

HANDBOOK

An Invitation to Chaplaincy Research: Entering the Process

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*Creation of this important new tool to assist
professional chaplains who want to be involved in
research was supported by a grant from*

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Preface

Whenever a professional group creates a groundbreaking book, it does so in order to affirm the history and traditions of the profession as it charts innovative and often necessary new directions for its future development. *An Invitation to Chaplaincy Research* explores how the profession, through research, may establish vital links between the time honored value of chaplain caring practices with the growing expectation that healthcare providers demonstrate the value of their practices.

This book is both invitation and challenge to the profession to contribute to the growth, effectiveness, and longevity of chaplaincy by increasing its research literacy and by supporting or participating in research opportunities. For a mix of reasons, empirical outcomes research has not been an inherent part of chaplaincy and to some it may seem incongruous with the heart and intent of chaplains' caring practices. We understand that many of us, having been informed by the content and methods of theology and the humanities rather than more empirical fields of study, may find the inclusion of research in the chaplain's portfolio to be a challenge and in some cases even an imposition. With this in mind we have tried to address not only the exciting possibilities of chaplaincy research, but also the concerns and obstacles that could discourage chaplains from exploring the role of research in patient care and chaplain education.

We wish to highlight some aspects of the development of this book. Creation of *An Invitation to Chaplaincy Research* would not have been possible without both the tangible and intangible support of the John Templeton Foundation. By awarding HealthCare Chaplaincy Network a grant to support research and the writing of this book, the Foundation has made it possible to invite established innovative researchers and authors from the fields of chaplaincy, medicine, psychology, and sociology to write a truly interdisciplinary text that expressly focuses on chaplaincy research. The topics for the chapters emerged from a sustained dialogue between chaplains and other researchers. A distinct feature of the book is its engaging narrative style. Realizing the importance of story and accessibility, the writers frequently use personal experience and clinical examples to create a narrative that engages readers in a "story of research."

Readers of this text will: increase their research literacy, share the personal journeys of chaplains into research, identify strategies for joining research projects, recognize obstacles and solutions related to adding research to the chaplain's portfolio, learn how to respect patients' needs while conducting research, and catch a glimpse of the future of chaplaincy research.

We are grateful to our writers for their fine contribution to this book and we hope that our readers will feel invited and equipped to join the future of chaplaincy research.

Gary E. Myers

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Introduction

Invitation and Rationale:

Why is it necessary to research chaplaincy care practices?

The Rev. Dr. Ewan Kelly

‘the real magic of discovery lies not in seeking new landscapes but in having new eyes.’
(Marcel Proust)

I wish there had been a resource such as this available when I began my exploratory journey into healthcare chaplaincy research over 15 years ago. Such a body of collated, reflected experience would have invited me not only into a whole new world, but into a world of new possibilities - new ways of seeing and understanding my vocation, my practice and myself. In addition, such an invitation would also have enhanced how I communicated the significance of my role and its impact to a wide and varied audience who, until now, may not have understood or valued either.

Therefore, it is a delight to be invited to write this introduction not as an expert in chaplaincy research, but as a fellow enquirer and learner; as someone who is curious to find out more about how and why healthcare chaplaincy makes an important and distinctive contribution to the health and wellbeing of patients, caregivers, staff, and organisations as well as ourselves as practitioners and persons. ‘Curiosity combined with a sense of reverence in our attending to...’ (Kelly 2012, p 27) is at the heart of specialist spiritual care practice. Combined with more than a touch of playfulness, discernment and resilience - what we are describing are not only assets required of a chaplaincy practitioner but also of a practice-based chaplaincy researcher. What I didn’t realise at the outset of my research journey was just that – that the abilities and skills I possessed and had developed to enable me to practice as a chaplain were fundamental to the research I went on to perform.

In our practice and in any research we are involved in as chaplains, we ourselves are our own primary resource in both therapeutic and investigative terms. Or rather, our reflexive selves—the self we are aware of in any moment—is our main resource. We are bearers of stories into any encounter or context as well as listeners to stories (Gerkin 1984). As we listen to others’ narratives as part of our practice or research we have to be aware of the lens through which we interpret them. Before I go any further with this introduction - to sketch the context within which this book is being written and to outline the reason for its need to be written - I want to share a little of my research story for two reasons. Firstly, it reveals something of the lens through which I understand chaplaincy practice and research (and the relationship between the two) and, thus, shapes what I write. You, the reader, will engage with this written text through your own interpretive lens. This not only mirrors your practice with living texts but it is at the heart of what it means to perform chaplaincy research. Secondly, by sketching out my involvement in chaplaincy research over a period

of years, whilst inhabiting different roles; I will briefly introduce many of the themes which colleagues will more fully develop in subsequent chapters.

My tentative journey into healthcare chaplaincy research had its genesis in my former professional formation and practice. As a medical student I was enculturated into an understanding that all practice should ideally be evidence based. Reading up-to-date research papers written by peers to inform best practice as part of university education and continual professional development and supporting and/or performing original research to enable career progression are cultural norms for doctors. Subsequently, on entering a healthcare profession in the mid-1990's in Scotland, which also cared for vulnerable people, healthcare chaplaincy, I was surprised not to find such norms. However, what I did find were opportunities to reflect on practice within supervision as an individual and in group settings with colleagues and students, I in turn supervised. In doing so, a rather obvious yet significant realisation occurred to me about the link between research and reflective practice – both were intentionally concerned with influencing future practice i.e. affirming what was already positive and appropriate and enhancing or correcting practice which may have been less helpful or even potentially harmful for patients, their caregivers and practitioners alike.

Like other members of the chaplaincy teams I worked in, I received feedback and sometimes thanks for the work I performed with patients, caregivers and staff. If I was fortunate it came in chocolate or liquid form! However, I increasingly became inquisitive about the impact my practice and that of colleagues had on those we supported and worked with. Was my practice consistently helpful or even appropriate? What about its long term consequences as well as its more immediate effects? Did I ever do harm? It wasn't easy in the 1990's in Scotland for patients to offer feedback if they felt their care was less than adequate, especially if they felt vulnerable or disempowered and the caregiver concerned was a representative of the church and in a role of perceived authority.¹ All the feedback I received was in relation to those people I seemed to connect with. What about those I never heard from or saw again? I tried to practice consistently and competently but every context and person is different and healthcare chaplaincy provision is so nuanced, requiring professional wisdom to be utilised in the present moment. As we know, when practised well it is a challenging and draining role to perform, yet potentially immensely fulfilling. I wondered, when faced with such diversity and the need for discernment in the here and now, what principles or approaches, informed by patient experience, could underpin, validate, and improve my practice in particular clinical contexts?

Stimulated by these questions and my medical background I began to read about research in an area of chaplaincy in which I was involved and had interest – the ritual support of bereaved parents whose babies had died *in-utero* or in the neo-natal period. A few relevant studies had been performed before by chaplains, midwives and doctors. Their work drew me in further; deepening engagement with issues I had noticed and wondered about

¹ For example, patient experience or satisfaction surveys were a novelty not mainstream in Scotland at this time and on-line patient opinion tools were still a thing of the future.

previously, but had not understood the depth of their significance.² What also struck me, like Canadian pastoral theologian Thomas O'Connor (2002), was that the majority of research into spiritual care in health and social care was not performed by chaplains but by other disciplines, most often those from a nursing background. Reading not only stimulated more interest and questions but seriously made me consider dipping my toe into research waters. I had many conversations with healthcare colleagues and researchers from different disciplines and backgrounds building up a network of contacts and an understanding of what may be involved.

They further helped to stoke my enthusiasm and encouraged me to take the research plunge. Why shouldn't chaplains research spiritual care practice in the UK when other disciplines already were?³ My chaplaincy colleagues and manager were supportive with the idea of me performing research (though also somewhat bewildered – this was a first for them as well as for me!) and I, therefore, embarked on a doctoral studies programme. I enrolled in classes to learn how to perform qualitative research knowing little more than I wanted to gather in-depth stories of the lived experience of bereaved parents who had been ritually supported by a chaplain, particularly those parents not actively linked to a faith community in a Scottish context. My aim was to enable such narratives to inform the future practice of myself and, hopefully, interested colleagues.

One example of a key aspect of parental experience which emerged from listening to their stories crucial to informing chaplaincy practice, recruitment and education was that of the significance of midwives acting as gatekeepers to chaplaincy services around the time of death and/or of their baby. Several of the thirty parents that I interviewed who had no live connection with a faith community had expectations that a chaplain would seek to proselytise them, act in a paternalistic, controlling manner or remain distant from their hurt, loss and distress. Thus, without midwives proactively talking about the personal qualities and relational abilities of chaplains as well as their professional competence many parents would have refused the offer of their services. This highlighted the importance of chaplains being an integral part of labour ward and neo-natal unit teams and having the appropriate character and formation as well as acquired knowledge and skills to enable their credibility to be established and trust developed within multi-disciplinary teams to then enable appropriate spiritual care to be provided to grieving parents.⁴

Such research activity and engagement occurring in our chaplaincy department stimulated much interest and energy both within our team and in the wider hospital. Internally, colleagues helped me to reflect on some of the parental stories I heard as well as to explore

² The most relevant original research on this topic at the time within chaplaincy circles had been performed in Sweden.

See Anderson Wretmark, A. (1993) *Perinatal death as a pastoral problem*. Uppsala: Bibliotheca Theologiae Practicae.

³ Peter Speck was one early example of a chaplain involved in spiritual care research in a UK context. See for example:

King, M., Speck, P. & Thomas, A. (1999) The effect of spiritual beliefs on outcome from illness. *Social Science and Medicine* 48: 1291-1299.

⁴ For further details see: Kelly, E. 2007 *Marking Short Lives*. Oxford: Peter Lang.

common or unexpected emergent issues from the research material gathered at team meetings or over coffee. This provoked a real depth of sharing and proved a creative and fertile ground for provisional naming of emergent theological themes from parental experience. In retrospect, such lively dialogue affirmed anew the work of our department because the bereaved parents I was interviewing had all been supported by my colleagues. We began to understand more fully the depth of the significance of our practice to parents as well as its unintended impact (Capps 1984) in ways we had never considered before. This was hugely revealing in terms of what bereaved parents potentially invest in chaplains in times of transition and loss. For example, parents reflecting on the importance of having a chaplain involved in blessing and funeral rituals, perceived chaplains as being conduits to God. Some felt that during such ritual marking they handed their baby over to the chaplain involved who in turn had the responsibility of ensuring their baby was transferred into God's care for eternal safekeeping (Kelly 2007). Not only did the enormity of such responsibility strike us but it opened our eyes to both our prior assumptions and actual parental perceptions.

Externally, we began to have conversations with those who had never shown more than a passing interest in our work before – especially with doctors and healthcare managers who had heard about the research through, for example, being involved in ethics or governance committees or recruitment for the study. I was fortunate to gain a small grant to help fund the research from the Chief Scientist's Office of the then Scottish Executive.⁵ Our department began to be seen in a new light—our professional identity in the acute, tertiary, teaching hospital where we worked, a place where research and practice development is normative, began to have an added dimension. This was evidenced by the fact that even before the study was completed I was asked to share some preliminary findings at an inter-disciplinary annual research conference run by the hospital's maternity unit. This indeed was a chaplaincy activity that was opening up new possibilities and enabling not just chaplains to see with new eyes!

My research journey within chaplaincy did not end there. I also had the privilege of sharing parental insights with chaplaincy and inter-disciplinary colleagues at seminars, meetings and conferences. The research findings formed the basis of two books I was then able to write and still underpins the university and clinical teaching I participate in.⁶ All such activity was, and is, performed with the intention of informing future practice and enhancing the spiritual care of patients, caregivers, staff and health and social care organisations. My practice deeply informed my research (it evolved out of it) and in turn my research underpinned and re-energised future practice as well as ongoing theological reflection. This was particularly exciting and life enhancing—I was able to perform such research within the context not only of healthcare but grounded in pastoral theology. In other words, being a chaplaincy practice based researcher not only enlivened my vocational caring but the beliefs and values that informed such.

⁵ Now the Scottish Government.

⁶ Kelly, E. 2007 *Marking Short Lives*. Oxford: Peter Lang.
Kelly, E. 2008 *Meaningful Funerals*. London: Continuum.

In recent years my research journey within healthcare chaplaincy in Scotland has taken me into the strategic role of developing spiritual care, including healthcare chaplaincy, within health and social care provision in Scotland. Why is this important for the purposes of this, a book inviting chaplaincy practitioners to engage with and in chaplaincy research? Why is mentioning strategy and political engagement significant in this context? It has become clear in recent years of increasing financial austerity that without an evidence base to underpin what chaplains do, certainly in Scotland, financial decision makers and other power brokers in health and social care would be reticent to continue to fund chaplaincy services to the same degree. Little credence within a culture of evidence-based practice would be given to a service which cannot show how it impacts positively on personal outcomes for patients or the wellbeing of staff, caregivers or organizations. The very fact that chaplains are involved in research raises our professional profile and makes decision makers take notice.

Another valuable learning for me is that while doing research and disseminating the findings within our vocational community is in itself significant for chaplains, also of importance is how and to whom our research findings are more widely shared with. Even the smallest of research projects and quality assessment/improvement studies if shared with the relevant health service leaders or managers at the right time can help to promote healthcare chaplaincy and its impact on health and wellbeing with far reaching consequences.

