Introduction

WHY BOTHER? DOES IT REALLY MATTER?

Peter Wells

Peter Wells is Lead Chaplain at the Royal Sussex County Hospital. He was previously a hospice chaplain and Head of Allied Health Professionals. He has been involved in teaching how to support patients and their spiritual needs to medical students and nursing staff, as well as non-clinical staff who support patients. His experience has led him to believe that if the staff in healthcare can ask patients about what gives their life meaning and purpose, this brings the staff much richer information in caring for the patient, and lets the patient know that their needs are being taken seriously. Peter is an Anglican priest, honorary Canon of Chichester Cathedral and an accredited sex and relationship therapist and supervisor with COSRT.

The briefest of online searches will uncover a wide range of books and articles on patients requiring healthcare services and their religious needs, as well as the religious influences and rituals at various stages of healthcare, and the role of the chaplain in facilitating the religious needs of both patients and staff. As not everyone is religious, this book takes a much broader look, and aims to provide those who work in healthcare with a 'window' into trying to support the spiritual needs of patients, and how a wide variety of clinicians aim to support their patients in both body and soul.

Anyone who needs to use any of our healthcare services knows how busy they can be and how long it can take to be booked in for an appointment and then wait for further appointments. When the appointment comes, patients can be anxious that there will be so little time that they will not be able to discuss everything they want to because the clinicians will have many other people to see. There can surely only be time to talk about one or two issues and then out or on to the next

clinic. In such a pressurised scenario why would you be able to talk about anything other than the body, and does anything else matter?

When young, I always remember older members of my family saying, 'you should never talk about sex, politics and religion; they are personal and private matters'. This led to the feeling that these must be very important issues to be kept secret. Alas, this means that there is no one you can talk to about such issues, and no one will want to talk to you about them either. You are on your own! Maybe I felt the call to be a cleric so that I would find out some of the answers and find others to talk to. As for the other two issues…?! Over the years social attitudes have changed, and the internet and social media now make every subject available, with a vast amount of information and debate, some very helpful, others very unhelpful.

Even in the 21st century there is, for some, a lingering notion that such issues as religion are still very personal and should not be discussed or mentioned. Add this notion to the reports of healthcare professionals seemingly imposing their personal beliefs on to their patients, and asking patients about anything other than physical symptoms is no easy task. Addressing the needs of the body and soul can be complex, and some healthcare professionals might consider that the needs of the body should be addressed by some healthcare professionals whilst the soul is attended to by other healthcare professionals. This division might be helpful to some, but how helpful is it to the patient, and to the healthcare clinician who regards patients as whole people? The division is really unhelpful and an anathema to providing holistic healthcare.

The years of being involved in healthcare have taught me that spirituality is much wider than religion, and that the body is more than the physical as it has a soul – all of which together are greater than the sum of their parts. Our journey through life is a composite one, made up of many elements interacting and reverberating with those around us, with the past, the present and our thoughts for the future. I know that spiritual care is not the preserve of the chaplain alone, and I know that clinicians trained to focus on the physical or mental have a great appreciation of their patients' stories and needs, their spirituality.

Both body and soul, both patient and clinician, need help in coming together to provide as much information and support as possible whilst someone requires healthcare services.

I wanted to give clinicians the chance to tell their story as to what they believe about body and soul. How do they engage with their patients in order to bring together their physical and spiritual needs? What I knew as I began to approach clinicians was that I was asking the converted! When I asked doctors, nurses and a radiographer to write about the way they work, most replied, 'I just do the job. I have never thought about how I do it.' My experience of them as clinicians, and their reputation, is that they, along with many others, are not just 'doing the job' of responding to physical symptoms but in many subtle, and sometimes not so subtle, ways, they are finding out the impacts on their patients' symptoms that can be regarded as spiritual and why it matters to find out. Due to a variety of expectations and interpretations, both within healthcare and without, the finding out is not easy.

Why bother with the 'spiritual' issues in healthcare when you have a chaplain?

My experience of meeting a broad cross-section of people in various healthcare settings is that when people need to access healthcare, whether needing an appointment with their general practitioner (GP), getting admitted to hospital following an acute episode or for an elective procedure, several things can happen:

- they are not in control of what is happening to them
- they hear and see a lot that they do not understand
- they can have a lot of time to think about life and what might happen
- they have a lot of time to mull over what is important in their lives, and what matters to them
- they write a story in their mind as to what is happening to them, their loved ones, their life

- questions and queries can begin to surface that they had not considered before.

