical care, with little given to psychological, social and spiritual well-being. I believe the palliative care model, now well established in, for example, cancer care, balances things differently and spends proportionately more on therapies, whole person care and quality of life.

In 2007, the LWP pilot in Guy's and St Thomas' Trust began by setting up a whole person assessment process. The available disciplines were counsellor, psychologist, physiotherapist, dietician, occupational therapist and chaplain. Doing whole person assessment did go against the grain of healthcare culture – assessing in someone else's professional areas infringes boundaries. But the LWP tried to represent the patients' own story of how they were doing in physical, mental, social and spiritual areas. The spiritual care team took the lead in 'working outside the box', setting up the LWP framework, doing assessments and offering a coaching role. Ongoing programmes were set up for exercise on dialysis and weight loss. A key early decision was that the physical therapy disciplines must be included in LWP, as renal patients suffer chronic pain, loss of energy and motivation, and poor mobility.

Description of the pilot

The pilot LWP ran from February 2007 to February 2008. It involved 20 dialysis patients and three 'coaches'. The method required coaches to complete 'Living Well' plans with patients and then to review these at three-monthly intervals. This was done during dialysis sessions. At the end of the pilot, a review was carried out to assess:

- what lifestyle targets patients had chosen to work on;
- how successful patients had been in achieving targets;
- whether there were other areas of need the LWP had missed.

The review was completed in February 2008. Its main findings were:

- The main target areas were physical fitness, diet, symptom and pain control. These target areas were seen as 'gateways' to better quality of life; patients could not go out and pursue different interests if they had unmanaged pain and symptoms.
- Another popular choice of target was spiritual growth. Patients with a very limited lifestyle seemed to turn to faith as a vital coping resource; some of the lowest-scoring patients in terms of quality of life had the strongest faith.
- Patients had a low success rate in achieving targets set. The average age was high and many also had secondary disabilities, limiting potential.
- In feedback forms, patients particularly valued the relational aspect of the programme. Although pastoral relationships are bread and butter for spiritual carers, other disciplines also develop strong ongoing personal relationships with clients. LWP aims to harness these for patient benefit via the coaching process.

Spiritual care implications

Many of the participants were faith group members, the majority being black Christians. Because, initially, the main recruiters to LWP were the Spiritual Care Team, we may have gathered a higher than average number of faith group members.

A number of practical issues were expressed. These were:

- inability to attend worship (due to mobility) offers of transport were not forthcoming;
- lack of spiritual resources for those visually impaired;
- onus on maintaining regular prayer and scripture reading discipline fell on individuals;
- little understanding in faith groups about chronic illness the focus was more on 'healing' and 'cure'.

Participants nevertheless expressed resilient faith; many expressed a strong conviction that without faith, they would never have been able to cope with the exacting demands (physical pain and limitation) the illness imposed.

The 'coaching' relationship within LWP altered the normal pastoral relationship between chaplain and patient in a significant way. It opened up discussion of nonreligious aspects, giving permission to discuss, for example, financial or job worries. The stereotype 'religious discourse' of a chaplain visit was to a great extent discarded, usually with positive results, giving a more rounded view of patient experience.

The 'Spiritual growth' target meant the team needed to offer some practical help to meet this aspiration. Chronic illness is in fact a direct challenge to faith. The classic description of this is the biblical story of Job, where Satan wagers with God that Job would lose faith if he lost all he had – family, wealth and health. Job's struggles are a classic expression of the faith struggle that followed, and they culminate in Job being lifted up in the whirlwind, metaphorically removed from the prison in which the illness had trapped him. This highlights the key function of spiritual care, offering the ability to transcend, to 'fly above', to create an opening and a new perspective.

But before he went on his round-the-world flight, Job had to work very hard. He had to re-examine all his most treasured beliefs, all that his life was built on, and to repel attacks on his honour and reputation. What Job needed and used were expressive resources and a solid faith structure, a strong self-narrative, coherence and integrity. He was forced into this faith quest by grinding affliction, loss and bereavement. His emotional labour and spiritual travail were the product of an assertive, resilient and resistant spirituality, not a passive, accepting one.

Next steps

The LWP has, therefore, prompted the spiritual care team involved in the next phase to devise and offer specific spiritual care resources that will assist and enable such faith work to take place. Though these are still in concept form, they can be described in rough outline:

- My Faith Story is designed as a resource that will set down in 20–30 minutes the faith story before and after illness, including any particular crises and turning points experienced. The purpose is to find out how faith changes in response to major disruptions.
- *My Living Well Journey: a pilgrimage through chronic illness* addresses the need for 'faith work' to make sense of the illness experience. Such faith work requires a strong commitment or faith quest on the part of the patient, who may need various resources including scripture, reflection and expressive media.

The key concept behind these resources is the idea of the patient as active agent rather than passive receiver of spiritual care. Just as the fitness and diet components of LWP required major discipline and motivation from patients themselves, so too does the spiritual growth target. It asks for faith work.

The lifestyle programme says to the patient – there is work to do: physical, mental and spiritual. There is physical effort required to lose weight or maintain mobility, to maintain social ties and to preserve time for leisure and enjoyment. A laissez-faire approach is not enough – there has to be coordinated resistance, a strategy, an escape plan; otherwise the illness will just take over. 'I just want my life back', a patient said. Yes, you can have it back – but it will need effort.

The pilot programme suggested that patients are ready to set themselves physical targets – exercise, healthier eating, and so on, so that they might achieve greater mobility and freedom. Bodies that are subjected to regular stress, deprivation, pain and discomfort need looking after, strengthening and refreshing in a planned and coordinated way. But what of the spirit? Does the spirit not get tired, too, as it struggles against limitation and loses the refreshment that engaging in worship and prayer and spiritual experience brings? Is there a special kind of spiritual fitness that can be developed so that the long-term challenges of chronic illness can be faced?

This programme has shown that some patients are willing to use self-discipline, to do exercise and weight loss programmes, and to eat healthier diets to get a healthier lifestyle. In the next phase, we hope to show that they may also be ready to engage with spiritual resources, to help them develop a deeper, long-distance independent spirituality. Instead of the patient passively receiving care, advice and spiritual input, within LWP the individual must do most of the work. The patient journeys alone in the wilderness on a spiritual quest, finding occasional oases and sources of refreshment along the way.

Spiritual care can be like venturing into the dark, responding to the fearful and incomprehensible great unknown. But spiritual care can also be life-giving and life-enhancing. Hospice care broke through the dark, fearful spaces at the end of life and brought light, warmth and laughter. Spiritual care for the chronically ill has to break through the weariness, resignation and unending toil of chronic illness, and bring new life and energy.

Palliative care achieves its aims through concentrating resources and providing a unique caring environment where quality, concern and kindness contribute as much as competence. Spiritual care for chronic illness has to take account of a very different environment: the patient's own life space, the specific needs of the lonely long-distance traveller: a harsh place, a kind of desert, one requiring specific survival techniques. The kind of provision found at the end of life is just not possible here – the time scale involved, months and years rather than days and weeks, means that healthcare provision is spread much more thinly over time.

Might these harsh conditions offer hidden special opportunities for spiritual growth? We can bear witness to great faith among our participants, especially some of the least physically able, but it would be perverse to claim on this basis that chronic illness creates spiritual growth in a cause and effect relationship. Yet where faith is already present, this hard experience might become a magnifying glass, a refiner's fire, testing and refining faith until it becomes tempered like steel.

The feeling of the team who participated in the pilot 'Living Well Programme' described here was of having just scratched the surface. Here is a whole new area of spiritual care, waiting to be explored and mapped out, full of new challenges and opportunities, but with little that is tried and tested in the way of therapeutic

approaches. This article, therefore, has aimed to raise awareness, promote interest and encourage others to participate and contribute.

The full 24-page review of the LWP is available in electronic format from the author.