For example, the evaluation of the impact of regular participation in a method of group inter-disciplinary reflective practice developed in the Scottish healthcare chaplaincy community, values based reflective practice (VBRP) reveals participants feel enhanced engagement and fulfilment at work. VBRP and the evaluation of its impact on staff wellbeing resonates with the Scottish Government's current policies on person-centred care. Sharing the reflective methodology, evidence of VBRP activity with a range of healthcare disciplines and the evaluation of its impact on participants with key government administrators and healthcare leaders has been highly significant. It has led to government funding of VBRP's mainstreaming in the Scottish health service and its inclusion in Scottish Government policy for enhancing staff experience as part of their national Person-centred Health and Care Delivery Plan.⁷

In addition to political engagement, exploring with chaplaincy colleagues research related issues strategically in Scotland led to the development of a national research strategy for chaplains, the outcome of which has enabled the formation of research champions (who promote the significance of engaging with research in chaplaincy teams locally) in geographical areas of health service delivery and a programme of training chaplains in

⁷ For further information about values based reflective practice see: Kelly, E. 2013 Translating Theological Reflective Practice into Values Based Reflection: A Report from Scotland. *Reflective Practice: Formation and Supervision in Ministry* 33: 245-256., and Paterson, M. and Kelly, E. 2013 Reflective Practice: a method developed for healthcare chaplains in Scotland. *Practical Theology* 6(1): 51-68.

qualitative research methods through participation in a national research study.⁸ Relationships developed with researchers from different disciplines with common interests in spiritual and person-centred care provision has led to my involvement in various research steering and advisory groups and projects in the fields of palliative care, psychotherapy, counselling and current involvement in a protocol development group exploring the impact of person centred care on patient reported outcomes and staff wellbeing. These are not only learning and networking experiences but help to promote healthcare chaplaincy as an evidence based profession with something unique to offer in multi-disciplinary research teams.

Writing the first half of this introduction has been immensely helpful in helping me to engage with the question I have been tasked to explore: why is it necessary to research chaplaincy practices? It not only has enabled me to signpost key themes in this book, illustrated by facets of my own research journey but in itself it has been an exercise in reflective practice. This is where I would like to start the second section; with the long held tradition of healthcare chaplains' critical exploration of encounters with patients.

Professional Imperative: Continuing a history of examination and discovery

From the example and inspirational influence of Anton Boisen to the present day formation and (re)formation of chaplains immersed in clinical pastoral education (CPE) and other educational approaches involving theological and values based reflection, healthcare chaplains are part of an ongoing tradition of intentional critical reflection on our practice.

Ours is a community where curiosity about, and attention to, what happens during moments of practice and the impact on those involved is not only culturally normative but imperative. This enables not only safe, culturally and contextually appropriate practice to be delivered but it enables personal and professional development i.e. the acquisition of new knowledge and insight based on reflection on previous experience (our own or that of another) which can be applied, informed by discernment and personal character in future encounters. Such is the nurturing of practical wisdom or *phronesis* within a practitioner. For me, intentional reflective practice, evaluation of services and research within healthcare chaplaincy are different points on a continuum. They are informed by the same premise—enhancing future practice by intentional and rigorous exploration of current practice utilising tried and tested methods or approaches. Such engagement is important to underpin and emphasise practice which is life-enhancing for patients and caregivers as well as identifying practice which is not.⁹

⁸ The impact of the development Community Chaplaincy Listening services in family doctor surgeries in different parts of Scotland on patient wellbeing has been assessed initially through a national action (qualitative) research project.

See for example Mowat, H., Bunnis, S. and Kelly, E. (2012) Community chaplaincy listening: Working with general practitioners to support patient wellbeing. *Scottish Journal of Healthcare Chaplains* 15(1): 21-26.

⁹ In addition, similar natural abilities and assets are required to perform these critical activities which can be enhanced with training and experience.

The decision for our profession, our teams and ourselves as healthcare chaplains whether or not to engage in critical examination of our practice through reflective practice and research is a moral issue; for as with other healthcare professionals we have a duty of care to those we work with who are often, but not always, vulnerable and distressed. In addition, as theologically or spiritually informed practitioners we also have a duty of care for ourselves as human beings who are also of worth and are beloved (Muse 2000). The fundamental bioethical principles of healthcare provision apply as much to healthcare chaplains' practice as they do to other healthcare professionals, such as doctors and nurses. Thus, acting with beneficence or intent to do good requires to be as inherent to our practice as the principle of nonmaleficence, to do no harm. Through researching our practice and reading up-to-date research relevant to our work—what Fitchett and Grosseohme (2012) call 'research informed' chaplaincy—as well as reflecting on our practice in the company of informed others, we can ensure we practice as ethically and responsibly as possible for our sakes and those we seek to support.

Economic challenges: Research as a strategy for strengthening chaplaincy in a changing healthcare culture.

Healthcare in the industrialised world is facing an array of challenges which require politicians and strategic leaders to increasingly scrutinise how, why, and where money is spent in the delivery of services. These significantly include rapid demographic changes which mean people will live longer in this and forthcoming generations with an increasing number of chronic long term conditions. The financial implications of this can be illustrated by some figures from my home country. In the next twenty years the number of people in Scotland living till they are over seventy-five will increase by sixty percent. Health economists predict the implications of such rapid changes in demography alone could increase expenditure on health and social care by over seventy per cent (Scottish Government 2013). The designers of health and social care services as well as policy makers in the industrialised world are currently pre-occupied with such concerns in terms of the re-structuring and re-configuration of the delivery of services to meet such need. The cost of caring for such an aging population is a huge challenge to politicians and leaders working in health and care sectors. Therefore, governance of budgets is tighter than ever before. The implications for healthcare chaplains within such an economic context cannot be underestimated. No longer can chaplains assume that because our services are well embedded or integrated and indeed are well utilised and respected within an organisation that our level of service provision is secure. As with any other health and social care profession chaplains in today's culture of evidence-based practice and increasing financial restraint are required to show that our services not only add value to the overall care of patients, their caregivers and staff but, indeed, positively affect the financial bottom line of the healthcare organisations that employ us.

On first reading this may seem like a huge cultural challenge to healthcare chaplains as historically this has never been a significant concern for most practitioners (though budgetary issues may always have been one for chaplaincy heads of department!). However, as chaplains we have many assets, relationships and interests which can aid us in our response to such challenges, many of which have already been alluded to in this

introduction. Our primary concern in practice has always been about how patients' experience ill-health or trauma and providing support for them in the midst of loss and transition as well as promoting their resourcefulness to live with such in the short and long term. Increasingly, healthcare research amongst other professional groups has begun to recognise how patient experience (including interaction with healthcare professionals and services) impacts on their recovery and their personal outcomes as much as their safety and the effectiveness of clinical interventions such as surgery or accurate prescribing (Doyle et al 2013). Increasingly, there are creative and collaborative opportunities for chaplains, given our interest and area of expertise, to help health and social care services understand more fully what patients, their caregivers and staff live through when dealing with ill-health, injury and loss. Chaplains are in a position to make a contribution to a body of evidence which reveals that caring for a person's emotional and spiritual needs in a health and social care environment improves their wellbeing and personal outcomes. Snowden and colleagues (2013) have shown in a small pilot study that following chaplaincy intervention in-patients felt more hopeful, in control of their situation and able to be more honest than before in their relating.¹⁰

Steve Nolan (2013, 58) an English palliative care chaplaincy practice based researcher recognises the need for such outcomes focussed research but also makes an important plea that in doing so we do not dilute or diminish the unique essence of what we are, or what we do, as healthcare chaplains. He sums up the significant relationship between research and what is at the heart of healthcare chaplaincy practice—the paradoxically simplest of concepts yet the most immensely complex and potentially difficult of embodied arts, being present with another in the moment of their need.

...the challenge is to understand and work in ways that are outcome-orientated and evidence-based, but that does so critically, and in ways that value and promote spiritual care through person-centred, person-focused, presence rather than technique. The distinctive contribution that chaplains bring to the MDT (multi-disciplinary team) is one that is rooted in the spiritual values and practices that lie at the heart of good health and good care.

Enlivening and sustaining: Research as a means to promote chaplaincy wellbeing

Throughout my research journey whilst working in healthcare chaplaincy it has never ceased to amaze me how being involved in, supporting or reading about relevant research can potentially deepen a chaplain's vocational engagement. Taking the opportunity to 'see through new eyes' whether gathering patient stories and analyzing them, helping to identify new questions or areas for research or reading an article offering new evidence to inform practice and discussing it with colleagues.

¹⁰ For fuller details of Snowden's research in specialist spiritual care patient related outcome measures (PROMS) see <http://snowdenresearch.co.uk/download/healthcare-chaplaincy-the-lothian-prom-2012-revised-col-online-only.pdf>

Chaplains, like others in caring professions, are always in danger not just of the extremes of compassion fatigue or burnout due to the cost of caring 'over the long haul' but of becoming stale or 'going through the motions' as our role drains us or perhaps becomes less fulfilling or energising than it once was. There is a need for variety and different sources of stimulation to keep us fresh and motivated at work. Traditionally, chaplains have sought supervision and spiritual direction as well as engagement in continual professional development through further study or specialisation in a particular area of chaplaincy to help promote wellbeing and keep our work meaningful. Involvement in, and support of, research and engagement with its findings offers other such opportunities. As American pioneer in chaplaincy research Larry VandeCreek (cited by Weaver *et al* 2008, p7) puts it '...research stimulates creativity,' which can be 'an antidote for the boredom and burnout that accompanies (a) heavy pastoral load.'

Not all chaplains will be interested in performing research, or feel that their gifts lie elsewhere, but research taking place within or involving chaplaincy teams and reading research papers may also be energising. For a few chaplains, such as George Fitchett, based in Chicago or Daniel Grosseohme in Cincinnati, developing a career majoring in spiritual care research may be a preference. However, career progression involving becoming a practice based chaplain researcher may be more of an opportunity and attractive option to provide mid-career stimulus and interest. This mirrors those chaplaincy colleagues who become accredited supervisors as well as retaining a significant clinical remit. It also ensures that research is closely linked to practice and thus ensures its relevance.

Theologically and spiritually significant: Research as a conversation partner to underpin practice

Delivering sensitive and contextually appropriate specialist spiritual care is not, of course, as simple as applying the most recent relevant research in a competent manner within a patient encounter. Who we are, how we relate, our attitudes and behaviours and our use of discernment in the moment are also crucial. These aspects of our practice are informed not just by acquiring and imparting up to date knowledge. They are informed by our values, our beliefs and our degree of self-awareness. This, therefore, involves ongoing theological or spiritual reflection as well as being 'research informed' to promote best practice.

Practical theologians and qualitative researchers John Swinton and Harriet Mowat (2006 p26-7) describe the aim of practical theology being:

...to enable personal and communal phronesis; a form of practical wisdom which combines theory and practice in the praxis of individuals and communities. This phronesis does not aim for knowledge for its own sake, but for an embodied, practical knowledge which will enable a particular form of God-orientated lifestyle.

Putting theory into practice is not just the application of appropriate research findings at a specific time in a particular context but is also combined with the incarnating and performing of a personal theology or spirituality. Ongoing continuing professional and personal development in healthcare chaplaincy is required which involves regular intentional engagement with recent relevant research **and** theological or spiritual

reflection on practice. This is in order not only to promote practicing ethically with practical wisdom but to keep chaplains motivated and well.

Conclusion

Our profession, like health and social care in general, is going through a period of rapid and challenging change. However, it is a hugely stimulating time to be a healthcare chaplain – with a wide array of career opportunities and interests available. Research was once seen as add-on in chaplaincy, something slightly esoteric which was performed by those who really should be academics with too much time on their hands. However, no more; research into chaplaincy practice is now increasingly recognised as a continuation of a longstanding heritage of critical examination of practice, affords us vital opportunities to enhance our practice, promote and evidence the significance of our work and to deepen our fulfilment in it.

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Chapter 1, Part A

Chaplains' Journeys: Why do chaplains decide to do research?

Rev. Stephen D. King, BA, MDiv, PhD, BCC

“Seizing the moment with determination and joy”

Initial interest

I love doing research. I am not well-trained and am coming to terms with the fact that I will never be as well-trained and capable as I would like. But I am making headway and I am making contributions. Perhaps some of my story will connect with you, give you some ideas, or inspire you in new directions.

My road in research has been challenging and exciting. When I was doing course work for my PhD, I saw no need to take statistics. About 15 years ago, I discovered empirical research. The path since has been one with a number of obstacles, hits and misses, and great enjoyment.

My initial interest probably began with reading publications of Larry VandeCreek's research. Later I began reading Kenneth Pargament's early articles on religious coping, specifically the “God help me” articles (Pargament, Ensing, Falgout, Olsen, Reilly, Van Haitsma, & Warren, 1990; Pargament, Olsen, Reilly, Falgout, Ensing, & Van Haitsma, 1992), and then articles on medical provider attentiveness to the spirituality of their patients (Armbruster, Chibnall, & Legett, 2003; Chibnall, & Duckro, 2000; Curlin, Chin, Selligren, Roach, & Lantos, 2006; Ehman, Ott, Short, Ciampa, & Hansen-Flaschen, 1999; Ellis, Campbell, Detwiler-Breidenbach, & Hubbard, 2002; Ellis, Vinson, & Ewigman, 1999; King & Bushwick, 1994; Kristeller, Rhodes, Cripe, & Sheets, 2005; Kuuppelomaki, 2001; Luckhaupt, Yi, Mueller, Mrus, Peterman, Puchalski, & Tsevat, 2005; MacLean, Susi, Phifer, Schultz, Bynum, Franco, Cykert, 2003; McSherry, 2006; Narayanasamy, 1993; Monroe, Bynum, Susi, Phifer, Schultz, Franco, Garrett, 2003; Piles, 1990; Tuck, Pullen, & Lynn, 1997;). These articles seemed relevant to my work and to the work of chaplains in general. As I read these articles, I became aware that I had difficulty understanding certain aspects of the articles, especially the statistics and the tables. I also had a difficult time differentiating the quality of the articles.