As these can lead to questions and concerns as to what is important in life, and about existence and mortality, I regard these issues as being spiritual and not necessarily religious. There may or may not be a religious context, but this would be dependent on whether the individual had a religious affiliation or not. They are certainly issues that can have a profound impact on how people make decisions about their healthcare and how they view life, which is spirituality at its heart.

If a patient is experiencing these issues whilst they are seeing their healthcare clinician, this could provide valuable information in responding to the physical and/or mental symptoms that the patient presents with. The General Medical Council (GMC 2013) has already established the need to include these issues:

> 15. You must provide a good standard of practice and care. If you assess, diagnose or treat patients, you must:
>
> a) adequately assess the patient's conditions, taking account of their history (including the symptoms and psychological, spiritual, social and cultural factors), their views and values; where necessary, examine the patient
> b) promptly provide or arrange suitable advice, investigations or treatment where necessary
> c) refer a patient to another practitioner when this serves the patient's needs.

And in nursing care in 2010 the Royal College of Nursing produced *Spirituality in Nursing Care: A Pocket Guide*, in which it is stated:

> The Nursing and Midwifery Council expects newly qualified graduate nurses to be able to: 'in partnership with the person, their carers and their families, make a holistic, person centred and systematic assessment of physical, emotional, psychological, social, cultural and spiritual needs, including risk, and together, develop a comprehensive personalised plan of nursing care.'

On the NHS England website, in the section entitled 'NHS Chaplaincy Programme', it is set out clearly why asking about spirituality and religion is necessary to patient care:

> The NHS Chaplaincy Programme is part of NHS England's drive to ensure good patient care and compliance with policy and legislation:
>
> - Compliance with the legal duties in the Equality Act 2010 – ensuring due regard to the protected characteristics on religion and belief.
> - Compliance with the NHS Constitution Principle 1 of ensuring comprehensive service for all irrespective of gender, race, disability, age, religion, belief.
> - Compliance with NHS England's business planning for 2013–14 'Putting people first' Priority 8 in promoting equality and reducing inequalities in health outcomes and the Five Year Forward View on Empowering Patients and Engaging Communities.
>
> (NHS England 2015a)

Chaplains have written a number of books about spiritual care. This book doesn't look at the role of the chaplain, but at how clinicians working in various disciplines of medicine define for themselves what is 'spiritual' and how relevant they consider it to be, and how they elicit from the patient information that can inform the clinician as to what is impacting on the patient's symptoms and how they can respond to the whole person. It can, however, be confusing to know what is meant by 'spirituality'.

Who defines what is spirituality?

However we might describe the process, some words keep on developing, evolving or changing, and 'spirituality' is one of those words. At times it seems that whomever you talk to has a different definition. In what follows are just a few examples of the current debate as to how some

organisations and institutions define what they mean when they use the term 'spirituality'.

NHS ENGLAND

In 2015 NHS England produced revised guidance that was first published in 2003. In the document entitled *NHS Chaplaincy Guidelines 2015: Promoting Excellence in Pastoral, Spiritual and Religious Care*, the following is stated:

> *Spiritual care* is care provided in the context of illness which addresses the expressed spiritual, pastoral and religious needs of patients, staff and service users. These needs are likely to include one or more of the following:
>
> - ways to support recovery
> - issues concerning mortality
> - religious convictions, rituals and practices
> - non-religious convictions and practices
> - relationships of significance
> - a sense of the sacred
> - exploration of beliefs
>
> It is important to note that people who do not hold a particular religious affiliation may still require pastoral support in times of crisis.
>
> *Religion or belief* is as defined in the 2006 Equality Act: (a) 'religion' means any religion, (b) 'belief' means any religious or philosophical belief, (c) a reference to religion includes a reference to lack of religion, and (d) a reference to belief includes a reference to lack of belief. (NHS England 2015b)

ROYAL COLLEGE OF PSYCHIATRISTS

Psychiatry and spirituality have not always had an easy relationship, but in recent years the Royal College of Psychiatrists has had a Spirituality and Psychiatry Special Interest Group. On the College's website is the following:

> What is spirituality?
>
> There is no one definition, but in general, spirituality:
>
> - is something everyone can experience
> - helps us to find meaning and purpose in the things we value
> - can bring hope and healing in times of suffering and loss
> - encourages us to seek the best relationship with ourselves, with others and what lies beyond.
>
> These experiences are part of being human – they are just as important to people with intellectual disability or other conditions, such as dementia and head injury, as they are in anybody else.
>
> Spirituality often becomes more important in times of emotional stress, physical and mental illness, loss, bereavement and the approach of death.
>
> All healthcare tries to relieve pain and to cure – but good healthcare tries to do more. Spirituality emphasises the healing of the person, not just the disease. It views life as a journey, where good and bad experiences can help you to learn, develop and mature. (RCPsych no date)

And to reflect that it is not only in healthcare that there are different interpretations, two non-healthcare examples follow.