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A PLACE FOR SPIRITUALITY AND ART IN HOSPITAL

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Abstract

Religious or spiritual space in NHS acute hospitals is generally provided for by the chapel and associated spaces provided for prayer and meditation, sometimes for specific faith groups. Such spaces have a number of functions, including the provision of a more or less private place given over to staff, patients and visitors for quiet reflection. Can such spaces be created in others ways? In this article I provide an account of one kind of alternative: an interactive artwork called *Artnaos* (funded by the Arts Council of England). This piece, created by Sally Sheinman, was placed in five different hospitals, each for a period of approximately five weeks. I describe the development of *Artnaos*, its placement in each of the hospitals, and the kinds of engagement that took place between staff, patients and visitors and *Artnaos* itself.

Key Words: Acute hospitals, interactive art, spirituality, therapeutic space

Main Article

Introduction: a place for spirituality and art in hospital

'Chaplaincy space' might be thought to include most of the Acute NHS hospital. However, the service is most readily and obviously associated with what is generally called 'the chapel'. Even a quick tour of hospitals in a single Trust will suggest that 'chapels' vary enormously from one to another. They vary in size and shape, in height, in decor, and so forth. However, they do have several things in common. First, they are fixed. That is, they are static spaces. Although this might seem obvious, even necessary, I will go on to describe an alternative kind of space. Secondly, they are more or less overtly religious spaces. That is, a typical chapel space is likely to contain items of religious symbolism. The degree to which a chapel is or should be overtly religiously is a moot point, both among chaplains, chaplaincy volunteers, hospital staff and members of the public. Thirdly, the chapel will be a place for sitting quietly (and praying, meditating, hoping, wishing, and so forth). Finally, each of the dozens of chapels I have visited has an aesthetic, although it has to be said that some are more beautiful than others.

Aesthetics has always played a part in the design and furnishing of NHS hospitals. This is more or less obvious both in relation to the building's overall design and also to the use of artwork in and around the building. Art has long been associated with hospitals. During the 18th century, the Age of Hospitals, artists such as Hogarth, Constable and Turner vied to have their work hung in the newly

built or refurbished London hospitals. However, in recent years there has been a blossoming of the arts in health and particularly in hospital. And although much of this art consists of visual art (especially paintings of one genre or another) there is a marked broadening into other areas including environments designed with aesthetic principles in mind, music, interactive and mixed media artworks and so forth. In recent years, many NHS Trusts have appointed a person (called for instance an 'art co-ordinator') to procure and curate artworks in its hospitals. Several bodies have emerged which seek to further the place of art in hospitals (including the charity 'Paintings in Hospitals'). Unsurprisingly, this flowering has lead to a similar increase in the amount of academic writing on the subject. Much of this writing is largely descriptive, but some scholars have made serious attempts to study the effect of artwork in hospital on patients, as well as on those who treat and visit them. There is sufficient evidence to suggest strongly that art in hospitals can have a therapeutic effect on patients. For a review of relevant literature see the report written by Rosalia Lelchuk Staricoff (*Arts in health: a review of the medical literature*, Arts Council of England Research Report 36, August 2004).

In this paper, my aim is to describe and briefly comment on the life and times of a piece of interactive art entitled *Artnaos*, an installation created by Sally Sheinman, a prolific American artist who has lived in the UK for twenty years. I am not concerned primarily with the aesthetic merits of the work but, since the artist's intention was to create an interactive piece, with the quantity and quality of engagement it generated among staff, patients and visitors across five sites. The artist's aim was to place *Artnaos* in five different hospitals for approximately four weeks in each case, and in this she succeeded, with the help of Arts Co-ordinators in each of the relevant NHS Trusts. *Artnaos* was installed in three London hospitals (Hospitals 'A', 'B' and 'C') and two hospitals in the midlands Hospitals 'D' and 'E'). *Artnaos* completed its tour at The Collection, an art gallery in Lincoln where, on November 14th 2007, a seminar took place at which the life of *Artnaos* was discussed. The paper draws on an evaluation of *Artnaos* carried out under the auspices of the Arts Council of England in each of the five hospitals

In what follows I will present Sally Sheinman's aims in creating *Artnaos* before going on to describe the development of the piece and its placement in each of the five hospitals. I will then discuss its reception in each place. After providing some examples of the written 'worries' collected from *Artnaos*, I will conclude briefly.

What is Artnaos?

The principle is very simple. *Artnaos* is a small sanctuary fabricated out of wood. It is a more or less enclosed space in which a person or persons can sit quietly and in private. Inside there is a light. The roof is open. On the outside is a rack with small orange envelopes and blank cards on which one is encouraged to write one's worry – or worries. The card can then be left just above the rack or posted into a perspex box. As we shall see, many people wrote cards. However, rather fewer people seemed tempted to enter *Artnaos*.

The goals of *Artnaos*, as established in the artist's original proposal, were to provide a personal sanctuary, a quiet space which would not necessarily be either religious or spiritual. Sally Sheinman is an artist and her primary concern in creating *Artnaos* was to produce a well-crafted piece of interactive art. She has no expertise in counselling or any academic discipline and was more concerned about the aesthetics, the robustness and the 'workabiliy' of the design.

In my own research on hospital chaplaincies I found that patients, visitors and staff felt that such spaces increase one's sense of well-being. Unfortunately such 'oases' remain all too uncommon in modern acute hospitals. There is, however, a parallel to be made with *Artnaos* and the Chapel, with worry cards and prayer request cards having a similar but not identical function. However, the explicit religiosity of the Chapel can be inhibiting for some people and the provision of more neutral spaces is becoming more common.



Fig.1 Artnaos, as installed in one NHS acute hospital (Photograph courtesy of Cat Stevens)

This is not the first of such installations developed by Sally Sheinman. Her earlier *Wishing Ceremony* was a successful progenitor, and many of the obstacles that might have blighted *Artnaos* were anticipated and therefore avoided by an artist who now has considerable experience in co-ordinating the installation of interactive artworks in public or semi-public places. Before and during the construction of *Artnaos* the artist liaised closely with each of the art co-ordinators in the relevant NHS Trusts. It is clear that painstaking planning is necessary if projects such as this are to succeed, particularly in the health sector where sensitivity to the needs of both individuals and the various

departments is essential. The artist spent more than 12 months planning *Artnaos*. In terms of the delivery of the project, *Artnaos* succeeded in meeting its objectives.

Placing Artnaos

Artnaos was installed in five different hospitals, as planned. In each case, the site was appropriate and facilitated easy access. Considerable thought and discussion was given by both the artist and the arts co-ordinator in each of the relevant NHS Trusts. Each of the arts co-ordinators considered the design of *Artnaos* to be very good. Its structure was robust, the colour, and more generally its aesthetics were described in positive terms. The writers of worries typically indicate a spectrum of responses to the aesthetics of the piece. The fact that there was no roof meant that at one site, occupants of the booth could be seen from above (though probably not identified) from a flight of stairs, but apart from that the booth did provide a very private space. Having said that, three of the sites were extremely busy and this may have put off some people (particularly staff) from entering the booth. It is worth noting that each of the arts co-ordinators were positive about the installation and told me that *Artnaos* (as a material object) was much as they expected – suggesting that the artist had prepared the ground carefully well in advance. The installation has been designed with easy wheelchair access in mind.

I should add, at this juncture, that although four of the sites were broadly similar, the fifth was quite different. The fifth site was a childrens' hospital and the arts co-ordinator, along with other members of the management team decided that *Artnaos* would be best placed in a large waiting room. This meant that there were no 'passers-by' and that those interacting with *Artnaos* were, almost without exception, children. This site was, therefore, considerably different to the other four, and quantitative data is less meaningful in the circumstances. In my discussion below, therefore, I exclude Hospital E from my presentation of quantitative data in that it is not comparable with the other four sites.

Degrees of engagement

Assessing the number and quality of interactions with *Artnaos* was not a straightforward task. By way of preparation I read scholars' accounts of describing and evaluating the interactions of museumgoers and visitors to art galleries with exhibits and artworks. For a number of reasons, including a strong sense that it would not be appropriate to intervene in interactions, I chose to use a method sometimes called direct observation. That is, I sat in the vicinity of *Artnaos* at each site and observed the interaction (and non-interaction) of passers-by with the installation. In this way I collected a great deal of quantitative (numerical or statistical) data and qualitative (non-numerical) data. The first largely involves counting, the second, description. Each type of data needs then to be interpreted. I shall talk about qualitative findings first, then go on to say something about quantitative findings.