While serving on an Institutional Review Board (IRB) committee, I read many research proposals and, as a result, became familiar with the basic elements of research as well as the requirements that insured that research met ethical standards. My participation in this aspect of research evaluation stimulated even more interest in research.

About seven years ago, while working in a major research center, it became apparent to me that research was becoming increasingly important to chaplaincy. To celebrate a departmental anniversary, we invited George Fitchett to deliver Grand Rounds for the faculty. Following Grand Rounds, George led a day-long workshop on research literacy for chaplains and interested others. He also offered consultation for chaplains and chaplaincy departments about their research projects. The workshop gave me hope about learning

how to better understand research that I was reading using the tools I learned. It gave me hope that I could start with my limited expertise and learn incrementally by doing studies that were manageable and doable for me at that time. I was hopeful, encouraged, and energized about research—both becoming more literate and actually doing it. My wife and I attended the weeklong research seminar at Duke (which also had consultation time) the following summer. I approached my administration at Seattle Cancer Care Alliance about having time to learn and do research. They were all for it ... as long as I could find a little time here and there or do it on my own time. At first, I couldn't and I didn't. Further, it seemed that the study protocols that I was considering were too broad and not well-designed, were overly complicated and not doable with the resources and knowledge that I had, and would not demonstrate what I had hoped. In short, I was told I was setting myself up for failure.

In collaboration with colleagues, I settled on a study that investigated medical provider attentiveness to the spirituality of their patients (King, Dimmers, Langer, Murphy, 2013), a study that took a number of years to complete and publish. Later, I became more interested in spiritual/religious struggle. As I read the literature, spiritual/religious struggle seemed to be a prevalent problem that had significant consequences for patients and opportunities for chaplains to make a difference in measurable ways. There were still a number of questions about dynamics, prevalence, and trajectory of spiritual/religious struggle, and there were no adequate screening tools for spiritual/religious distress. I identified these questions as a significant clinical research area.

Challenges and seizing the moment

My interest in research continued to grow. I was also becoming very interested in continuous quality improvement and began to think about how research could help in these improvement efforts. One person with whom I consulted suggested that I needed to dedicate significant time to research. However, I realized with great disappointment that there would be no administrative support for any dedicated time for research other than reading articles and having some meetings during work hours. I was discouraged and did nothing for a period of time. But I also knew others in my system did not receive time to do research except as funded by grants. I decided that I valued research; I had always enjoyed learning and enjoyed theoretical research (e.g., theology) as well as math; I enjoyed reading research and learning; through this process I was also developing questions I wanted to answer that I thought might be doable. In conclusion, I wanted to do research enough to invest my own time after hours to do it. Who knew? Maybe the results would lead to some type of funding or support for my work.

I lacked both training and money. I work in a major academic and research-oriented health care system. Although research is part of its mission, in my institution within that system, the employees are not employed to do research. My administrator's sister is a nurse researcher who was charged with transitioning my center to also being a place where the employees can do research. I consulted with her about research ideas, about how to learn to do research, and more specifically about how to do research in my context. She helped

me narrow my research ideas, recommended learning research by doing it, and helped me navigate doing research as a chaplain-researcher.

First, let's address contextual issues, especially access. Because I was employed by the Seattle Cancer Care Alliance, I did not have access to an Institutional Review Office (IRO) for review of my research, to online research articles, or to discounts that made statistical software affordable. I needed to be affiliated with other organizations. The nurse researcher helped find me a sponsor and I became an affiliate of the Fred Hutchinson Cancer Research Center (FHCRC). This allowed me remote access to databases and on-line articles. More importantly, it allowed me access to submit research proposals to a nationally recognized IRO. For access to a larger library (e.g., online articles) and other research needs, I needed to seek affiliation with the University of Washington and its School of Medicine (UWSOM). I was working with a colleague in one department at the UWSOM and approached another colleague about affiliation through another department. These affiliations required additional after hours work but provided me the resources I needed for research, including research on human subjects training every three years in order to submit research proposals to the IRO.

Next, let's address learning by doing. The first study I worked on was in collaboration with another chaplain and with a psychologist/researcher and then another chaplain/statistician (King, Dimmers, Langer, Murphy, 2013). The study was not funded and therefore needed to be manageable within the hours we had available. This study of medical providers was an on-line survey that was mailed to providers. By navigating through the IRB process as well as through issues we discovered during the study, I learned a lot. For example, in the IRB application, we used the language "MDs" rather than "doctor." A number of our doctors were trained in other countries or are doctors of osteopathy, i.e., not MDs and, therefore, had to be excluded. We used survey questions with three responses, including a "neutral" response. Both having only three options and using "neutral" limited our analysis. We used "other" as an option along with pediatric, pediatric oncology, adult oncology for professional focus. A large percentage chose "other" which both confused us about what they meant and limited our ability to analyze the data. We also wish we had offered a token for completing the survey, e.g., a five dollar Starbucks card, thinking that might have increased the response rate.

These issues have made me more attentive to details in both the Institutional Review Board (IRB) application and the study instruments and made for better studies. I have frequently consulted with George Fitchett for whom I am incredibly grateful. Collaborating with others regarding the analysis and publication has taught me more about statistics, about tables, and about how one organizes and writes the paper. Submitting articles for publication has taught me to be a better writer. Through the studies I have engaged, I have had the opportunity to look at consent language, demographic issues, data transfer agreements and IRB authorizations when data was going to another organization, confidentiality/privacy and security issues involved in on-line surveys, etc. I have been fortunate to work with people whose work is designing and implementing studies. This has

been especially helpful in thinking about how to write study protocols and carry out studies. These are just some of my learnings-by-doing.

Department

Our Chaplaincy department is committed to research literacy. Several years ago, we established a Fellowship in Oncology Chaplaincy. A side benefit of this has been the opportunity to create a “learning-culture” where our Fellow, my staff, and I learn together and gain research literacy by discussing articles we have read in our research literacy seminar. We prepare for the seminars by using a guide for reading research, the [Rush Research Summary Outline](#). For the first several years we often had another person who taught us about the statistics in these articles. More recently, we have been attending APC’s Webinar Journal Club series on research literacy taught by George Fitchett and Patricia Murphy.

Now

Several factors have resulted in my recently receiving 4 hours per week of dedicated research time: the research is generating results; administration recognizes that I am committed to research and willing to work on my own time; and the organization is aware that there is a growing need for evidence-based care in supportive care services. I love to read and learn and to see how others approach the questions. I enjoy thinking about how to best approach an issue while keeping in mind my level of expertise. I think about possible collaborators who are funded and might be interested in adding some questions to their studies. I keep in mind my lack of funding. If I could go back in time, I would take a more quantitative-research approach in my academic training. Perhaps I will still engage in some type of intensive research training, e.g., a summer intensive. If I were at a different place in my life, I would complete a degree in epidemiology or statistics, perhaps an MPH with an emphasis in those areas and/or pursue a research training grant. I will continue to learn as I go, doing the research I love while continuing to be creative and persistent in doing better research. I hope others will be creative and persistent in a quest for research literacy and that some will collaborate with experienced researchers and/or do research on their own. May we seize the moment with hope, grace, and determination.

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Chapter 1, Part B

Chaplains' Journeys: Why do chaplains decide to do research?

Rev. William Iler, M.Div., B.C.C.

My personal journey into the field of chaplaincy research was one that had its roots in at least two things. First of all, I majored in psychology at Wake Forest University and one of the required (and also dreaded!) courses was "Research Methods." For psychology majors, this was considered the toughest course and, in addition to this, I also had an extremely demanding professor. However, it was not until about 14 years after completing this course and after about 10 years of being a chaplain that I decided to delve into this mysterious fascination within my chosen profession. Secondly, there has always been a part of me that knew, intuitively, that the ministry I participated in, as chaplain, made a positive difference in the lives of patients. As time went by, there became more of a passion to show how chaplaincy interventions could be quantified in a way that communicated to hospital administrators and others within my field the benefits of receiving pastoral visits. The very word "research" can also be looked at as "re-search" - a renewed search for something that I believed was already there in the first place.

Obstacles which may affect one's ability to do chaplaincy research

As a one person pastoral care department with volunteers, working in a medical center that averages between 200-250 patients and with a staff of about 1500 employees, I initially came up with many excuses as to why it would be difficult not only to set up and do the research, but also to have it be good enough for publication. Time and energy were the two pit-falls which I encountered on a regular basis. "If I am to do research, what will potentially be sacrificed?, I initially asked myself. The way I overcame the time and energy obstacle was to give myself permission to take a more relaxed pace with the study, which focused on how daily chaplain visits affect 4 variables in patients who were admitted into our hospital with C.O.P. D. (Chronic Obstructive Pulmonary Disease). The variables I focused on were length of stay, anxiety level at time of discharge, satisfaction with stay, and recommending our medical center to others. The project, from start to finish, occurred over a two year period, allowing me time and energy for all of the other essential functions in my work as chaplain. Another way of navigating the time and energy issue is to simply say "no" to some of the other non-essential aspects related to work, during the course of research. For many of us, this can also be a challenge.

I believe that is both fear of failure ("What if I'm wrong?") and fear of success ("What if I'm right?!") that are lingering obstacles for many people interested in doing research. It certainly was for me. I will, first of all, examine the fear connected to potential failure. Although I had read other studies about how chaplain visits positively affect specific, measurable variables, I was not sure that this could be duplicated in my hospital. It is probably normal to have such fear. However, a big part of my personal spirituality relative to fear comes from two passages of Scripture. The first one is Psalm 34:4, "I sought the LORD, and (God) answered me; (God) delivered me from all my fears." (NIV) The second one is found in II Timothy 1:7, "For God did not give us a spirit of timidity (fear), but a spirit

of power, of love and of self discipline.” (NIV) My personal theology of fear instructed me that God is one who delivers us from fear and also that God wants to replace fear with power, love, and self discipline.

The fear of success did not come to my realization until I was beginning to collect the data and was coming to the conclusion that some of my hypotheses, going into the study, were correct ones. As I sat down with a local college professor who assisted in doing the statistical analysis, I then began to struggle with questions like this: “what will I do with this information?”; “who needs to be aware of the information I have gleaned from this study?;” “how can I accurately and articulately communicate this to people who need be aware of this?.”

A concept I remembered from college and seminary philosophy courses was that of “epistemology,” or “how do we know the things that we know?.” One of my philosophy professors taught that the ancient philosophers tended to believe that the bulk of our knowledge base fell into four categories: reason, tradition, experience, and revelation. As an intuitive person, I believe that all four of these ways of knowing had a positive impact upon my work as a chaplain. However I was intrigued with the reason part, and desired to find a way to show a more quantifiable way to see the impact of chaplaincy ministry. I suppose, looking back, that there were probably some fears connected to translating something I knew from tradition and personal experience into something which could be viewed in a more analytical way.

Perhaps, a last barrier or “fear” one must contend with is that of finding the right people to assist in a research project. There are two things I would recommend that were helpful to me. First of all, find someone in your place of ministry who knows more about the group of people you are wanting to research than you do. Secondly, if you are not comfortable with doing the statistical analysis of such research, there are more than likely a plethora of people in your community, perhaps affiliated with a local college or university, who can assist with this.

Potential benefits of chaplaincy research

For one to proceed with research, it is my personal belief that the potential benefits to a study should always outweigh the potential limitations. If this is not the case, very few chaplains will motivate themselves to find the time and energy to continue. As already mentioned, it was very fulfilling for me to think about the idea of quantifying, in a meaningful and intentional way, the benefits of the ministry of chaplaincy. I must admit that some of the initial motivation for doing research was also connected to a misinformed belief that if I could prove that what I do makes a positive difference in several measured variables that this would equate to the addition of more paid staff. This belief, though not always accurate, is probably in the minds of many who do such research. However, just because one has empirical evidence that what one does can affect, in positive ways, many different outcomes, the decision to hire additional paid help is usually established by other constraints, often beyond one’s control. So, while this may have been an initial motivation, I would admit that my frustration with continued communication of these results and the

futility of finding additional paid chaplaincy help, have educated me to see the benefits of research in a broader perspective. I am sure, however, that others in the field of chaplaincy have been able to fund additional paid positions in their departments by assertively communicating, in measureable ways, the value of their services.

I have read many research studies, throughout the years, looking at interventions with specific diagnostic groups. Sometimes, in doing such studies, a chaplain may discover as much through subjective information they have gleaned along the way, than through the decision to examine specific data which was predetermined. Though I have only published one research study, which did look at a particular diagnostic group, I will occasionally administer brief surveys to patients, according to diagnosis or condition. Surveys do assist us in understanding how the spiritual needs of oncology patients may be different from dialysis, cardiac, or psychiatric patients. In my research with C.O.P.D., I learned many things about the needs of respiratory patients. This information has assisted me, over the past many years, to know how their needs may be different than patients being treated for other conditions. It was interesting for me to learn how many issues related to anxiety and depression they encountered. Also, as many of them had breathing issues that were controlled in the hospital, but not always as much at home, it became evident that many of our C.O.P.D. patients felt so comfortable, while here, that some of them had a sense of dread about going home. Though I did not record information in the study, I did notice that C.O.P.D. patients seemed to have numerous difficult family dynamics issues. More so than other patient groups with which I have visited.