ROYAL SOCIETY OF ARTS

In 2014 the Royal Society of Arts (RSA) produced a report entitled *Spiritualise: Revitalising Spirituality to Address 21st Century Challenges*. The report argues for 'reimagining' the spiritual in four ways, one of which is:

> Spirituality is ambiguously inclusive by its nature and cannot be easily defined, but at heart it is about the fact that we are alive at all, rather than our personality or status it's about our 'ground' in the world rather than our 'place' in the world. It is possible and valuable to give spirituality improved intellectual grounding and greater cultural and

> political salience. The primary spiritual injunction is to know what you are as fully and deeply as possible. (RSA 2014, p.7)

Another way the RSA report aims to reimagine the spiritual is:

> Spirituality struggles to differentiate itself from religion on the one hand, and wellbeing on the other… Our inquiry led us to four main features of human existence that help with this process, and unpack what it means to say the spiritual is about our 'ground' not our 'place':
>
> - Love – the promise of belonging
> - Death – the awareness of being
> - Self – the path of becoming
> - Soul – the sense of beyondness.
>
> (RSA 2014, p.8)

In attempting to define spirituality, the RSA report quotes Sheldrake's definition:

> Spirituality is a word that, in broad terms, stands for lifestyles and practices that embody a vision of human existence and of how the human spirit is to achieve its full potential. In that sense 'spirituality' embraces an aspiration approach, whether religious or secular, to the meaning and conduct of human life. (2012, p.17)

AN EXAMPLE IN THE UK NATIONAL PRESS

On the 500th anniversary of the Christian Reformation in Europe in 2016, *The Guardian* newspaper published this opinion:

> The great question confronting Europe now is whether the values of liberal democracy can sustain themselves. Through the fat years when religion faded it seemed that an appeal to reason and self-interest was enough. In the age of Trump, of Brexit, and the Polish Law and Justice party it is obvious that it is not. Emotion and imagination are needed

> too, and these are the qualities that make up spirituality. Without a belief that human rights are a way of talking about objective reality, and that morality – however disputed – is a matter of fact and not of preference, the web of trust and decency that holds our societies together could be ripped to shreds.

The following example is from a chaplaincy perspective.

UNITED KINGDOM BOARD OF HEALTHCARE CHAPLAINCY

In 2009, the United Kingdom Board of Healthcare Chaplaincy (UKBHC) created a set of *Standards for Healthcare Chaplaincy Services*. In the document UKBHC use the following definitions:

> Spiritual and religious care
>
> - Religious care is given in the context of shared religious beliefs, values, liturgies and lifestyle of a faith community.
> - Spiritual care is usually given in a one to one relationship, is completely person centred and makes no assumptions about personal conviction or life orientation.
>
> (UKBHC 2009, p.4)

The UKBHC definitions have been adopted and adapted by various NHS Trusts. At Brighton and Sussex University Hospitals NHS Trust the following adapted version is used in the Trust's *Religion and Belief Policy*:

> *Spiritual care* is completely person centred and makes no assumptions about personal conviction or life orientation and focuses on whatever belief animates or gives their life purpose which may or may not include a god.
>
> *Religious care* supports patient choice regarding beliefs, rites and cultural traditions which are practised by specific groups. (2015, p.3)

My personal working interpretation endorses the above, but I am keen that there is a dynamic element to spirituality that is about movement and action.

Spirituality is whatever animates someone, giving their life meaning and purpose that transcends and permeates the essence of who they are and motivates their actions. This may or may not include a belief in a god or gods, but impacts on how they respond to life's events.

Religion is whatever binds a group of people together in their doctrine, dogma and beliefs to a god or gods. These doctrines, dogmas and beliefs should animate and thus combine the religious with the spiritual.