How did people react to the presence among them of this 'large greeny-blue box', as one member of staff described it? I might say 'well, in many different ways' but that hardly increases our understanding of the reception of art installations in hospital. After some hours observing the

response of people to *Artnaos* at Hospital A, I discerned what might be called a scale of response, from no response at all (0) to what I first termed 'the full monty' (9), which might be the degree of interaction with the piece which meets the artist's objectives most perfectly. Here is the scale or typology, I developed to describe the response of individuals to *Artnaos*:

- 0: no observable engagement
- 1: maintains pace, glances at Artnaos
- 2: slows pace, glances (gestures)
- 3: slows pace, regards (gestures, comments)
- 4: regards, pauses/stops
- 5: regards, stops, reads information and/or cards
- 6: level 5 *and* writes card (then posts or carries away)
- 7: looks inside Artnaos
- 8: enters the booth
- 9: all actions described in 1-8 above

This typology acknowledges the broad spectrum of responses to *Artnaos* I observed at the five hospitals – from the apparently slight to the apparently great. I say 'apparently' because we cannot easily measure or determine the depth or meaningfulness of such experiences for individuals. The following table provides an indication of the number and type of interactions observed (over a period of about 5 hours in each case).

Level of	Hospital			
engagement	А	В	С	D
1	10	28	22	203
2	3	14	13	15
3	7	2	13	8
4	16	3	21	22
5	17	1	2	10
6	5	2	13	6
7	3	0	0	1
8	6	0	2	1
9	2	2	1	1
Total	69	52	109	267

Table: Degrees of interaction across hospital sites

What is immediately obvious is the relatively small number of type 6-9 interactions, that is, those which involve writing a card. Such interactions involve aspects of decision-making which are hard to fathom without introducing a different kinds of research methods. The high number of 'low level'

interactions which were evident at Hospital D is explicable primarily in terms of the siting of *Artnaos* in the entrance foyer. All of those entering and leaving the hospital passed through a narrow corridor and therefore very close to *Artnaos* and I expected a relatively high proportion of at least minimal interaction from passers-by. However, the fact that a high proportion of passers-by at least glanced at the installation did not lead to more 'worries' being written.

I became especially interested in the nuances of engagement, and particularly with the minutiae of group interaction in relation to *Artnaos*. To cite an actual instance let us consider three women who passed by the installation while I was observing it at Hospital A. They seemed relaxed and chatted as they walked along the corridor until, at about five metres from *Artnaos*, one glanced across to it (on her left), slowing down as she did so; she paused to look more closely and then walked across and began reading the instructions; she look up and called to her two companions and while one stopped and looked back at *Artnaos*, the other continued walking until she disappeared around a corner. Apart from the fact that one stopped to investigate, another paused at the behest of her companion, while another showed not the slightest interest and walked on, in what ways do these women differ? What do such differences in response tell us about people, about art installations, about hospitals?

Apart from the academic interest such incidents arouse, there is also, in each such case, a story, a brief, perhaps non-verbal, narrative which stirs the attention, and sometimes at least the imagination of those involved. It soon became clear that *Artnaos* has the power to provoke; but to understand why some and not others rise to this provocation is not at all easy to understand.

There is a lot more to say about people's responses to *Artnaos* as you might imagine. As an anthropologist, the question that occupied me the most during this project was, 'why do people engage with such installations, or with any artwork?' Of course, many do not engage at all. There may be a number of reasons. First, *Artnaos* stands out, partly because of its prominent position (especially in four of the five hospitals where it stood in the entrance area). Second, its colour – teal is not a hue often employed in NHS buildings – serves to attracts attention. Third, for those who work in a hospital an installation such a *Artnaos* is likely to break the monotony of the physical environment (although this might be less likely in new buildings). Fourth, there are patients, visitors and even staff who may have time to explore what would be, in this environment, a novel space. Finally, and this is especially the case for some staff in two of the hospitals, *Artnaos* focussed attention, for better or worse, on what they see as funding problems in the NHS. Even though a notice indicated that *Artnaos* was funded by the Arts Council of England (and not the NHS), some people took the opportunity to voice their grievances with the NHS through their engagement with the installation. In this later case, *Artnaos* was reconstructed by participants as a symbol for 'all that is wrong with the NHS'.

Why do so may people apparently not engage with *Artnaos*? In the case of staff one answer might be that they do and that I did not observe them doing so. After all, the installation was on site in each

hospital for about four weeks, while I spent only around five hours in observation. It is likely that for some staff, the installation would sooner or later have become a part of the furniture – some passing it on dozens, maybe even hundreds of occasions: familiarity breeds blindness not contempt!

One index of the success of *Artnaos* must be the quantity and quality of written 'worries'. It is interesting that the proportion of cards posted in envelopes and not in envelopes is roughly the same in each case. Over 100 have been collected from each site and more than 600 altogether.

Hospital A	109
Hospital B	147
Hospital C	195
Hospital D	108

On the other hand, no one will be surprised, or especially interested, in the fact that some hospital sites were busier than others. What is particularly worth noting is the proportion of interactions to the number of passers-by:

Hospital A	1:5
Hospital B	1:38
Hospital C	1:27
Hospital D	1:7

So, for example, in the case of Hospital A, one person out of every five passers-by in some way with *Artnaos*, whereas at Hospital B, only one out of every 38 passers-by in some way interacted with *Artnaos*. In a nutshell, then, at the two busiest sites (Hospitals B and C) proportionately far fewer passers-by interacted with *Artnaos*. At the least busy site (Hospital A), a relatively high proportion of passers-by interacted with *Artnaos*. Hospital D is interesting in that it was quite difficult for passers-by not to at least glance at *Artnaos*. However, 'lower level' interactions were comparable with the other busy sites. We can conclude that greater 'traffic' need not increase levels of interaction. My observations at (childrens') Hospital E (where *Artnaos* was situated in a large waiting room) support this point in that a relatively small number of potential interactants gave rise to relatively intense interaction. However, it is also true that the children were waiting for up to 30 minutes or more to be seen by a doctor in the vicinity of *Artnaos* – and may have explored the piece out of sheer boredom. The level of interaction by children with *Artnaos* tended to be high – broadly speaking, they clambered all over it!

Recording and interpreting the 'worries'

I found that the content of the cards posted was very diverse. Although the majority were clearly 'worries' of one kind or another, there was an important second category consisting of notes which could not be easily understood as 'worries'. Numerically, the most common inscriptions concerned

the writer (and especially their health) and others (again, particularly in relation to health) – given that *Artnaos* was installed only in hospitals this is hardly surprising. Also prominent were comments relating to relationships, to work and to personal finances. Most were short and to the point, a few were obscure and hard to categorise. I have provided examples of each of the categories below. First, some 'true' worries, concerning...

self (except health)

I worry about my future. I worry about the responsibilities it holds. I worry that I won't be up to it.

I am lost, alone and confused where am I going and what will become of me??

other(s) (except health)

I'm worried how dad will cope without mum I worry that my boy will turn into the kind of man I dislike

health of self

I don't like having Tourettes because (they) bully me about it I worry that I don't have enough time, patience and courage left. Am I going to relapse and start self harming and stop eating? Am I ever going to feel worthy. I am a flaw.

health of others

I worry about my son's health, my finances and all sorts of minutiae in between all the time. We're worried that we will receive a phone in the middle of the night letting us know that Sylvia has passed away. God bless mum X

advice

Don't be sad it's over, smile because it happened. If you don't want to be criticised, say nothing, do nothing, be nothing.

work/study

I worry that I'm not going to be strong enough to be a nurse. I worry that I'm not going to survive living away from home. But hey, that's what uni is all about!

Bleep bleep testing cardiac arrest crash bleep I need a full response bleep bleep bleep...

I worry that I will keep on feeling pushed around by my manager till I break down.

the NHS

I am worried about the cuts and safety.

I worry that NHS management concern themselves more with 'art' projects rather than making people healthier.

Worry about the future of the NHS and health.

I worry about not enough nurses in the NHS.

relationships

Does he still see her?