In a day and age in which many hospitals are seeing their Quality Management Departments growing exponentially, chaplains must communicate that their work contributes to quality issues. At this point, I will make a rather bold statement. Again, it is probably based more upon intuition and experience than upon empirical knowledge. I would like to see some hospitals take the risk of seeing their chaplaincy departments as such a large part of the quality management scheme, that they would take the risk of employing more chaplains and see how the additional pastoral care staffing contributes to overall patient and staff satisfaction. Most hospitals live by the mantra “we are all about taking care of our patients.” This is true. However, chaplains have the distinct privilege of helping to encourage and offer spiritual counsel to staff members and physicians, which is also an essential service and one which trickles down to the care of patients. Yes, for the most part, chaplains are part of a non-revenue producing department; however, every hospital should see the work of the chaplain as being revenue saving. Countless studies have already examined how much we save hospitals through our services.

Although I am primarily addressing the need for chaplains to do research, on their own, I believe that is equally important to participate in the research done by other chaplains. Several years ago, a number of “One Person Pastoral Care Departments,” including my own, were asked to participate in a research project being conducted by the Department of Religion, Health, and Human Values at Rush Health System, Chicago, IL. This was a useful metric for those of us who work in such systems to understand how various chaplaincy activities and the time spent in these activities compared with other departments.

Sometimes we ask the question of ourselves, “Am I spending my time in ways which use my resources wisely and honor the needs of those I serve?” Participating in such studies can help to clarify the answers to such questions. Whenever one has the ability to collaborate in other’s research, for the benefit of understanding particular metrics or issues related to chaplaincy, I would heartily recommend this.

Finally, and perhaps most importantly, those of us in chaplaincy ministry need to have a developed sense of stewardship: of time, abilities, wisdom, and other resources. As one of the New Testament parables speaks about, we are to use and multiply our God given resources in ways which will honor God and respect others, rather than burying them in the ground. Chaplaincy research conducted with God honoring intentions and which is respectful of people’s rights and needs will always produce information which will be helpful to many.

Chapter 1, Part C

Step by Step:

My Baby Steps in Learning about Chaplaincy Research

Martha Dimmers, MDiv, MSW, BCC

I never once imagined doing research. In the course of my graduate studies, clinical pastoral education training and chaplaincy work, I never extensively studied chaplaincy research, research strategies, or how to lead research studies. Nor had there ever been extended discussions about chaplaincy research during these times. Although I had done a great deal of scholarly reading in the course of my master's degrees, statistics was the primary course I had taken directly related to the topic. During the course I realized how much I needed to learn in order to fully understand statistics. Now that I have delved further into the research realm I realize that was an accurate assessment.

My connection with chaplaincy research came about as a direct result of a conversation I had with two pediatric providers at Seattle Children's Hospital where I work. Chris Feudtner, MD, PhD, and then pediatric resident Jeff Haney, MD, approached me about collaborating on a research project. I distinctly remember them sharing their proposal and then inviting my participation. What a wonderful opportunity! Being able to learn something entirely new and to have an additional opportunity to partner with providers at the hospital sounded intriguing.

Their fortuitous inquiry led to my taking baby steps in developing my interest in and passion for research. My first questions became: "What do I need to know? What will this mean?" From our initial conversations and eventual collaboration, I deliberately began to expand my knowledge related to research. As my horizons broadened, so too did my appreciation for the unique and significant voice that chaplains bring into the pediatric academic healthcare world and research overall.

One way for me to effectively enter the spirituality/religion research conversation was by participating in the larger world of research. I explored the possibility of joining the Institutional Review Board (IRB) at Seattle Children's Hospital. They were looking for non-clinicians to join the IRB. A chaplain colleague and I joined. Participating on the IRB was an eye opener. From this launching pad the intricacies of behind the scenes research became clearer. I learned how one gains IRB approval, what concerns arise based on how questions are asked and answered, as well as what information will potentially be gained. I saw close up how carefully data is analyzed, questioned, and then reanalyzed. By reading numerous IRB applications and actively participating on the IRB, I became aware of studies taking place using a variety of research methods in diverse settings with varied populations and a variety of foci. In the late night hours while reading applications and as a result of many IRB discussions, I slowly began to perceive the meaning of the words, the flow of ideas and the studies overall. I gradually became able to read studies through more thoughtful and critical lenses.

Over time, I found myself further drawn into the research world. I began to understand small pieces of the “research lingo” and found researchers and clinicians with whom I could dialogue while asking research-focused questions. By reading articles in a wide variety of professional journals and informative books, my vocabulary and knowledge about research grew alongside my appreciation for the dedication required for this work. The most important readings for me were those from the chaplaincy field. Articles written by George Fitchett, George Handzo, and Larry VandeCreek were significant for me. Initially I read and re-read their articles until I began to understand even a bit of what they were stating. At first, it was as if I were in a foreign territory and so I gave myself permission to be a beginner. Eventually I found the articles easier to digest. I began to rely on the information from these articles to inform my chaplaincy work and subsequent research.

Additional significant learning for me occurred as I conversed with individuals in my institution who had an interest in or were knowledgeable about spirituality/religion and research, or other areas of research that might intersect with my areas of interest. Each individual shared information with me, and they often sent me to another person they felt might have some additional information or a new connection that would help me in my quest. Along the way I met intellectually astute and caring individuals who generously helped me. Our conversations often led to my inquiring if this work would fit into the work clinicians in Seattle were already doing. Integrating this work with other research became an important, even essential, topic. I began to understand why people had said I needed to do this work with others. It rapidly became apparent how small and specialized the world of research on spirituality, religion and chaplaincy is both in Seattle, WA and beyond.

One significant boost to my education came when George Fitchett, D.Min., Ph.D. offered a research class in Seattle, and I participated. This was a beginner’s course in chaplaincy research, and was just what I needed in order to increase my knowledge and gain access to more information related to research. I left his class feeling empowered about more actively participating in spirituality/religion, and chaplaincy research.

During this same time, Seattle Children’s Hospital began hosting pediatric grand rounds focused on pastoral & spiritual care and eventually offered day-long symposiums. By bringing in experts from across the country with experience in spirituality and religion research to share their knowledge with the hospital multi-disciplinary team and the Northwest community, awareness was raised about spiritual and religious needs and the research that addressed those needs. A number of benefits came from these offerings. The speakers raised awareness about these issues and conversed with providers who could take this further. Additionally, staff and providers at Seattle Children’s began to be more comfortable in adding spiritual questions to their research studies. As a chaplain, I became more comfortable learning about research and was able to converse with multi-disciplinary colleagues about participating in research projects. The connections between academia, research, and the bedside became clear to me and my enthusiasm for this work grew.

With this surge in connectivity, I began to focus on my own research interests. With notebook in hand, I wrote down questions and areas of interest for future study. Now with

a plethora of ideas and interests, I heard from colleagues that I needed to more narrowly define the focus of my work in this area. As one who thrives on variety, these were challenging suggestions to hear.

At the same time I was exploring my interests, I found myself bumping up against questions of how to continue my research work in the course of everyday patient and staff care at the hospital. The balance was difficult to achieve. I still find that much of my research-focused time takes place late in the evenings and on weekends. While I love the idea of incorporating this regularly into my daily work, it has proven difficult to carve out time to focus on research.

Fortunately, my husband and fellow chaplain, Stephen King, has also developed a passion for research. When we are together, we occasionally converse about spirituality/religion and chaplaincy research. Our discussions and shared research interests led to our collaborating on research, as well as to many helpful conversations about our chaplaincy work overall.

A big step forward for me in my chaplaincy research education process was attending the [Duke Summer Spirituality & Health Research Workshop](#). The week of focused instruction and mentorship was key to increasing my competence and to feeling more confident about my work.

Back at Seattle Children's Hospital, the librarians have been a huge help in the process. They have assisted in everything from helping me determine what information I needed for my work, to searching for specific research-relevant articles. Their generous assistance demonstrated to me once again how important it is to have knowledgeable, patient, and thoughtful partners in this work.

When I became engaged in research activities, and occasionally during hospital meetings, colleagues and others mentioned that something I was involved in might be publishable or should be published. Being fairly new to spirituality/religion research, I was unfamiliar with what was necessary to have my work published. As in much of this process, this aspect has been a team effort; I have relied on colleagues to help guide the way. Now I can sometimes help others as they look ahead to publishing and presenting.

Beyond completing the research, writing it up, submitting it for publication or for a poster presentation, is a major step in the process. Determining who publishes the specific type of research work the team has been focusing on or where it might be presented is imperative. Sometimes we determined this early in the process and other times our ideas changed as new possibilities opened up. I have looked to others to help navigate this path. My relationships with experienced, published researchers who are knowledgeable about a variety of academic journals and professional conferences have been highly valuable.

After we wrap up the writing component of our research, it is essential to set aside additional time for any of these possibilities: responding to post submission feedback;

rewriting sections of the piece; resubmitting the manuscript; or general correspondence regarding the submitted work. In order to complete the process, one needs continuing focus on and dedication to the research process. Naturally, it is exhilarating when we as the research team hear that our work has been accepted for publication. The relief and joy is palpable when our research and writing is fully finished as well as when our team's work is finally viewable in print or online.

While doing my research, other ideas and questions to study quickly pop into my head, even for a second. It begins to be never ending. I find that enriches my life and my chaplaincy work.

Chapter 1, Part D

Research: A Backdoor Approach

Paul Bay, D.Min, BCC

About twenty years ago, I entered the field of research by way of the backdoor. I had been a chaplain in general hospitals for nineteen years and found my energy level growing around examining an idea in depth. I also was finding it difficult to have energy around seeing patients as my only responsibility. If someone had said, “You are doing research.” I would have disagreed and told them I was doing a study. I am, and have always been, first of all, a clinician or spiritual care provider. Still, my path did change to include research along with spiritual care.

So, what combination of factors came together at that time in my life to turn me toward doing research? What was motivating me to do research? I have always done teaching as a chaplain and frequently when I gravitated toward teaching or learning a particular subject something in my personal history indicated a deficit or need. For example my pursuit of learning family systems came from such a need. Later, when I committed to teach an in-depth course on boundaries, I became aware that I needed to do some serious boundary work myself. I wondered if that was the same way I got into doing research.

In 1992 I felt discontent in both the leadership of my department and my particular workload. Eric Hoffer’s concept of discontent being at the heart of the creative process comes to mind. I was discontented and part of my passion for new learning came from that discontent. I had a burr in my saddle. I am a driven person and I had passion around the issue of values in healthcare leadership.

At that time, there were several factors that converged that offered me direction:

1. I was part of a Catholic healthcare system, and in that arena there was a lot being written about values in leadership.
2. Our nation was in a leadership crisis, so leadership issues were commonly in the forefront of public thought.
3. My systems training contributed to my thinking that I could make a larger contribution to our profession.
4. I have an academic bent and had developed networks with many friends who had doctorates and were continually engaged in research.

My daily work of providing therapy in a primary care center and teaching resident physicians contributed to a strong sense of self-confidence. I met weekly with several of these professional friends and talked freely of a study to examine values of healthcare leaders and how those values got integrated in day-to-day decisions. My friends said, “You are going to do the work, you might as well get credit for it. Go back and get your doctorate.” So that is what I did. They were very supportive of my ideas but also offered a suggested structure to get this done.

Several other factors were a part of this equation. I have always enjoyed expanding my learning and breaking new ground in my field. I had become a Clinical Member of the American Association for Marriage and Family Therapy in 1981 while continuing fulltime chaplaincy. I moved from hospice/oncology chaplain to oncology only, then on to becoming a pastoral counselor in a primary care center in 1993. This gave me the time needed to do research in my doctoral program. The encouragement to live your life in chapters, offered by Elton Trueblood, influenced me. I need the variety of new challenges in ministry. My desire to learn and ability to network moved me along this path toward research. I had enough discipline to complete the doctoral work which included two research projects.

I received my doctoral degree in 1997 and continued my ministry as a pastoral counselor and teacher in the primary care center. I continued to take on-call chaplain duties and see hospitalized patients as a chaplain throughout my career. In 2000 my drive and need for variety in ministry helped me write and receive one of the first-ever John Templeton Spirituality and Medicine Awards in Primary Medicine. At the same time my networking with three major health care systems as part of my doctoral research paid off. I got noticed. The manager of Spiritual Care of IU Health invited me to join their staff as a half-time researcher and half-time spiritual care provider. I took that opportunity. I was continuing to move into research by the backdoor. I had not intentionally moved toward research. It had been required in my doctoral work and now I was being invited to be a researcher/chaplain.

Reviewing what got me to this spot, I find the confluence of both personal and systemic factors. My family of origin taught me to work hard. The five years given to obtaining my doctorate was in addition to fulltime employment. Self-confidence and assertiveness were needed to talk with CEO's and CFO's of four large health care systems in which I did my research. I used the same qualities and persistence to obtain funding to complete my research studies. I was often told "No" but kept on asking until I got "Yes".

On the other hand, networking meant teams of people made the research work in multiple locations. System leaders were eager to learn how their values influenced their leadership decisions. They freely gave of their time and told me the best leadership books and articles to read as well as tests to use. Openness to recognizing that others had better ideas than I did help me to complete my studies. Seminary professors and colleagues made many useful recommendations as to how do the research.

There were barriers that I had to overcome to complete my research. Early in my planning I talked with my Vice President about the possible study. She thought it was a very bad idea. She told me she didn't think I had the ability to do this research nor did she feel I should do it. Thankfully, others I trusted encouraged me and thought it would be good research. Time was another barrier. I made choices to use my own time as well as part of my work time to complete the research. Vacation days and some weekend time were relinquished to meet my goal. Discouragement is part of research, and people dropped out of the study and potential data was lost. One's *attitude* as a researcher is major. I find this

quote by Nelson Mandela on my door describes research as a major project nears its end, "It always seems impossible until it's done."