How people live out their understanding of spirituality and religions varies widely. My experience has been that for many people who have a religious affiliation, their faith forms and informs their spirituality and they would not differentiate one from the other. There are also people who have a religious affiliation and sit lightly towards some, or many, of the practices and dogmas, but who hold on to the tenets of the faith that their religion is based on. This leads to people claiming the same religious affiliation but living it out in a different way, which means that assumptions should not be made that all people who claim the same religious affiliation will live it out in the same way. There are also a large number of people who would not describe themselves as religious but who do believe in some form of 'divine' presence, and for whom such beliefs are very important but who find it difficult to articulate out of concern to not appear disrespectful or non-committal. There are also religious people who understand the doctrine and dogmas as to what binds them together but alas, the beliefs do not animate them or permeate their lives. People who regard themselves as spiritual and not at all religious will often comment, in a halting and guilty way, that they are not sure what they do believe, but that they do believe in something. People cannot always be put into neat boxes as to what they believe. Asking people about their spiritual and religious needs is not a straightforward tick-box question, but for ease, that is how it often ends up.

So how do we ask about spirituality?

Given the above, it is not at all surprising that many clinicians can find it complex and confusing to ask patients about their spirituality because of the range of definitions and answers that could be given. Unlike other areas of patient care such as pain relief or toileting requirements, there is no set protocol as to how to ask about spiritual or religious needs, and no guidance, matrix or algorithm as to what to do with the response. This can easily lead to the scenario: if you do not want to know the answer, it is best not to ask the question.

The clinicians who have contributed to this volume have found ways to be with their patients in order to find out about what they, the patient, regard as being spiritual, and to use the responses in how they treat their patients. The clinicians know why they bother – because it matters to find out.

How to use this book

Each of the contributors was given the opportunity to write in their own personal style so that they could write from their own very personal experience and reflection. You will find that there are repetitions of references and quotes, and you will find very distinctive and individual styles of writing. You might want to read the book from cover to cover, or you might want to select specific chapters. Either way, you will find a rich diversity of opinion, approach and practice.

Bobbie Farsides lectures in ethics at the Brighton and Sussex Medical School, and is responsible for the training of future doctors, and here she helps us think about the responsibility that professionals have to find out about their own spiritual concerns as well as those of their patients. Many people requiring healthcare will first present to their local GP, and Jo DeBono describes how important it is to find out from patients more than just the physical symptoms, and how these inform what is going on for the patient. Many other people will present with mental health issues, and Tim Ojo and Andy Nuttall, who work in the discipline of

mental healthcare, help us understand that for their patients the issues are not physical, and that patients often present as broken spirits.

As a gynaecologist, Peter Larsen-Disney tells us that caring for the whole person is the key to care. This is reflected in Cathy Garland's experience as a neonatal consultant who focuses first on the needs of the baby, but always wants to include parents' needs and what is spiritual to them in order to help the whole family unit. Somnath Mukhopadhyay is chair of paediatrics, and demonstrates the expertise that is required when seeing patients, but also the frustration of not having enough time to explore all their and their families' needs, as he knows this would really help.

Pat Shields offers a frank view of her work, believing it to be difficult for patients who may feel shame and embarrassment to express what is really important to them in order for the clinician to care for them and they for themselves. Patients living with dementia often cannot tell us what is important to them: Muna Al-Jawad's chapter on spirituality and dementia care starts from her view as an atheist, and leads us through her work with patients and teaching with doctors, using her own cartoons and the concept of autobiofictionalography to describe how she cares for her patients.

Caring for patients when there are difficult decisions about which treatment option to choose, which one might be most appropriate for body and soul, is discussed by Adam MacDiarmaid-Gordon in his work with renal patients. Another group for whom it can be difficult to find out what is important, and therefore what the most appropriate way forward might be for, is stroke patients, for whom communication is often not at all easy. Nicola Gainsborough and her team run a stroke unit, and whilst time is of the essence, taking time is also important, and thus staff must be flexible and adaptable to the needs of their patients. The unit completes a form about the needs and wishes of every patient, a copy of which is included at the end of this chapter, which helps to highlight what is 'spiritual' to the patient.

Using forms and assessment tools can be useful for patients who are at the end of life, but as Nigel Spencer and Rachel Reed discuss in their

conversation about caring for patients at the end of life, it is so often our own experience and attitude that can give patients and families the ability to talk and share what they regard as being spiritually helpful as life is ending.

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