My family make me feel like killing myself. I really wish I was dead. Away from them. In peace. I found out my husband of 12 years had an affair 5 years ago... What now? He does not know I know, yes......

reflective (on worrying)

I worry about simple things but not big things weird shit. I'd like everyone to stop worrying about me. I'm always worried. Give me a break!

miscellaneous worries

I am worried that I forgot to defrost the fish for tea tonight.

I worry about the craziness in this world -x.

Time!

I am worried about strting [sic] the juneirs [sic]. Joe

And also, 'worries' that at least appear not to be ...

humour

Is the Hokey Cokey really what it's all about?

religious statements

God said 'Do not worry – look at the birds in the air – they do not worry about what they will eat...

thanks (secular)

I've just had a stoma reversal op. and would like to thank all the staff here at X hospital, also friends, family and God for looking after me. Dee.

comment on Artnaos

I'd feel a bit silly sitting in this but a quiet place for reflection is needed.

This is a great idea. My worries are so many and so heavy that I feel a little less burdened just by writing them down. Thanks.

wishes/requests/hopes/prayers

I hope my son has a good life better than mine. Please! Pray for my wife to passing her English Test this morning so she can stay with her family in the UK. God bless you all.

I wish that someone would see that I am losing my grip. Everything is running away from me. Help me!

miscellaneous

I love my Dog, he loves me never lets me down always there for me. I am excited.

Envoi

Artnaos can be many things: a sacred space, yes, a work of art - of course, but also a diversion, a symbol of wasted opportunity, a playhouse. The responses (whether written down or not) have been diverse, ranging from the sublime to the ridiculous. One participant wrote (of Artnaos) 'What is the point of this?' For the artist, Sally Sheinman, the point is to offer all of those people who find themselves in hospital, for whatever reason, a private space in which to consider their demons. In this it has been entirely successful. For many, there is clearly a cathartic or therapeutic outcome in writing these things down and I'm sure that a psychologist could say a lot more about this process. What has struck me, apart from the huge range of written responses, is the sheer, immediate rawness of some of them. On one card someone had written, 'Does she still see him?' Confronted with such questions, analysis, both impossible and pointless, comes to a full stop. Perhaps the greatest contribution that like Artnaos made was to provide people with the opportunity to distil and confront their gravest fears and celebrate their bravest hopes. It is interesting that one writer compared Artnaos with the hospital chapel, claiming that the former is an impostor. Although the two can usefully be compared, this judgement seems a little harsh. Artnaos, apart from being moveable (an important quality), does not connote institutional religion and is likely to offer a rather different guality of space in comparison with the chapel, which is often set firmly in the Anglican (or at least Christian) tradition.

Hospital design is more and more likely to include a variety of kinds of solution to the problem of providing space for those staff, patients and visitors who wish a moment's peace and quiet, a time to reflect. Hospital chaplaincy facilities play a key role here. *Artnaos* and similar projects provide a different kind of solution.

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THE CRAFT OF SPIRITUAL CARE

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Introduction

Whenever we begin a new spiritual care encounter we undergo a kind of death. The moment of engagement signals death: death (at that moment) to books, to lectures, to questions to mentors, supervisors and teachers: it is too late now for any of that. That kind of death, though, is, of course, also the potential for a new birth, the creation of whatever comes from this new encounter. What we bring to that encounter and how we are with the material of that encounter as spiritual carers is what I want to think about in this paper. I am going to suggest that we think of spiritual care as a craft. And I have chosen 'craft' rather than 'art' for a number of reasons, in particular because 'art' carries too many connotations of 'natural ability' for our purposes.

Currently, 'art' is perhaps too readily associated with the stuff of galleries and national museums. 'Craft' on the other hand includes the everyday as well as those activities that lean more towards art. For example, along with drawing, painting, sculpting, pottery, bookbinding, needlework, we might want to include cooking, gardening, parenting, sustaining relationships, and I would want to add the caring professions, including chaplaincy. 'Craft' has to do with work, labour, toil: the repeated process of coming to the same medium and the same task over and over. It has to do with learning, in the sense of acquiring skills traditionally by apprenticeship; learning through the discipline of watching and copying, acquiring the necessary attention to material and to touch. The apprentice (unlike in the TV programme of that name, which seeks to find a ready-made employee) is inducted into a tradition and goes on to embody that tradition by making it their own, later on bringing in experimentation, trying-out and reflection.

This line of thinking was helped along by a review of a recently published book, *The Craftsman* by the sociologist Richard Sennett. Giving a sense of Sennett's argument, the reviewer writes:

The best craftsmanship relies on a continuing involvement. It can take many years of practice for complex skills to become so deeply engrained that they are there, readily available, almost without the craftsman being conscious of it. An obvious example is the glassblower, dependent on tried and trusted ways of using tools, organised body movements, understanding his idiosyncratic raw materials with a depth of involvement so complete the process of making becomes almost automatic. (McCarthy 2008)

I want to suggest that in similar ways we can talk of the craft of spiritual care. Before that, however, I want briefly to review what we might find of craft in our wisdom traditions – that holistic intelligence of our ancestors that is still available to us.

Cultural and spiritual background

In the Greek pantheon we find Hephaistos, the Olympian god of the crafts. Hephaistos worked at a great forge in a deep cave in the depths of the earth. He brought objects of great beauty out of the dark depths, having heated metals and hammered them at the forge. This is a wonderful image of raw creativity – transformation through the fire of feeling and emotion. Hephaistos carries a wound: he has a club foot and is not known for his own beauty. This is helpful, as this tradition can enable us to see that the wounded craftsperson can create out of their woundedness in a similar way to the idea of the wounded healer (Nouwen 1972).

In the Judaic tradition we have the craft of rabbinic learning and story-telling, the narration of tradition, the narration of interpretation, the weaving of story to maintain wholeness where there is brokenness (we find this continued in the post-Holocaust writing of, for example, Primo Levi). In the Christian tradition we perhaps too quickly gloss over Jesus' formative years alongside Joseph the carpenter. Perhaps there is more to reflect on here, the idea that Jesus learnt a craft, for example; and could we see the disciples, as apprenticed to Jesus, learning to embody love by living alongside and watching the Love of God being crafted in a human being? It is interesting to note that this very model of apprenticeship became established in early Christian monasticism. The fourth-century desert dwellers formed clusters around the more experienced men and women of the desert who nurtured these apprentices/disciples in the craft of prayer (Chryssavagis 2003). Through John Cassian, this wise 'craftsmanship' became the foundation to the Benedictine Rule (where daily work is united with prayer and study) and the Western medieval monastic traditions that of course were bastions of so many medieval crafts.

In the Eastern spiritual traditions we can find a clear relationship of spirituality and craft in the way I am describing. In Indian religious expression in particular the guru–disciple relationship is of great importance, the guru teaching the disciple the crafts of yoga, meditation, devotion, music. The methods of meditation taught in the different

Buddhist traditions also suggest a sense of craft – with the right effort in the right conditions under the right guidance, this inner craft can be learnt. But it is from the Chinese Taoist tradition that I would like to quote as this picks up the relationship of craft and spirituality:

Engraver Ch'ing chipped wood to make a bellstand. When the bellstand was finished viewers were amazed, as though it were daemonic (spiritual). The Marquis of Lu paid him a visit and asked, 'By what secret did you make it?' 'Your servant is a mere craftsman, what secret could he have? However, there is one point. When I am going to make a bellstand I take care never to squander energy on it, I make sure to fast, to still the heart. After fasting three days, I do not care to keep in mind congratulation and reward, honours and salary. After fasting five days, I do not care to keep in mind your blame or praise, my skill or clumsiness. After fasting seven days, I am so intent that I forget that I have a body and four limbs. During this time ... outside distractions melt away, and only then do I go into the mountain forest and observe the nature of the wood as heaven makes it grow. The aptitude of the body attains its peak; and only then do I have a complete vision of the bellstand, only then do I put my hand to it. Otherwise I give the whole thing up. So I join what is Heaven's to what is Heaven's. (Graham 1986: 136)

This might be slightly overstated! I don't want to suggest that we fast seven days prior to offering any spiritual care, but the description of the craft is important because it is a description of a quality of presence that is recognized as absolutely important by the craftsman. I shall return to this.