In my new setting of IU Health, my manager and vice president had confidence that I could do research. However, they also knew I had to learn more. So they sent me to Barnes/Jewish Hospital to learn from chaplain Art Lucas and his staff. Those few days were invaluable in learning how "The Discipline" works and later applying some of it to my research. My system gave me time to form questions about which I was passionate. Research calls for passion! I was given space to see fewer patients than other staff chaplains in order to do research well. I needed the time.

There are several kinds of research. What IU Health leadership wanted and what I did, was randomized controlled studies. My own initial ignorance of what it takes to complete a good randomized controlled study was probably a gift. I had the wisdom to ask for a good deal of help. I had the gift of generous doctors, a biostatistician, a vice president consultant, and investigational review board members to guide me. Both chaplain/authors Larry VandeCreek and George Fitchett offered direction in my thinking which sometimes lacked the focus needed to be successfully researched.

I probably went into research partly because on an unconscious level I needed to learn how to be more disciplined in my spiritual care and in the documentation of spiritual care. I was painfully aware that people of other disciplines had written some of the best books about spiritual care. For example psychologist Paul Pruyser, (*The Minister as Diagnostician*) greatly contributed to our field. Harold Koenig and other physicians had written much of the research that chaplains read. So I felt a sense of duty that I should contribute research into our field. I wanted my studies to be directly about spiritual care interventions and their effectiveness—and they have been.

So what has worked and not worked for me in this researcher journey? Passion to learn something new in our field has been major. In my experience, research has always encounters unexpected obstacles so endurance and motivation are essential. Know your strengths and weaknesses. Use your strengths and address your weaknesses. For example, I have the strength of being able to recruit players who are willing to contribute to a project. I have the weakness of not being thorough or detail-focused. Yet, I was able to hire a research assistant for three projects who compensated for these weaknesses. Doing a pilot project to test the feasibility of a proposed study can help you to correct potential problems and anticipate obstacles that otherwise could delay or even derail your project. Talking with doctors before you make any intervention with their patients is necessary. Communicate with your research colleagues continually throughout the study. Follow the suggestions of any board that is giving you grant money and develop an advisory board with whom to share concerns and results throughout the study. Have someone else obtain the informed consent, and do all testing. I believe people have a bias to please clergy so we should not expect unbiased self-reporting to us. Don't get too attached to the results. Rather view research as a learning tool. You will always learn something from doing research.

I have let research be a tool for me to accomplish better spiritual care. I have provided better spiritual care to my heart surgery patients during my studies. I provided better spiritual care to nurses in a study enhancing their understanding of spirituality as a form of self-care. I am also humbled to have built on the work of many other researchers and contributed some small pieces to our understanding of better spiritual care.

Chapter 2

Identifying and Overcoming Obstacles to Chaplaincy Research

Initial Thoughts and Observations – General Obstacles to Chaplains Engaging in Research in Health Care

Dane Summers, D.Min., BCC and John Lantos MD

Those of us who have done graduate and post-graduate theological studies -- an in-depth immersion in sacred texts -- most often came out of undergraduate programs in the humanities, literature, and social sciences. That does not mean that we no longer believe in the merits of science or feel the need to divorce ourselves from the great achievements that have resulted from science; it only means that we may have spent our time and energy elsewhere. Our domain is built on exegesis and homiletics, community development and pastoral care, justice and vision.

As chaplains we focus on narrative, both hearing and telling stories about people and their encounters with the sacred. We seek to understand and define the nature of existence and discover the essence of self and other. There may have been little or no time to grapple with the key elements of research as they exist in health care. The result may be that one of the biggest obstacles to research in chaplaincy is our lack of education: *we just never acquired the skills to know where to begin.*

Introduction

Chaplains face real challenges as they give more consideration to the importance of research. This chapter describes some of the factors that have prevented chaplains from developing a robust research tradition.

To explore these issues, we will discuss what we have learned from our experience in a research project involving a full department of chaplains within a hospital. Our project was designed to observe the interactions of chaplains with patients, families and health professionals during the first 72 hours after a child was admitted to the hospital with a life-threatening condition.

The chaplains involved in this research project had many responsibilities:

- They helped us design the study. They, themselves, were both research collaborators and study subjects.
- Each time a new eligible family was present, the chaplain who would be providing pastoral care had to notify the research assistant (RA).
- The chaplain then met with the RA before their first interaction with the family.
- The chaplains involved in the study were the ones who sought the initial verbal consent from the family (the RA would return, later, for a full written consent.)
- The chaplains had to allow the research assistant to observe all of their interactions over the next few days.

- The chaplain then had to write a verbatim-like report about the case.
- Finally, the chaplain then discussed their report with an interdisciplinary panel of experts a few weeks later.

Different ways of knowing and valuing experience

The nature of the work that chaplains do gives a clue about the reasons why they might be reticent or skeptical about the value or the appropriateness of observation and measurement. Chaplains' work is more focused on empathic or spiritual attunement with patients and families than it is on quantitative measures of their work or its outcomes. Daily, chaplains are drawn into emotionally complex situations that involve multiple family members, multiple psychological and spiritual and sometimes economic agendas. The chaplain must quickly assess the situation in a way that allows them to offer the sort of care and comfort that are most needed without overstepping poorly defined boundaries or breaking un-codified rules.

Chaplains are adroit and balanced in moments and in situations that often leave other health care professionals confused and imbalanced. They do the things that they do in particular ways because those ways of doing things reflect the ways in which they think about who they are and the ways that they conceptualize their work. For many, an important aspect of their work is their relationship with the divine or the sacred. There is some justifiable skepticism as to whether empirical studies will adequately capture this aspect of their work in an accurate, meaningful, or even minimally comprehensible way. We were able to document these types of general chaplain concerns when we did pre-study interviews with the chaplains involved in our research. In these interviews, we asked, among other things, about their attitudes and concerns about the research project. Here are some of their responses (their names have been changed) from the pre-research interviews:

- **Chaplain Barbara:** I think all of us are a little nervous about being observed because that's the kind of mysterious nature of chaplaincy.
- **Chaplain George:** The most amazing thing about this God that I am kind of getting introduced to is that He makes himself accountable to us. I think we should be accountable even more than we are. It's no ding on my character if somebody looks at me and says 'boy you really screwed up there.' I would say: 'man, thanks. Let's see how we can try to address this.' And that comes from age, experience, and theology. My theology says if I'm not willing to be accountable, then I've missed the point. So I like it.
- **Chaplain Teri:** I think it's a good project. I just kind of wonder how it's all going to work out. I think it's a good start. There's some anxiety about it too. I think it's just the timing. More patients and more responsibility on the floor, more deaths. I just think it also is the timing, for me. But do I think it's a great thing that we can make it a model? I do, and I'm excited that we've had it.
- **Chaplain Charlotte:** I don't like to be hovered over, nobody does. At the same time I think about what I've learned. One of the themes in spirituality is to learn to let go of the ego and the pride in that sense of accomplishment and so forth, and to be more open, just be present, and let whatever it is God wants to have worked through happen. I can still be anxious but I know that when I come to the time and I get myself centered, I'll just do it. And

I might not even be happy with the results, but that's true with anything. You pray and may not be happy with the results.

- **Chaplain Kim:** In the beginning, I was skeptical. I had a lot of questions because it was so free-ranging. I didn't think that (the researchers) had any concept of what it is we really do. I think it's anxiety-provoking for myself and I think some of my colleagues, just the part of being observed.
- **Chaplain Jen:** The good, the bad and the ugly. I'm sure someone has probably already told you this, but we have a lot going on in our department right now and I think it just feels like another layer of, you know, how can we do all this and do all the other stuff. On its own, I think there's probably some very good things that can be learned from it, and I think we will grow as chaplains, but I think we are all going to feel kind of a burden right now, for the next few months, from it.
- **Chaplain Kiera:** I think it's great. I think it's wonderful. I think, you know, I'm all for doing that. The only thing is, is this really going to work if I'm working nights?
- **Chaplain Nina:** It is somewhat uncomfortable for me. I almost feel like we're warriors coming in on a tragic time on people. The other is a personal thing. Whenever I am followed around, those are always my worst encounters. Having someone look over me makes me a worse chaplain, and I don't want to do that to somebody.

Implementation of the Research Project

One of us, DS, is the Director of Chaplaincy Services. We had initially designed the project without collaborating with the chaplains themselves in the study design. We had hoped that he would have been able to anticipate many of the chaplains' concerns. He could. But it would have made more sense to involve the chaplains from the very beginning.

Once we were funded and ready to implement the project, we called a meeting to explain the project to the staff chaplains. We explained how they would be both collaborators with the researchers as well as study subjects in the research. This split role took some discussion. They were collaborators when, in meetings such as the one we called to introduce them to the project, we sought their input into the study design and methods. They relished this role, and had many excellent suggestions for ways to improve the study design.

For example, one of the issues was whether the research assistant who would be observing the chaplains ought to be a chaplain himself or whether we would be better off finding somebody who was trained in ethnography and so had expertise in participant-observation but who knew little about chaplaincy. The chaplains clearly preferred the former approach. The reasons, it seemed, reflected their concerns about the ways in which an observer might interfere with the work that they were doing with families. A chaplain-observer, they thought, would be more likely to understand and therefore not be a barrier to the work. We had discussions about the best way to seek parental consent to be observed. We wanted to be sure that they felt free to refuse, wanted to explain the ways in which the observation would be unobtrusive, and didn't want to introduce the study in a way that would distract from the important work that the chaplains were doing in their first interactions with a suffering family. With the input of the staff chaplains, we developed a two-phase consent process. During the initial meeting, families would be asked to give a brief oral consent to allow the observer to be present during the initial interaction. If they agreed to that, they would be re-approached sometime during the next 24 hours with a full

written consent form, explaining the reasons for doing the study and the details of how the study would work.

From Our Research Project:
“Obstacles” To Chaplain Participation In Research
and Ways We Approached These “Obstacles”

Time Concerns

Chaplains are quick to point out that there are “obstacles” that prevent them from even considering the possibility of making research part of their work. Concerns that we heard frequently were:

- participation in the research was going to be time consuming
- participation would require them to work extra hours
- participation would require them to sometimes work in settings outside their usual comfort zone, and
- participation would require them to face the stress of an evaluation in a multidisciplinary group meeting.

These were all valid concerns. There was, undeniably, extra work. We reimbursed the chaplains for their extra work but, even so, the work had to be done. And much of the work was the work of detail write-ups of their cases that took not only time but also energy and creativity. Much of the anxiety related to research can be lessened by acknowledging that most of the obstacles related to research in chaplaincy can be anticipated and managed with a clear understanding of the goals of research.

**Understanding What “Research” Actually Is
and Why Chaplains Should Participate**

Chaplains often think that research is synonymous with “experimentation,” that is, engaging in unknown, unusual and risky interventions with patients. Thus, a key component of our initial work with the staff chaplains was to spend some time articulating a clear and concise definition of research as a direct way to help them overcome resistance to doing research.

Definitions of research are contentious in many fields and even in federal regulations. For some people “research” is synonymous with “experimentation.” In that sense, research is almost inevitably risky and exploitative. We are trying new things on patients or families who cannot understand that they are, essentially guinea pigs. Informed consent is designed to ameliorate these problems. However, there are well-known problems with informed consent.

Research, as defined by federal regulations, is categorized by its intentions rather than by its level of risk or its innovativeness. Research is any activity that has as its goal the creation of generalizable knowledge. The activities that lead to this goal generally involve systematic

collection of data and analysis of the data. Something is considered research if there is an intention to publish or share publically the results of new information that is being gathered by an investigator. Sharing the data publically is a necessary aspect of making it “generalizable.”

So, for example, if a chaplain is gathering data about how many visits are made in a week but only intends to share that information with a manager, that chaplain is not engaging in research. If, however, a chaplain gathers the same data with the intent of demonstrating the efficacy of her work with a particular patient group, or to compare two different approaches to, say, making a spiritual assessment or conducting a life review, that may be research. It may also be quality improvement. If the chaplain *intends* to publish the results in a journal article or use the data in a public workshop, then the chaplain is engaging in research. This definition broadens the idea of research. It also distinguishes many low-risk research activities from higher risk activities that are not research.

The reason why data should be shared is that it allows others to try to replicate the study. This is an important component of the scientific method. The science behind research is designed to assure that the conclusions being suggested by an investigator can be repeated and thus that the data are generalizable and, therefore, valid. When results can be repeated they can be studied for their effectiveness, the results of which continue improvement of the quality of care and establishment of “best practice.” While the aim of internal quality improvement initiatives also seeks to define best practice, research has a broader and less-defined audience.

Further, as part of our initial work with the chaplains and finding ways to overcome their resistance to engage in research, we also had discussions about the ways in which research is essential to the ongoing professional development of chaplaincy and pastoral care. In these discussions, we talked about research as a component of personal professional development – that is, each chaplain might find new sorts of career paths and career fulfillment by getting involved in research – as well as a component of the professional development of the field of chaplaincy and pastoral care.

Research and Institutional Mission

The relationship between a chaplains’ regular work, their work on research projects, and a hospital’s institutional mission can be complex. In our own situation our hospital has not traditionally prioritized research. Instead, its primary missions have been patient care and medical education. But this is starting to change. As a result of the change, many of the chaplains in the department were caught – as it were – between missions. They couldn’t figure out whether participation in research was now to be seen as part of their job or whether the project was a sort of extra-curricular activity. In a sense, this intra-institutional confusion or change mirrored a change in the field of chaplaincy nationally. Traditionally, the field has not been research-oriented. But that is starting to change. It is essential that chaplains get connected with the research vision of their organization. Research has an enormous impact on current and future health care. Patients of all ages take part in research protocols as a routine part of their care. Funding sources for new

drugs and procedures come from private, commercial and governmental sources that are interested in new treatment possibilities.

Internal management decisions are sometimes made on the basis of the likelihood that new programs can generate research dollars. Chaplains must ask themselves if they are being left out of the security and creativity that is research. Does this increase the split between chaplaincy departments and other departments that can create revenue streams by applying for grants and other funding sources?

Even if chaplains have a visible connection with the research vision of their institution, many are concerned because there just isn't enough time in the day to get everything done, much to less spend time on research. Admittedly, chaplains are stretched by the emotional and spiritual needs of the patients, families, staff and communities they serve. We are sometimes forced to make decisions about where to put our creative energy. In most cases chaplains are embedded in departments that are non-revenue producing and may not have enough staffing to cover essential functions for emergencies or night time staffing. The vision of having time to sit at a desk in the middle of the day to read journal articles and write papers is a luxury that many chaplains can't even afford to ponder because of the daily needs of seeing patients and providing staff support. It is hard enough to complete the daily requirements for documentation and productivity reporting without finding more time to think about research.

One of the great challenges for many chaplains in many institutions is the gap between their activities and the overall goals and mission of the organization. Chaplains often work in an environment where there is a perception that they are isolated from administrative decision making. This may result in departments that are underfunded and understaffed. This may also make it difficult to become attached to research programs and goals that promote research for many departments or individuals but do not reach all the way to chaplaincy.

So, is research something left to the handful of departments of chaplaincy service that are large enough to cover the broad clinical needs of an institution and have resources adequate for extra activities? Is it left to departments that are connected with and/or found within university settings or post-to graduate medical education? Is it left to departments that are connected to Clinical Pastoral Education (CPE) programs? Or is research relegated to departments that are large enough to have managers who are freed from daily clinical assignments? Each of the settings described in the above questions brings with them certain concrete obstacles that are well known by those who work in these settings. Each has their own specific combination of opportunities and obstacles that depend on available resources and the institutions' role expectations for chaplains. In the next section we identify a more personal source of obstacle.

Hesitance For the Sake of Hesitance?

While the above mentioned concerns seem fairly obvious are there obstacles to research that are less definitive, almost ethereal? Are chaplains hesitant to engage in research for

reasons that have more to do with the essence of what it means to be a chaplain? Are we hesitant to do research because we are...hesitant? Hesitance is a good word to use here. There may be some chaplains who are “resistant” to doing research. Our conversations about research may include notions that research gets in the way of the development of communication and relationship building. Some might say research is awkward or unwieldy. Most of the time, however, we are hesitant to engage in research because we are not sure how it will impact the notion of a sacred presence that is implicit to all chaplaincy interactions.

Chaplains have not been drawn to research as a central component of their professional identity. Like many other health care practitioners – social workers, child life workers, and patient advocates, for example – they have seen their work as being of a nature that makes empirical research difficult and often meaningless. When chaplaincy work is studied, the chaplain becomes an object of study. When the chaplain is also the researcher, s/he can be called upon to play the roles of scientist, practicing chaplain, and research subject all at the same time. Some chaplains fear that they will lose balance as they try to play these three roles.

Conclusion

Five Recommendations for Overcoming Obstacles and Barriers

There are five things that every chaplain can do to overcome the obstacles and barriers that seem to get in the way of doing research:

First, chaplains must acknowledge that the future of health care rests on the shoulders of research. The enormous cost of health care has already eroded the philanthropic vision from many health care institutions. Hospitals that are affiliated with religious organizations are seeking corporate partners from the “for profit” world. Community hospitals that once proudly provided care to uninsured or disempowered populations are facing enormous difficulties to stay fiscally secure. The “safety net” is becoming unraveled and frayed. The ability to predict the furtive targets of concerns such as access and reimbursement makes the job of many administrators akin to staring into a crystal ball for guidance. The old reliable formulas for funding based on predictable numbers of patients with private insurance have slowly dwindled as few individuals in the work force are fully insured. Research may provide the means for funding much of the infrastructure of health care. Pediatric cancer programs may provide the paradigm that will mark the future of health care. At the current time, nearly every pediatric patient who is diagnosed with cancer is enrolled in some type of oncology research protocol. New drugs, singly and in varied combinations, are used in trials where enormous amounts of data are collected measuring the efficacy of these new drugs and other methods. And some of the cost of treatment is being borne by drug manufacturers and research groups that use private and government funding to find a cure to childhood cancer.

Whether it is our study of genomics or genetics, cybernetics or nanotechnology, within the next decade nearly every person will be involved – perhaps without their knowledge – in some type of health related research. The corollary will be that every thriving discipline

will demonstrate best practice through research. Papers will be written, talks will be given. Our knowledge will increase. And a major portion of the funding will come from research sources. We must make the presumption that our funding in the future will come from sources that are interested in exploring the confluence of body and soul. We must drop our naïveté about the challenges that are confronting health care and move forward with the presupposition that the future of our discipline is dependent on our ability to become active contributors in the realm of research.

Second, every chaplain can benefit from developing a research mentor. Research requires skills. Some skills can be learned by taking courses in epidemiology, biostatistics, survey research, or social science. Others, however, require one-to-one mentorship. The most difficult problem in research is coming up with a good study question. The question must be focused, finite, interesting, not yet answered, and worth studying. This takes time and the experienced eye of an experienced researcher.

Third, chaplains must join the party. Health care in the U.S. is a sprawling, expensive, research-driven enterprise. Chaplains have long been part of this enterprise but have often remained on the periphery. Collaborative research is one way to join the party. To do so, chaplains will need to be willing to do studies, willing to be studied, and willing to present the results of these studies in the various venues in which biomedical research is disseminated, analyzed, and discussed.

Fourth, we must engage our administrators in the possibility of research. Research requires resources. Any important part of any institution's mission must be funded at a level that is realistic and sufficient to accomplish the mission. Research is no different. Chaplains need education in research methodology. They need dedicated mentors. Specific projects will have specific budgets. Chaplains, like other researchers, will eventually be required to seek and obtain extramural funding if they hope to continue their research. But it will be impossible to compete for extramural funding without a track record of success in research and such a track record can only be established with institutional start-up support.

Our **fifth** recommendation is perhaps the most crucial. Chaplains must insist that research is an essential part of our job description. In doing this, chaplains should keep in mind the definition of research that has been offered above. Research does not necessarily involve innovation or change or risky interventions. Research is an activity defined by its goal – the goal of creating generalizable knowledge. To make research an essential part of each and every chaplain's job description means that each and every chaplain understands that the nature of the work we do requires a commitment to understanding what works, what doesn't, and how things work. We need to be curious, to interrogate ourselves and our world, and communicate the results of our searching explorations. We offer these lessons that we learned in carrying out a complicated project in pediatric palliative care. We hope they start conversations among others that will lead to similar and better research.

Chapter 2

Identifying and Overcoming Obstacles to Chaplaincy Research

Initial Thoughts and Observations – General Obstacles to Chaplains Engaging in Research in Health Care

Dane Summers, D.Min., BCC and John Lantos MD

Those of us who have done graduate and post-graduate theological studies -- an in-depth immersion in sacred texts -- most often came out of undergraduate programs in the humanities, literature, and social sciences. That does not mean that we no longer believe in the merits of science or feel the need to divorce ourselves from the great achievements that have resulted from science; it only means that we may have spent our time and energy elsewhere. Our domain is built on exegesis and homiletics, community development and pastoral care, justice and vision.

As chaplains we focus on narrative, both hearing and telling stories about people and their encounters with the sacred. We seek to understand and define the nature of existence and discover the essence of self and other. There may have been little or no time to grapple with the key elements of research as they exist in health care. The result may be that one of the biggest obstacles to research in chaplaincy is our lack of education: *we just never acquired the skills to know where to begin.*

Introduction

Chaplains face real challenges as they give more consideration to the importance of research. This chapter describes some of the factors that have prevented chaplains from developing a robust research tradition.

To explore these issues, we will discuss what we have learned from our experience in a research project involving a full department of chaplains within a hospital. Our project was designed to observe the interactions of chaplains with patients, families and health professionals during the first 72 hours after a child was admitted to the hospital with a life-threatening condition.

The chaplains involved in this research project had many responsibilities:

- They helped us design the study. They, themselves, were both research collaborators and study subjects.
- Each time a new eligible family was present, the chaplain who would be providing pastoral care had to notify the research assistant (RA).
- The chaplain then met with the RA before their first interaction with the family.
- The chaplains involved in the study were the ones who sought the initial verbal consent from the family (the RA would return, later, for a full written consent.)
- The chaplains had to allow the research assistant to observe all of their interactions over the next few days.

- The chaplain then had to write a verbatim-like report about the case.
- Finally, the chaplain then discussed their report with an interdisciplinary panel of experts a few weeks later.

Different ways of knowing and valuing experience

The nature of the work that chaplains do gives a clue about the reasons why they might be reticent or skeptical about the value or the appropriateness of observation and measurement. Chaplains' work is more focused on empathic or spiritual attunement with patients and families than it is on quantitative measures of their work or its outcomes. Daily, chaplains are drawn into emotionally complex situations that involve multiple family members, multiple psychological and spiritual and sometimes economic agendas. The chaplain must quickly assess the situation in a way that allows them to offer the sort of care and comfort that are most needed without overstepping poorly defined boundaries or breaking un-codified rules.

Chaplains are adroit and balanced in moments and in situations that often leave other health care professionals confused and imbalanced. They do the things that they do in particular ways because those ways of doing things reflect the ways in which they think about who they are and the ways that they conceptualize their work. For many, an important aspect of their work is their relationship with the divine or the sacred. There is some justifiable skepticism as to whether empirical studies will adequately capture this aspect of their work in an accurate, meaningful, or even minimally comprehensible way. We were able to document these types of general chaplain concerns when we did pre-study interviews with the chaplains involved in our research. In these interviews, we asked, among other things, about their attitudes and concerns about the research project. Here are some of their responses (their names have been changed) from the pre-research interviews:

- **Chaplain Barbara:** I think all of us are a little nervous about being observed because that's the kind of mysterious nature of chaplaincy.
- **Chaplain George:** The most amazing thing about this God that I am kind of getting introduced to is that He makes himself accountable to us. I think we should be accountable even more than we are. It's no ding on my character if somebody looks at me and says 'boy you really screwed up there.' I would say: 'man, thanks. Let's see how we can try to address this.' And that comes from age, experience, and theology. My theology says if I'm not willing to be accountable, then I've missed the point. So I like it.
- **Chaplain Teri:** I think it's a good project. I just kind of wonder how it's all going to work out. I think it's a good start. There's some anxiety about it too. I think it's just the timing. More patients and more responsibility on the floor, more deaths. I just think it also is the timing, for me. But do I think it's a great thing that we can make it a model? I do, and I'm excited that we've had it.
- **Chaplain Charlotte:** I don't like to be hovered over, nobody does. At the same time I think about what I've learned. One of the themes in spirituality is to learn to let go of the ego and the pride in that sense of accomplishment and so forth, and to be more open, just be present, and let whatever it is God wants to have worked through happen. I can still be anxious but I know that when I come to the time and I get myself centered, I'll just do it. And

I might not even be happy with the results, but that's true with anything. You pray and may not be happy with the results.

- **Chaplain Kim:** In the beginning, I was skeptical. I had a lot of questions because it was so free-ranging. I didn't think that (the researchers) had any concept of what it is we really do. I think it's anxiety-provoking for myself and I think some of my colleagues, just the part of being observed.
- **Chaplain Jen:** The good, the bad and the ugly. I'm sure someone has probably already told you this, but we have a lot going on in our department right now and I think it just feels like another layer of, you know, how can we do all this and do all the other stuff. On its own, I think there's probably some very good things that can be learned from it, and I think we will grow as chaplains, but I think we are all going to feel kind of a burden right now, for the next few months, from it.
- **Chaplain Kiera:** I think it's great. I think it's wonderful. I think, you know, I'm all for doing that. The only thing is, is this really going to work if I'm working nights?
- **Chaplain Nina:** It is somewhat uncomfortable for me. I almost feel like we're warriors coming in on a tragic time on people. The other is a personal thing. Whenever I am followed around, those are always my worst encounters. Having someone look over me makes me a worse chaplain, and I don't want to do that to somebody.

Implementation of the Research Project

One of us, DS, is the Director of Chaplaincy Services. We had initially designed the project without collaborating with the chaplains themselves in the study design. We had hoped that he would have been able to anticipate many of the chaplains' concerns. He could. But it would have made more sense to involve the chaplains from the very beginning.

Once we were funded and ready to implement the project, we called a meeting to explain the project to the staff chaplains. We explained how they would be both collaborators with the researchers as well as study subjects in the research. This split role took some discussion. They were collaborators when, in meetings such as the one we called to introduce them to the project, we sought their input into the study design and methods. They relished this role, and had many excellent suggestions for ways to improve the study design.

For example, one of the issues was whether the research assistant who would be observing the chaplains ought to be a chaplain himself or whether we would be better off finding somebody who was trained in ethnography and so had expertise in participant-observation but who knew little about chaplaincy. The chaplains clearly preferred the former approach. The reasons, it seemed, reflected their concerns about the ways in which an observer might interfere with the work that they were doing with families. A chaplain-observer, they thought, would be more likely to understand and therefore not be a barrier to the work. We had discussions about the best way to seek parental consent to be observed. We wanted to be sure that they felt free to refuse, wanted to explain the ways in which the observation would be unobtrusive, and didn't want to introduce the study in a way that would distract from the important work that the chaplains were doing in their first interactions with a suffering family. With the input of the staff chaplains, we developed a two-phase consent process. During the initial meeting, families would be asked to give a brief oral consent to allow the observer to be present during the initial interaction. If they agreed to that, they would be re-approached sometime during the next 24 hours with a full

written consent form, explaining the reasons for doing the study and the details of how the study would work.