If Spiritual care is a craft, what is the material and what are the skills of this craft? I want to suggest that the material is what emerges in the field of encounter and the skills are what are honed in one's spiritual practice.

The material: the field of encounter

By the field of encounter I mean the unique socio-psycho-spiritual-physical space that constellates in the one-to-one encounter. I use a simple model of human being and acknowledge its limitation as a spatial metaphor for what is a dynamic inter-related system.

DIMENSIONS OF BEING

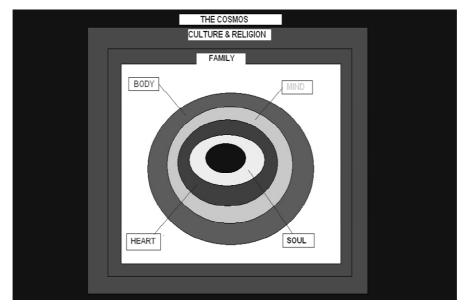


Figure 1: The dimensions of being within the family and cultural containment

The four dimensions of being are shown in figure 1: body, mind, heart and soul. At the centre of the circles is the empty space that also surrounds the total diagram; this depicts the mystery at the heart of all things, the mystery explored in different ways by the natural sciences, by religions, by philosophers and metaphysicians, and by all the world's spiritual traditions. It is the mystery depth that psychology refers to as the unconscious. Diagrammatically, this is an attempt to show the relationship of the inner to the outer, the microcosm to the macrocosm.

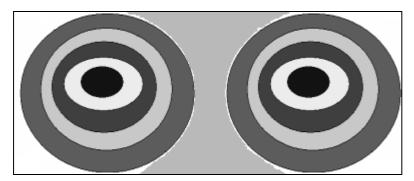


Figure 2: The field of encounter, showing the emergent material within the unique one-to-one engagement

Figure 2 shows the space within the one-to-one encounter; the material that emerges between the two circles is dependent on the craftsmanship of the spiritual carer, the craft of being open to each dimension (body, mind, heart and soul) within the encounter. The emerging material is unique to each encounter as different narratives are brought, different emotions expressed, different somatic manifestations sculpted, and different trails of meaning are found and lost (and thus finding resonance within each dimension of the spiritual carer).

The skills of the craft: honed in spiritual practice

I am going to restrict myself to what is frequently thought to be the core skill in both pastoral and spiritual care – that of listening. I want to think about how as spiritual practitioners we learn to listen. I am using the term 'listening' more broadly than just in the sense of hearing, because I am also using it as a metaphor for what we more colloquially call 'connecting', 'tuning in', 'getting a feel for' the different dimensions of being.

Silence

In any spiritual practice there will be the discipline of attending to silence. In silent prayer or meditation we learn to listen to the dimension of mind – to the chattering of the thought processes that seem to run themselves. If we can listen further in silence we can learn to listen (by engaging feeling) to the heart dimension – drawing closer to our emotional life. If we listen still further in silence, we can find another relationship emerging, that of listening (by letting go) to that interface with the mysterious heart of being as we listen through the soul dimension.

Expressing

In vocal prayer we can become discerning of the movement of the spirit, that which can enable mind articulating heart as we find expressions of yearning for the sick and weary, the oppressed, the very vulnerable; through the heart dimension we can find an empathy of spiritual connection that is more to do with 'suffering with' than with any expression of pity.

Interpreting

In listening to holy texts and recited prayers we can discover how we receive words and learn about our interpreting, which is part of making those words our own. How is it, for example, that we can hear a piece of well-known scripture and find something completely new within it? Listening in this way can teach us to be aware of the interpretative framework we bring to any listening; we might even learn how to let this go.

Attunement

When we are unwell we can learn to listen to the body, we can learn to attune ourselves more carefully to our physical needs and to take this attunement into our well-being – learning to listen to the wisdom of the body, the physical dimension.

Listening

When we face life's problems we can learn to listen to our wounding of heart or soul, for each problem is really an opportunity to discover what trips us up, what interrupts our sense of flow in life, and this will inevitably be an invitation to embrace our personal and collective baggage, to befriend and learn to listen to our shadow (Jung 1953).

Dreams

We might find that we can learn to listen to our dreams, which for millennia were thought to be messages of the soul dimension and which Jung has rehabilitated to a place of spiritual importance with his insight that dreams are the language of the personal and collective unconscious (Jung 1954).

Music

Listening to music will help us listen to rhythm, texture and tone in the one-to-one encounter. While listening to nature, the sounds of the wind, sea, birdsong – and attending to the seasonal rhythms – will help our ability to wonder, which is integral to the spiritual care encounter – to be able to hold a sense of wonder about another human being.

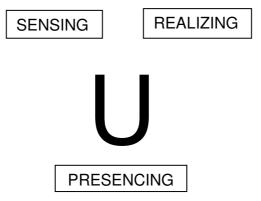
The above are seven ways in which we can hone some of the skills of our craft, skills that are rooted in basic spiritual practice and the cultivation of human awareness. We hone these skills even before we begin any spiritual care work; they are part of our apprenticeship as well as our ongoing development.

Spiritual care: the craft in practice

So how do we put this craft into practice? To remain 'listening' to each dimension in the field of encounter requires the spiritual carer to bring a quality of presence to the encounter, a quality that is entered by undergoing the 'death' I referred to at the beginning – a death to anything that distracts us from the task of attending to the person before us, to the field of encounter and to what is emerging within ourselves through the encounter. This becomes more familiar the more we are able to engage our spirituality within the spiritual care encounter. This I believe has as much to do with the craftsman's 'knack' as it has with 'professional skill'. Consider this passage from Chuang Tzu (with apologies to vegetarian readers):

Cook Ting was carving an ox for Lord Wen-hui. As his hand slapped, shoulder lunged, foot stamped, knee crooked, with a hiss! With a thud! The brandished blade as it sliced never missed the rhythm, now in time with the Mulberry Forest dance, now with an orchestra playing. 'Oh excellent!' said Lord Wen-hui. 'That skill should attain such heights!' Cook Ting replied, 'What your servant cares about is the Way, I have left skill behind me. When I first began to carve oxen, I saw nothing but oxen wherever I looked. Three years more and I never saw an ox as a whole. Nowadays, I am in touch through the daemonic [spirit/life force] in me, and do not look with the eye. With the senses I know where to stop, the spirit/life force I desire to run its course. ... A good cook changes his chopper once a year because he hacks. A common cook changes it once a month, because he smashes. Now I have had this chopper for nineteen years, and have taken apart several thousand oxen, but the edge is as though it were fresh from the grindstone. However, when I come to something intricate, I see where it will be hard to handle and cautiously prepare myself, my gaze settles on it, action slows down for it, you scarcely see the flicker of the chopper – and at one stroke the tangle has been unravelled, as a clod crumbles to the ground.' `Excellent,' said Lord Wen-hui, 'listening to the words of Cook Ting, I have learned from them how to nurture life.' (Graham 1986: 63)

The 'knack' is to be so fully present that we come to rely on what becomes present in the field of encounter, something that is both of ourselves and not of ourselves. In a recent book on organizational learning, this process has been described in a U-shape that moves through the process shown in figure 3 (Senge *et al.* 2005): Figure 3:



Sensing describes suspending judgement to take in as much of the current situation as possible and not to get caught in detail or judgement, bringing a sense of wonder to the situation. In the encounter we move down the left side of the U into the state of *presencing*, which is the spiritual carer's 'knack' I have been trying to describe. In that state of openness new insights emerge and then the task is to bring those up the right side of the U, to *realize* them, for our purposes, to embody them in the lives of the people in the spiritual care encounter.

We could say that in ongoing spiritual care work the U becomes a wavelike process, learning when it is time to move down into deep presencing, when it is time for sensing and when it is time for realizing. There's the knack!

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Reflective Practice - Case Scenario

The following case is based on a real-world situation, although the patient's name has been changed to protect her confidentiality. You are invited to reflect on the case and consider the questions that follow, plus any of your own. The Editor would welcome written responses of up to 500 words, the most interesting of which will be published in the next edition of the *Journal*. If you have a case you would like colleagues to consider and comment on, please submit it (up to 300 words), with questions if possible, to the Editor.