From Our Research Project:
“Obstacles” To Chaplain Participation In Research
and Ways We Approached These “Obstacles”

Time Concerns

Chaplains are quick to point out that there are “obstacles” that prevent them from even considering the possibility of making research part of their work. Concerns that we heard frequently were:

- participation in the research was going to be time consuming
- participation would require them to work extra hours
- participation would require them to sometimes work in settings outside their usual comfort zone, and
- participation would require them to face the stress of an evaluation in a multidisciplinary group meeting.

These were all valid concerns. There was, undeniably, extra work. We reimbursed the chaplains for their extra work but, even so, the work had to be done. And much of the work was the work of detail write-ups of their cases that took not only time but also energy and creativity. Much of the anxiety related to research can be lessened by acknowledging that most of the obstacles related to research in chaplaincy can be anticipated and managed with a clear understanding of the goals of research.

**Understanding What “Research” Actually Is
and Why Chaplains Should Participate**

Chaplains often think that research is synonymous with “experimentation,” that is, engaging in unknown, unusual and risky interventions with patients. Thus, a key component of our initial work with the staff chaplains was to spend some time articulating a clear and concise definition of research as a direct way to help them overcome resistance to doing research.

Definitions of research are contentious in many fields and even in federal regulations. For some people “research” is synonymous with “experimentation.” In that sense, research is almost inevitably risky and exploitative. We are trying new things on patients or families who cannot understand that they are, essentially guinea pigs. Informed consent is designed to ameliorate these problems. However, there are well-known problems with informed consent.

Research, as defined by federal regulations, is categorized by its intentions rather than by its level of risk or its innovativeness. Research is any activity that has as its goal the creation of generalizable knowledge. The activities that lead to this goal generally involve systematic

collection of data and analysis of the data. Something is considered research if there is an intention to publish or share publically the results of new information that is being gathered by an investigator. Sharing the data publically is a necessary aspect of making it “generalizable.”

So, for example, if a chaplain is gathering data about how many visits are made in a week but only intends to share that information with a manager, that chaplain is not engaging in research. If, however, a chaplain gathers the same data with the intent of demonstrating the efficacy of her work with a particular patient group, or to compare two different approaches to, say, making a spiritual assessment or conducting a life review, that may be research. It may also be quality improvement. If the chaplain *intends* to publish the results in a journal article or use the data in a public workshop, then the chaplain is engaging in research. This definition broadens the idea of research. It also distinguishes many low-risk research activities from higher risk activities that are not research.

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Chapter 3

Chaplain Research: What is it? How is it done?

Betty Ferrell, PhD, RN, MA, FAAN, FPCN, CHPN

Introduction

My entry as a nurse into the world of research came about probably in a way similar to many chaplains. I was dedicated to a clinical career and the idea of research was far removed, in many ways opposite to all that I thought was important. My place was at the bedside. As an undergraduate nursing student I vowed that if I survived and graduated to become a nurse I would never go to school again.

So how did I go from reluctant researcher to now 37 years later having completed a doctorate in 1984 and having devoted the 30 years since to research? My draw to a research career was based on my initial 3 years in clinical practice during which I became acutely aware of the need to improve the quality of care I observed in the clinical setting. I became increasingly aware that in order to make change, I needed data. To convince administration of the services that patients needed, I needed data. And to “prove” that the care I had advocated for was indeed successful, I needed data. Thus my Master’s degree and Doctoral program were essential steps to provide me with tools I needed to improve care.

The emphasis on outcomes and the need for data has increased exponentially in the years since my decision to pursue research. Measuring outcomes of medications or physical treatments is challenging but documenting outcomes of psychosocial and spiritual care is extremely difficult. Yet there has never been a more important time to measure aspects of spiritual care in order to document needs and evaluate outcomes.

Over the past 30 years most of my research has been guided by the City of Hope conceptual model of Quality of Life (QOL). The QOL model (Figure 1) includes four domains of physical, psychological, social and spiritual well-being. My colleagues and I have developed several versions of our QOL instrument and models which are available through our website, the City of Hope Pain / Palliative Care Resource Center (<http://prc.coh.org>). With great confidence I can share that inclusion of the spiritual domain has added valuable information for every study we have conducted at City of Hope over these years. We have assessed spiritual well being as a component of quality of life in those newly diagnosed with cancer, those undergoing treatment, in long term survivors, and in those at the end of life. We have also assessed spirituality in family caregivers.

Example Study

The study I have selected to share here is provided as an example of collaboration to advance research and clinical practice. It involves both quantitative and qualitative data. The study began when a colleague, Dr. Christina Puchalski, approached me with a request to assist in evaluation of the FICA tool used for many years in her clinical practice. The FICA tool (Figure 2) is widely used by researchers and clinicians around the world as a clinical

assessment instrument as well as a research tool. FICA is an acronym for Faith, Importance and Influence, Community and Address and is described further below.

Dr. Puchalski is often approached by clinicians and researchers to share her tool and those interested in its use frequently have asked for any psychometric data available to support the FICA tool as a valid and reliable instrument.

Study Methods

As described above the aim of this study was to provide preliminary clinical evaluation of the feasibility and usefulness of the FICA Spiritual Assessment Tool. The study was approved by the Institutional Review Board (IRB) which approves any research involving human subjects. IRB review is concerned with issues such as assuring that subjects understand the research they are agreeing to participate in and potential benefits or harms.

Seventy-six patients with solid tumors (breast, lung, colon, prostate) participating in a larger NCI funded study (Reducing Barriers to Pain and Fatigue Management, R01-CA115323-4; B Ferrell, P.I.) in one comprehensive cancer center were asked if they would be willing to answer questions regarding their spirituality. Their responses were written by the patient on the survey or recorded by the nurse. Eligibility criteria from the larger study included (1) cancer diagnosis greater than one month, (2) age over 18, and (3) English speaking. Patients were asked the FICA interview questions by the research nurse in a private area in the clinic. Demographic data and Quality of Life items were derived from the parent study using the City of Hope Quality of Life (COH-QOL) Tool, a 45-item multidimensional tool encompassing the four domains of Physical, Psychological, Social, and Spiritual Well Being.

Content analysis is a common way to test new instruments in order to establish their validity. This means that the researcher wants to know if the instrument is really measuring the right content, so in this case, the question was to determine if this tool was really useful in assessing spiritual needs. Content analysis of the FICA interview questions was used to develop relevant themes or categories in order to understand subject's responses to the four items of the tool including: **Faith, Importance and Influence, Community, Address**. Using content analysis methods described by Waltz, Strickland, and Lenz (2005), data were summarized from each open-ended question and all data was entered into preliminary tables by question. Responses were coded by the investigators. All data was reviewed independently by the 3 investigators. The investigators then jointly reviewed the data, created final summary tables which were reviewed and discussed. Descriptive analysis of demographic data was conducted, as well as descriptive and correlational analysis of the QOL item scores and FICA. The study was published in *Journal of Pain and Symptom Management* and the demographic characteristics of the sample are included there. (Borneman, Ferrell, Puchalski, 2010)

Study Findings

Importance of Faith/Belief from FICA

The FICA is an open ended subjective scale and for this research we wanted to create a quantitative measure as well. After completing the open ended items of the FICA survey, subjects were asked “On a scale of 0 (not important) to 5 (very important), how would you rate the importance of faith/belief in your life?” This data was transposed for analysis to a 0 – 10 scale for comparison to the QOL items rated on a 0 -10 scale (Table 2). The mean score was 8.40 indicating subject’s beliefs that spirituality was an important aspect of their experience of illness.

Quantitative Assessments of Aspects of Spirituality (Table 3)

In order to understand the potential relationships between aspects of spirituality, correlations were computed between variables. Data for this analysis included the items of the Spiritual Well Being subscale of the QOL tool (spiritual activities, change in spirituality, uncertainty, positive life change, purpose, hopefulness) and the single items of pain, control, anxiety, depression and isolation from the physical and psychological subscales of the QOL tool. These variables were selected as aspects recognized as potentially contributing to spiritual distress. Additionally, the single item QOL rating was included. Correlations above $r=.30$ are included in bold to illustrate variables with moderate or strong correlation. The most significant information is shaded in Table 3 presenting the correlation of the FICA quantitative item with the other variables. The FICA item was moderately correlated with all items of the Spiritual subscale and the subscale total with the exception of the uncertainty item and the FICA item was not associated with the physical symptom items. This is an example of research which attempts to understand the relationship between different aspects of a person’s quality of life.

Qualitative Analysis of FICA

Tables 4 through 7 present the summary of themes from the qualitative analysis of responses to the FICA tool and representative comments from this question. Table 4 is a quantitative summary of key issues in response to the “F-Faith/Belief/Meaning” themes. The most common responses were related to Appreciation of Life and Family followed by Life Activities. Other responses included relationship with God and many other broad aspects of spirituality.

Table 5 describes the quantitative summary of the responses to the question of “I-Importance and Influence” themes and examples of patient comments regarding the importance and influence of spirituality. Faith or spirituality was important or very important and that faith or spirituality was identified as helping them control their stress. A number of subjects described their faith or spirituality as a major factor in their treatment decision making.

The “C” of the FICA tool represents a patient’s spiritual community. Subjects referred to family and friends’ support or referred to these supportive others who were praying for

them or were part of a church community. Table 6 presents the quantitative summary and comments.

The “A” of the FICA tool asks how the patient wishes spirituality should be addressed in their care. Some subjects believed that health care providers should focus on the “medical aspects” of care and should not focus on Spiritual Needs. Others did feel that attention to Spiritual Care was supportive and a chaplain should be available (**Table 7**).

Challenges in Spiritual Care Research

There are many challenges in conducting spiritual care research. Funding is often limited for research in this area and this study was possible without separate funding as we were able to amend an ongoing study related to pain management in which we had research nurses available and a population of patients. Chaplains should look for opportunities to collaborate with others to seize such opportunities. Chaplains can share their expertise to enrich the research of others so all can benefit.

Conducting spiritual care studies often is also a challenge as Institutional Review Boards are accustomed to pharmaceutical studies or clinical intervention trials so the instruments and methods may be unfamiliar to them. IRB’s may also be concerned that asking patients about sensitive topics such as spirituality will involve “harms” such as emotional stress. In this study and each of our projects involving spirituality we often have to devote significant time to IRB revisions in order to explain our studies and assure the IRB that we are prepared to respond to emotional concerns, including having chaplains available for patients who may voice spiritual distress in the process of participating in the study.

Across the years of my involvement in research, I do believe that there are important strides in advancing the importance of spirituality research. Increasingly, studies have documented that spirituality is a key domain of quality of life and patients do want spiritual care integrated into their health care. As with all aspects of care, improving the quality of spiritual care is dependent on an evidence base to guide that care.

Implications of the Research

Why research?

This study is an example of a project designed to support the use of the FICA spiritual assessment tool. The study used both quantitative and qualitative data. Responses from the subjects illustrate the importance of spiritual assessment and the valuable information that can be obtained to guide patient care. Research can be a vital tool for any clinician dedicated to improved care. Data from research can serve to assess needs, evaluate care provided, and to understand the relationship between key concepts or variables. Through research we can give voice to patient and family caregiver concerns and we can advocate for attention to needs that are often ignored.

Why now?

While there are many constraints in the current burdened health care system, there are also many opportunities. Attention to patient centered care and to quality improvement opens doors to address spiritual care as a key element of care. Professional chaplains are becoming valued members of interdisciplinary care across settings. Chaplains can be valued colleagues in palliative care research. Their knowledge and expertise adds unique perspectives to the interdisciplinary team.