Case study

Maureen had been 'devastated' when she had been diagnosed with oesophageal cancer. She had never smoked or drunk alcohol (both usually contributing factors for her kind of cancer) and, as both parents had lived long lives, aged 74 she felt she should have many more years left to her.

Supported by her husband and two adult children, Maureen accepted all treatments offered, including a stent. However, this had displaced, leaving her only able to tolerate a soft or liquid diet and to speak in a whisper. This later was especially bitter as communication had always been an important part of Maureen's life; having conversations cut-short by coughing, pain or fatigue was very frustrating for her.

On admission to hospice, Maureen was far from ready to give up or die. A well-educated and articulate woman, she had always been a very disciplined, and her need to control her decision making – her sense of self-determination – was central to her sense of identity. The multi-disciplinary team was challenged by Maureen's determination to make all the decisions regarding her medications and care.

Two interventions seemed particularly helpful to Maureen. After several weeks of getting to know her, one of Maureen's nurses took the initiative and offered to pray with her, asking God for 'healing'. Shortly following this, Maureen began to receive regular sessions of spiritual healing.

You are asked to visit ...

Questions to consider:

1. What might be the key spiritual issues faced by this patient?

- 2. How ethical was the action of the staff nurse who offered to pray with Maureen? How would you respond to her action?
- 3. How would you respond to her request for spiritual healing?
- 4. How would you begin to work with her?

An interview with ...

DAME CICELY SAUNDERS OM DBE (1918-2005)

Revd Maureen Turner MA was formerly Chaplain to Myton Hamlet Hospice, Warwick (1998–2001), now Chaplaincy Team Leader of the Jersey Group of Hospitals.

Background

This article is based on an interview with Dame Cicely Saunders that took place in October 2000 when she was aged 82. This originally formed part of a dissertation for an MA in Healthcare Chaplaincy (Leeds). The theme under research was 'the changes and developments of hospice and palliative care'. Dame Cicely, the founder of the modern Hospice Movement, reflected upon the major developments since its foundation and shared her personal views and thoughts. Her lifetime's work and devotion to improve the quality of care for the dying continues to develop and grow today, not only in the UK, but worldwide.

Interview

As a former hospice chaplain I welcome the recently published *End of Life Care Strategy* by the Department of Health (2008). This national strategy aims to improve the provision of care for all adults at the end of life, and for their families and carers. It builds upon the vision and expertise of hospices, specialist palliative care services and newer models of care developed within the NHS and voluntary sector. As the first comprehensive framework in the country that promotes holistic end of life care, its target audience includes, among others, the Primary Care Trusts, NHS Trusts, Strategic Health Authorities and allied health professionals. How we die is now well and truly part of the mainstream healthcare agenda, where the founder of the modern Hospice Movement, Dame Cicely Saunders, always hoped it would be.

One cannot talk about the founding and subsequent development of the modern Hospice Movement without mentioning Dame Cicely Saunders, a legend in her own lifetime. Among numerous awards for her pioneering work, she received the Order of the British Empire in 1967 and became a Dame of the British Empire in 1980. She was a charismatic person who inspired others and was and remains held in high esteem throughout the hospice and palliative care world. James & Field (1992), citing Weber, comment that charismatic leadership was vital to get a new movement off the ground, and that leadership came from Doctor Cicely Saunders, who was 'able to challenge and alter value-orientations'.

She was also a modest person and when she set out on her quest to improve conditions for the dying, she was not aware of the great impact she would make. DuBoulay (1995) notes that, when she opened Saint Christopher's Hospice in 1967, she did not realize that she was starting a Movement; she simply wanted to do something about the poor quality of care given to the dying.

Her selfless attitude, alongside her sense of Christian vocation and medical expertise, influenced others in the medical field. With extensive personal and media appearances, and publications, she became a highly visible leader of the Hospice Movement. Her model of care offered an influential alternative to the dominant model of cure and rehabilitation. In 1990, The World Health Organization defined palliative care as the `active total care of patients and their families by a multi-professional team when the patient's disease is no longer responsive to curative treatment'.

I was privileged to meet with and interview Dame Cicely in her office at Saint Christopher's as part of my MA dissertation, 'Continuity and Change within Hospice and Palliative Care'. I share her personal thoughts and views below.

Original vision

Generally speaking, Dame Cicely was pleased with the way in which hospice and palliative care had developed over the years since its foundation, especially in three areas. First, it had retained its personal concern for the whole family as the unit of care. Second, it was well established as a multidisciplinary specialty with a growing research base. Third, since 1987 it had become a recognized medical specialty, and was respected as such by most of the professionals in related fields.

She made it quite clear that the Movement had to be formed outside of mainstream healthcare provision because there was no other way of developing this new model of care. However, it was always her intention that it should join the existing system at some point:

I didn't set up in opposition or as a critique; I just set up as doing something that needed to be done. We moved out of the old charities ... and the health service because it couldn't have happened and it had to be done separately, but

I certainly did it in order to demonstrate basic principles to move back into the health service. So the aim was that we would promote as well as provide the best possible hospice care because the word 'palliative' didn't really come on the scene until about 1975.

Her original vision was of home care integrated with local hospitals, family doctors and district nurses. In some places this had happened, in others cover was more patchy. Quoting from one of her articles published in 1958, she read:

Patients always rely on their own hospital. It seems best that they should stay at home as long as possible and then go to a home for the dying if and when it becomes necessary. Continuity of treatment by the doctor in charge should somehow be combined with this. One has in mind some form of home care ... with that hospital working in cooperation with the family doctor.

Developing ethos

Dame Cicely founded Saint Christopher's on a medical and Christian foundation, having been influenced by the nuns of Saint Joseph's hospital, with whom she had worked earlier:

I'd started there in 1958. So a couple of years only and I was very impressed by the strength of community of the nuns. But in discussion and so on I realized that it was going to be something quite different ... and I said: 'I think we shall know when we get there.' We've been trying to be some kind of a community ever since, tipping over into failure every now and again, and having a rather transitional period at the moment.

She accepted that hospices in the UK were generally seen as white, middle-class and Christian. But as early as 1960 she had had discussions with theologians, friends and social workers, and gradually the concept was broadened to include other faiths:

The letters that I wrote show how it opened out and widened until we put in our Articles of Association that there should be a chapel available for Christian worship ... and we do avail it for Muslim patients.

When I was talking to our Muslim visitor recently, I said I know sometimes the Asian people don't want to be admitted. Is it because they see us as a Christian hospice or is it because they don't want to look at the idea of death? And he said it's the second. So I think we certainly have a reputation of being Christian but we've also a reputation of being extremely open and you just have to work on that.

It is a Christian imperative to heal, but it's different in India. The Bangalore hospice has got nuns in home care and a thoroughly secular business man who's vaguely Hindu. We're growing more open, I think, as time goes by but there is something special about our God who's actually died and risen again, which gives to some of the Christian staff, even if they never speak about it, something of fundamental support.

Spirituality

Dame Cicely was critical that spirituality in the wider sense of the word was not better understood in palliative care circles. She believed that many healthcare employees found the concept difficult:

I would perhaps use the word 'spiritual' as being wider than the purely more structured 'religious'. I think we need to keep a better look at that whole aspect of which a great many people, particularly nurses and doctors and social workers for that matter, find a difficult area to address.

She commented, in practical terms, on the valuable and informal spiritual care already being done in healthcare settings:

A lot of it is done indirectly. I think some of the things that are happening, like the way care is given, can reach most hidden places and be a spiritual comfort when no words are exchanged, and the creativity of some day centres helps people to see a facet of themselves that they didn't know existed. I think creativity is very much a link with spirituality.

Intrusive surgery

Dame Cicely was not very impressed with the view of some critics that medicalization dominated hospice care to the detriment of holistic care. Her immediate response was brief but profound:

Why should they be in contra-distinction? I mean the medical care should be holistic.

She did not agree that intrusive or aggressive surgery was right for dying patients, unless it would make a major difference to distress:

... if you've got pus under pressure or something like that; if you need a stent put in. That is intrusive, but I wouldn't give that the title of aggressive. But I think that young patients who say that they will do anything with a very meagre chance of success just to stay alive for their children a bit longer, then that's a different scene. ... It could be suitable for that particular person. It has to be decided very much on an individual basis.

She believed in the principle of respecting the autonomy of the patient, provided that they were in a position to give their informed consent. But she added a comment that I, as a lay person, found disturbing – that even when proper communication takes place and patients have all the information they ought to have to make a decision:

A patient doesn't have the autonomy that enables them to demand what the doctor knows is really futile.

Training medical students

Dame Cicely believed that the training of medical or other students in palliative care was essential:

I think the teaching of medical students is probably very well done actually in the wards where they see it going on. ... How you teach medical students in this area is quite an open question. I think they need possibly a visit, but a rather social visit early to see that hospices are lively, living places. Then they need a more structured lecture as they come towards finals and to get a question asked [about palliative care] in the finals. But the real time to meet them is when they're housemen and they suddenly find they have to cope with symptoms and breaking bad news and so on.

Her training method appeared to have inspired students over the years, as she testified:

I was talking to a Japanese medical student who's here on a placement and he's been very inspired by it and thinks he probably will look at palliative care which is very much developing in Japan. There are forty hospice units. There's not much home care because there are no visiting nurses or district nurses in Japan. But then in towns and cities that have tiny apartments, home care would be difficult, but you expect to die in hospital in Japan.

I'm always meeting people who say: 'I heard you talk forty years ago and that's why I'm in oncology', so a one-off lecture can do something.

Multidisciplinary team

Dame Cicely believed that good multidisciplinary team working was essential in providing holistic care. Having herself had a background in three disciplines – nursing, social work and medicine – she could appreciate the differing facets of the multidisciplinary team:

I think each person has their own contribution to make and you must have multidisciplinary team meetings, and the person who knows the patient best might be the physio. I think we tend not to give enough weight perhaps to the tremendous contribution of the social worker. When I've been looking back at the beginnings of my own interests and development of the hospice, the social work input was very important.

As a nurse during the war, when we had none of the drugs that we've got now, we certainly weren't magic lights! We had nothing to offer but ourselves. My social work experience and home visits and some of the writings about social workers in the '50s and '60s were very important in seeing the patients' psychological and spiritual and family pain, so everybody in the multidisciplinary team, including the chaplain has a lot to offer.

She emphasized the importance of good team working:

I think what is important in a team is that you should be as secure as you can be in your own role and be also aware of the roles of the other members of the team. So, to do that in the discussion of patient care is probably the most constructive way. But learning to work as a team and not be threatened by each other is all part of the learning process. There are times when work overlaps ... and there's blurring of roles, and places where things overlap and that's where you have to trust each other.

She believed that hospice staff should be

cheerful and ordinary and prepared to work hard! Sensitive, but not too desperately focused on work as compared to anything else. You need to have something going on for you outside, because if your total life's commitment is only to hospice work that's a dangerous place to be, you've got to be yourself if you're going to be able to help other people. That means you must look to your own development.

Funding

Dame Cicely didn't believe that hospice and palliative care hospitals should be totally funded by government:

Well there's not a hope that it would and I don't think it should. And if working towards 50/50, I think that's probably as much as we should go because what is so important is that hospices belong to their community. The precariousness of our life is a major difference to the difficulties that they have with their reimbursement system, which can be 100% in the States, because they can't do what they want to do whereas we have a freedom. If we were totally funded by government they'd have control on our staffing and on our services and even with 50% they have every right to know what sort of service we're giving. There isn't a hope of being funded totally, but I hope that there will be palliative care going on in every hospital and every cottage hospital that will be funded by Government ... and whether eventually there won't be the distinction, I don't know. It shall be after my time.

The future

Regarding the future of hospice and palliative care, she advised:

Just keep praying! I think the future is that wherever a patient is dying they should be either met by somebody who knows what to do, or by somebody who knows how to call in a specialist, and there should be plenty of literature, plenty of knowledge, that it should be built into a medical and nursing training, and that end of life care, which was completely left out of the Health Service when it was founded, should become part of the commitment of all care.

Dame Cicely died three years ago and, although she did not live to see the launch of the new national strategy, her wish that the unique model of care should move back into the Health Service is now being realized within our lifetime. Her contribution to end of life care will be remembered and honoured by many for years to come. Her own words that appear on the front cover of the strategy are a fitting tribute on which to end: '*How* people die remains in the memory of those who live on.'

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CREATIVE PIECES

In the normal run, marriage blessings and the renewal of marriage vows are celebratory occasions. When they happen in a hospice or palliative care unit emotions are very mixed – happiness for the couple darkened by the realization that the next such family gathering will likely be a funeral. The following 'services' were written for couples in which one partner was terminally ill. In each case, the couple was not particularly religious, but they wanted the chaplain to conduct a service.

A Service of Blessing on a marriage

Name and Name

Already,

you have lived a lifetime together,

you have given more to each other in a few

years than others will give in many,

you have strengthened and upheld each other in hard times,

and you have come to have your relationship blessed. We bless you,

and we ask God to bless you.

Today,

surrounded by family and friends,

you have declared your intention to be for each other,

you have symbolized in the giving of rings the love you hold for each other,

and you have come to have your relationship blessed. We bless you,

and we ask God to bless you.

Ahead,

you who are two are now joined as one,
you have bound yourselves together by
the strong intentions of your promise,
now you belong to each other and are the subject
of each other's hope.

You have come to have your relationship blessed. We bless you,

and we ask God to bless you.

So we ask Almighty God,

the Origin and Source of all our loves,

to hold you,

to nurture you

and to honour your intent.

May the Spring of all desires

fire your hearts with the heats of his eternal passion,

May the Fountain of all joys

flood your souls with the bliss of his eternal peace,

May the Cause of all truths

fill your minds with the knowledge that nothing 'neither the present nor the future, nor any powers, neither height nor depth, nor anything else in all creation'

will be able to separate you from your encounter with the love of God in and through your love for each other.

Amen

A Service of Rededication of marriage vows

Name and Name, we're here because you want to recognize and affirm the gift of love shared between you.

This is a time of pain that has only come about because of the deep experience of love that you have shared together.

You have known each other for many years, and over many years your love has germinated and grown. From that first meeting when you pierced each other's hearts with a simple, captivating smile, your love has flourished and blossomed into a thing of rare beauty; the beauty of your love is evident to those who have nurtured you, and even to those of us who have come to know you only briefly.

And through your many experiences, the roots of your love have deepened, nourished by the deep pools that spring from within both of your very tender souls.

You have given immeasurably to each other, and it is because of what you have shared together that this loss is made so painful.

But what you have shared together also makes this a profoundly loving moment.

Name and Name, as your family and friends, we recognize the gift of love you have given to each other. It is a love that has been meant to be, it is a love that has risen above the sufferings you have shared, and it is a love that will endure beyond this journey.

Name and Name, in giving this simple token of your love,

do you honour the promise you made to each other

to love and care for each other,

in good times and in bad;

do you honour the promise you made

to seek the best for each other in every circumstance;

and do you honour the promise you made

to put each other above all others?

Name and Name: We do

Those of us who have known you, and seen your love together give you our blessing. You have touched us with what you have shared and given to each other, and we are blessed by you. And now we ask God, the source of all light and love and enduring presence, to bless you:

May the Source of light,

who shines in your lives,

surround you in the light of life;

May the Source of love,

who holds you, nurtures you and gives you hope,

continue to keep you in the shelter of his enduring love;

And may the Source of enduring presence,

who binds you to each other and to those who love and care for you,
bless you with the knowledge that nothing

`neither death nor life ... neither the present nor the future, nor any powers, neither height nor depth, nor anything else in all creation'
will be able to separate you from your encounter with the love of God in and through your love for each other

Amen

Revd Dr Steve Nolan

Chaplain The Princess Alice Hospice, Esher

BOOK REVIEWS

Supporting the Child and the Family in Paediatric Palliative Care

Erica Brown with Brian Warr Jessica Kingsley Publishers, London 2007 ISBN 978-1-84310-181-9; 304 pp. £22.99

Approximately 15,000 children and young people under 20 die each year. Some 1.5 in 1,000 children between birth and 19 years are likely to have an illness from which they will die prematurely. Public perception of child mortality is that it is remote, whereas to those concerned it is a stark reality. The authors of this important book address an under-researched and sensitive area of concern.

This is a wide-ranging handbook, which covers pre- and post-death issues for children with life-limiting conditions, and the needs of their families and carers. Most of the chapters are written by Erica Brown, who is Head of Research and Development at Acorns Children's Hospice, Birmingham. Brian Warr is Director of Care at Acorns.

The scope of the book is excellent, including chapters on continuing bonds, siblings and grandparents. The chapters are well structured with 'Key Points' and 'Implications for Practice' at the end of each chapter. Chapter 10, 'The Child's Developmental Understanding and Emotional Response to Death and Dying', is very useful for all working with dying children and their families. There is a chapter on 'Religious, Cultural, Secular and Spiritual Aspects of Care': Christianity, Judaism, Islam, Hinduism, Sikhism and Buddhism are covered. The authors acknowledge that there has been scant attention to cultural and religious care in existing literature and that further research is needed. There is a chapter on funerals and ways of honouring the memory of the child. Some powerful stories are told within a basically analytical approach.

The sequence of chapters is odd at times: 'The Education of the Life-limited Child' comes after 'Post Mortem, Organ Donation and Tissue Retention' and the child's funeral before counselling support. Understandably, this book focuses mostly on the sharp end, but there is perhaps more to be said about the things that enhance the quality of life, including the role of 'wish' charities.

The book is strongly recommended to anyone who may be accompanying a child and their family on the journey to death, and its thorough referencing and list of useful websites offers the reader plenty of opportunities for further reading.

> Revd Nick Ball Church of England Chaplain Birmingham Children's Hospital

Design for Nature in Dementia Care

Garuth Chalfont Jessica Kingsley Publishers, London 2008 ISBN 978-1-84310-571-8, 176 pp. £19.99 (paperback)

Garuth Chalfont has organized his book into two parts. Part 1, Nature Indoors, contains three chapters: 'Living with nature', 'Nature-based activities' and 'Ethical issues concerning nature indoors'. Part 2, Nature Outdoors, contains four chapters: 'The natural world', 'Activities outdoors', 'Ethical issues concerning nature outdoors' and the summary.

This is an artificial division, simply a convenient means to organize the information. Each chapter ends with a list of suggestions for implementation from three perspectives: the person with dementia, the social environment and the physical environment, and is followed by a brief take-home message.

Chalfont concludes by saying:

The reason for writing this book was to demonstrate the benefits of nature, and to inspire care practitioners to think about their practice in a new way – a way that will result in an improved quality of life for people with dementia. But I want to end by stating that I don't believe nature to be a benefit: nature is a human right. To live without access to it is to live dislocated from our most primitive and essential humanity.

Designing therapeutic environments for people with dementia has no strictly architectural solutions. It is not realistic to hope that the design of gardens and outdoor areas alone will adequately address the complex needs of those we intend to use them. Where solutions lie is in relationships between architects, those writing the regulations and those implementing them, those caring and those being cared for; relationships between people with dementia and people without. Whether we are designing a porch or planning someone's day, design is not something that can be imposed, but is something that becomes manifest. Along the edges where difference meets, design is not built, but grown. And therein lays the potential for beauty. (p. 155)

This book is written to help understand and care for those in the early stages of dementia. However, those who have no previous insight or experience of dementia may

find the book helpful, while those who already have experience in this field may find it rather elementary.

I don't think it gives enough practical advice for carers looking after loved ones while maintaining their employment. The book is very idealistic in its approach: actually caring for people with incontinence, wandering and confusion is not dealt with effectively, and there is no mention of social services and what support is available.

> Graham Reaper-Brown Chaplain Sherwood Forest Hospitals NHS Foundation Trust King's Mill Hospital

Working with Adult Abuse: A Training Manual for People Working with Vulnerable Adults

Jacki Pritchard Jessica Kingsley Publishers, London 2007 ISBN 978-1-84310-509-1, 413 pp. £50.00

While the issues of child abuse have been taking centre stage for some years now, awareness of the problem of the abuse of vulnerable adults is comparatively recent. And just as the problem of child abuse took far too long to be acknowledged, so has the problem of the abuse of vulnerable adults. Jacki Pritchard's book aims not only to raise awareness of the issues of adult abuse, but also to provide a training manual for those who may encounter it through their work. To quote the author: 'People do not naturally think about an adult being abused; ... Therefore it is vital that awareness about adult abuse is raised not only within society but also amongst everyone in a work situation who may come into contact with a vulnerable adult' (p.15). Pritchard takes her definition of a 'vulnerable adult' from the Stationery Office's publication, *Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults* (1997). It is a person

who is or may be in need of community care services by reason of mental or other disability, age or illness; and who is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation.

This is a very practical book. Pritchard does not spend unnecessary words arguing the case for the awareness of adult abuse; she is far more concerned that those whose roles and professions involve the care of vulnerable adults are thoroughly well trained in all aspects of their work. While the manual has been primarily written for those responsible for training a wide range of professionals – domiciliary care workers, the police, healthcare staff, social workers, volunteers and even NVQ assessors – it is also a useful resource for anyone in these professions to read for themselves. It can stand alone or be used in conjunction with a series of videos, which Pritchard has directed and produced.

As a resource for trainers, it has been very well thought out. Each chapter includes a short discussion of the topic under consideration, case examples, key questions for group discussion or individual reflection, and handouts which can be photocopied for participants and/or used as OHP slides. In addition there are suggestions for experiential exercises, case studies and role-plays. Pritchard has used symbols throughout the manual so that each of these training resources can be identified at a glance (very helpful for preparation!) and has also included a short glossary of terms used in the manual to avoid confusion in terminology. Each chapter includes a short list of suggested reading for participants, and there is a comprehensive index and bibliography at the back of the book.

The chapters cover a good range of topics relevant to those working with vulnerable adults. They include, amongt other topics, chapters on defining and recognizing adult abuse; how to handle disclosure sensitively and what to do if abuse is suspected; reporting and investigating abuse; assessing risk and formulating protection plans; the why and how of record-keeping. There are chapters specifically focusing on working with the abuse of older (i.e. elderly) people, of younger adults who are vulnerable by means of mental or physical impairment, and the abuse of black and ethnic minority people. However, while she consistently emphasizes that all service users should be treated equally regardless of age, gender, race, culture, religion, sexuality and disability, there are no sections specifically about abuse on the grounds either of religion or of sexual orientation.

As a trainer, psychotherapist and someone who works with vulnerable adults, I thoroughly recommend this book. It is comprehensive, easily accessible for trainers and participants alike, practical, and suitable for both beginning and experienced professionals. Experienced trainers will be able to use some of the exercises and case examples as 'jumping-off points' for their own training courses. One caveat I would include, however, is that there is no warning about the effects that role-plays can have on participants, and no specific techniques for debriefing afterwards. However, this is a very small criticism of a very important and useful book.

> *Revd Christine Wood* Chaplain Rampton Hospital Nottinghamshire Healthcare Trust

BOOKS AVAILABLE FOR REVIEW

Extreme Parenting: Parenting Your Child with a Chronic Illness

Sharon Dempsey Foreword by Hilton Davis Jessica Kingsley Publishers, London, March 2008, ISBN 978-1-84310-619-7, 208 pp. £13.99 (paperback)

Grief in Children - A Handbook for Adults

Second Edition Atle Dyregrov Foreword by Professor William Yule Jessica Kingsley Publishers, London, March 2008, ISBN 978-1-84310-612-8, 208 pp. £14.99 (paperback)

Ageing, Disability and Spirituality.

Addressing the Challenge of Disability in Later Life

Edited by Elizabeth MacKinlay Jessica Kingsley Publishers, London, February 2008, ISBN 978-1-84310-584-8, 272 pp. £19.99 (paperback)