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Figure 1.
QOL Model

Dimensions of *Quality of Life*

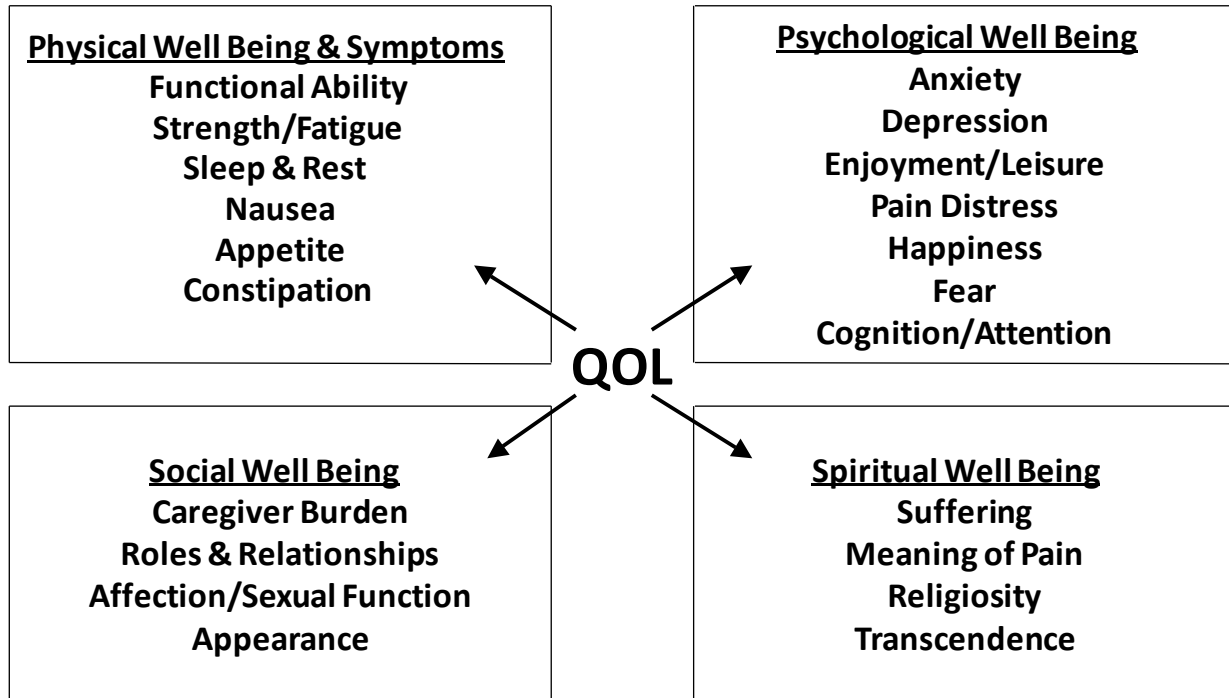


Figure 2.
FICA Tool

F – Faith, Belief, Meaning	<p>Religious/Religiosity – Pertains to one’s beliefs, behaviors, values, rules for conduct, and rituals associated with a specific religious tradition or denomination (O’Brien, 1999).</p> <p>Spirituality – Generally, an “individual’s attitude and beliefs related to transcendence (God) or to the nonmaterial forces of life and of nature...the dimension of a person that is concerned with ultimate ends and values” and meaning (O’Brien, 1982, p. 88; Taylor, 2006).</p>
<ul style="list-style-type: none"> Do you consider yourself spiritual or religious? 	
<ul style="list-style-type: none"> Do you have spiritual beliefs that help you cope with stress? 	
<ul style="list-style-type: none"> What gives your life meaning? 	
I – Importance and Influence	
<ul style="list-style-type: none"> What importance does your faith or belief have in your life? 	
<ul style="list-style-type: none"> On a scale of 0 (not important) to 5 (very important), how would you rate the importance of faith/belief in your life? 	
<ul style="list-style-type: none"> Have your beliefs influenced you in how you handle stress? 	
<ul style="list-style-type: none"> What role do your beliefs play in your healthcare decision making? 	
C – Community	
<ul style="list-style-type: none"> Are you a part of a spiritual or religious community? 	
<ul style="list-style-type: none"> Is this of support to you and how? 	
<ul style="list-style-type: none"> Is there a group of people you really love or who are important to you? 	
A – Address in Care	<p>We have talked a lot about your spirituality and/or religious beliefs and how they may or may not be of help to you during your illness. How can your health care providers best support your spirituality?</p>
<ul style="list-style-type: none"> How would you like your healthcare provider to use this information about your spirituality as they care for you? 	

Table 1.

Table 1 Inter-Item Correlation Matrix of Items from QOL Tool and FICA Quantitative Rating														
	Religion	Activities	Change	Uncertainty	Positive	Purpose	Hopeful	Pain	QOL	Control	Anxiety	Depression	Isolation	Spiritual Subscale
Activities	.617													
Change	.459	.433												
Uncertainty	.173	.104	-.190											
Positive	.421	.457	.508	.114										
Purpose	.422	.412	.352	-0.25	.391									
Hopeful	.299	.346	.225	.186	.268	.650								
Pain	-.173	-.237	-.131	-.007	-.188	-.129	-.046							
QOL	.065	.139	.030	.272	.160	.223	.321	.298						
Control	.069	.019	.009	.100	.016	.177	.392	.183	.458					
Anxiety	.043	.069	.043	.503	.013	.043	.115	.186	.249	.336				
Depression	.045	.063	.085	.465	.044	.005	-2.35	.122	.097	.304	.702			
Isolation	.230	.169	.074	.145	.078	.012	.136	.311	.346	.454	.376	.560		
FICA Quantitative	.535	.545	.405	.014	.306	.568	.369	.208	.115	.024	.063	.037	.066	.467

Key: Actual Items Used:
 Religion = How important to you is your participation in religious activities such as praying, going to church?
 Activities = How important to you are other spiritual activities such as meditation?
 Change = How much has your spiritual life changed as a result of cancer diagnosis?
 Uncertainty = How much uncertainty do you feel about your future?
 Positive = To what extent has your illness made positive changes in your life?
 Purpose = Do you sense a purpose/mission for your life or a reason for being alive?
 Hopeful = How hopeful do you feel?
 Pain = To what extent are general aches or pain a problem for you?
 QOL = How good is your quality of life?
 Control = Do you feel like you are in control of things in your life?
 Anxiety = How much anxiety do you have?
 Depression = How much depression do you have?
 Isolation = How much isolation do you feel is caused by your illness/treatment?
 FICA Quantitative = How would you rate the importance of faith/belief in your life?

Table 2.

<i>"Do you consider yourself spiritual or religious?" or "Do you have spiritual beliefs that help you cope with stress?" If the patient responds "no," the physician might ask, "What gives your life meaning/"</i>	
Faith/Belief/Meaning Themes	N = 73
Appreciation of Life and Family	47
Life activities (work sense of purpose, friends, accomplishments, self sufficiency, productivity)	31
Faith/Hope in healing or in a higher being	18
Relationship with God/serving God	12
Appreciation for everything in life	7
Reading Bible	5
No identified faith tradition/Agnostic	5
Positive state of mind	5
Examples	
FICA001: Yes, I consider myself Catholic. I seek God almost every single day. I thank him for another day in life and... for opening my eyes to everything that's around me – the flowers, the trees, the beauty of things, the beauty of people. And, uh, I'm happy that I have the faith and that I have a lot of people that have been praying for me and my recovery. Oh, my family. I just love my family... I want to see my grandchildren grow up and enjoy life, you know, with my husband, get old with him.	
FICA004: I guess spiritual in some way, not formally religious because I was raised Catholic but I don't practice anymore. But I did appreciate the chaplain coming to see me. There's something about that that just makes you feel – just makes you feel good, so I did appreciate that. You know, everybody says, "Our thoughts and prayers are with you." I guess I appreciate that. I have a lot of friends who are religious and say that prayer helps them and I say, "Well, I hope your prayers help me."	
FICA007: Oh religious, well both. But spiritual kind of has a bad connotation, lots of people feel spiritual is a cop out... People can go to church regularly and be religious and not have a spiritual life so I would have to say both. God's in control and he is using me in some way... There has been a lot of people in our church with cancer... many of whom have died, but have been content... with their disease and situation and trusting God... the ones that have died they're like a great cloud of witnesses to me. They're my heroes... I got people in Turkana, Japan, Italy, Africa praying for me... I love the people in my church...I love being at my church... I have been blessed with a real good wife, who when she came to Christ uh just showed a difference... she wasn't pushy or anything but she was.	
FICA034: I consider myself a spiritual person not a religious person. We don't attend a church. But I do believe in a Higher Being and I have had to come to terms with my own mortality... as far as I feel there is a God... there's some plan to all of this and I have been given something that's difficult to get through, but I don't believe that I've been given anything more difficult than I can do... I do a lot of visualization, in order to maintain my level of anti-nausea... I call it "going to my zero place"...that helps my spiritual being as well.	
FICA036: I am a Christian. With God nothing is impossible... He has moved mountains for me. One thing I have realized is that it's not about me. I'm here to give Him the glory. I meditate on God's word... I believe that God is God and he is in control... I stand on His words. God is the whole source of my life. I just realize I am here to love Him, to serve Him, to serve my family, to serve others. It's just a neat time.	

Table 3.

<i>What importance does your faith or belief have in your life? Have your beliefs influenced you in how you handle stress? What role do your beliefs play in your healthcare decision making?</i>	
Importance and Influence Theme	N = 73
Faith is important or very important	56
Faith helps control stress	40
Prayer/faith as factor in treatment decisions	26
Faith equips in preparing/fighting/coping illness	10
Faith is not important/minimal importance	9
Faith helps make meaning	7
God is in control/doesn't give "more than we can handle"	5
Examples	
<u>FICA001:</u> Without faith and belief there is nothing, so you have to have faith in God that he's going to help you through this and also help your family to cope with it. So, having faith and showing that you have faith is very important. I try not to get stressed any more, because I find that some of these things that bring stress are so tiny compared to... how life is for other people.	
<u>FICA002:</u> Well, you know, God's in control of everything and for me to believe that he lost control when I got cancer is a pretty odd thing to think. I've come to the other side of this cancer and realized that with God even this cancer is a positive thing. Our relationship, husband and wife, is now closer. We had a good marriage. It was surrounded by our mutual belief in Christ... Stress is really just a feeling of chaos. When we're stressed it's because we don't think somebody's in control. And if you understand that God's always in control, there's no reason to be stressed out. I also believe the grace of God is enough to allow us to face anything.	
<u>FICA012:</u> What importance does it have? I think it makes sense of your life. I do believe that things happen for a reason. I do believe that there are lessons that we're supposed to learn while we're here on this earth. I think it helps you get through situations that seem unfair.	
<u>FICA032:</u> My faith is of foremost importance in my life. I've attended church continuously since childhood and I was a Sunday School teacher. Yes, Reliance on my belief helps me to deal with stress, which is generally relieved through prayers. When making healthcare decisions, I offer prayers of thanksgiving and ask God to aid in my decision making.	
<u>FICA036:</u> That is the whole substance of being... Definitely. It calms me. It assures me. It gives me light. It gives me hope. He directs my path. I would say no because I just know that... Dr. X is a gift from God. I think he anoints doctors and nurses to take care of the sick. The ultimate healer is God, but he uses his people, medicine.	

Table 4.

<i>Are you a part of a spiritual or religious community? Is this of support to you and how? Is there a group of people you really love or who are important to you? Communities such as churches, temples, and mosques can serve as strong support systems for some patients.</i>	
Community Key Themes	N = 73
Family/Friends	49
Church	26
Prayer	8
Does not identify with a community	5
Examples	
<p><u>FICA002:</u> Absolutely. My church is a spiritual community. And also there's a whole network of people on the internet. I sent out one letter and about three days later (Name of Spouse) gets a letter... unsigned and it's anonymous... Somewhere in Florida someone got that letter from somebody else and sent it to (Name of Spouse) in hopes of helping me... there's a whole internet full of people who are part of that... You've never met any of these people, but I know they're there... there's also (Name of Spouse) and then I'm part of a church staff... there is also my Bible study group.</p>	
<p><u>FICA005:</u> My church. Yes, people constantly kept in touch either through phone or cards. There are the few times I was able to get to church... and they mentioned my name under "Prayers and Concerns" when the time came in the worship service to pray for people and our prayer chains are always praying for me. My family, first and foremost, and my church family, then my friends, and I have a really close relationship with my work colleagues.</p>	
<p><u>FICA034:</u> Only amongst family and friends. Like I said, we do not go to an organized church, so talking with friends and being with family members in that respect – that's my community.</p>	
<p><u>FICA035:</u> Yes. It's a support because—it's the Catholic Church that I belong to. I'm a Eucharistic Minister, and again it's the bonding with the people there and the other ones that have gone through cancer episodes and, you know, the care is there – the hug, the handshake. My colleagues at work are like a professional sister group. I have a group that I'm with at church. I have another group that I'm involved with and that would be our junior high group when we graduated from junior high, so you know, 40 years ago; we're still in touch. And my family group is the most important.</p>	

Table 5.

<i>How should the healthcare provider address these issues in your healthcare?</i>	
Address in Care Themes	N = 73
Not necessary	15
Be supportive	13
Unsure	10
Should be addressed	8
Provider should do what they believe is best	7
Chaplain availability	6
Provider should not be involved	5
Examples	
<p><u>FICA010:</u> I think it's to be more open with it. A lot of people don't like to talk about it. They think that it's a very private thing. Some people are embarrassed to bring it up like the healthcare provider to a patient... they don't want to bring it up because they think that they shouldn't and I think that its important to people.</p>	
<p><u>FICA034:</u> In my health care? I think here at City of Hope they do, because they have the social work department. I've had long discussions with nurses. I've become friends with several of the nurses and staff here, so I think they do address that. They are willing. The attitude here is that they're willing to talk with you about more than just your physical well-being, your mental and social well-being are as important to the staff here. Over the years in the 12 years that I've been a patient, I've had many late-night discussions with nurses. If I'm fearful of this or that, they'll come in and that accessibility is always there.</p>	

Chapter 4

Identifying the Research Question

Daniel H. Grosseohme, DMin, BCC

I did not set out to become a research chaplain. True, my undergraduate degree is in astrophysics and I did some research on binary stars. My grades were not so stellar and I understood enough about academia to know that having some research experience would look good on graduate school applications. I thought I had left that behind, though, when I graduated. I was going to work with people, not data. And one day shortly after my wife became pregnant, I was sitting in an armchair in the back of the hospital chapel and my eyes fell on the open notebook in which people wrote prayers. I wondered if people prayed differently, depending on whether their prayers were addressed to God, or Jesus, or if they used some other Name to approach the Divine. The question stayed with me and I kept wondering why. I realized I needed to be generative, to “give birth” to something of my own, and that question became the germ of the first chaplaincy research study I published (Grosseohme, 1996). We bring who we are to every situation, and without intending to, I brought some basic research experience and a brain that likes to question to my vocation as a pediatric chaplain. I realized I enjoyed developing ways of describing people’s experience and their use of faith, and I made my research time fit into the early morning hours when it was too early to visit on the floors, or when I had too little time before a meeting to go up to a patient’s room. It probably helped that the institution I served had no prior experience with professional chaplains and assumed, when I gave some time to research efforts, that this must be what chaplains do, and it was never questioned. I was able to carry out six more studies in that setting. My passion for exploring the questions, combined with some significant support from others over the past eight years, has enabled me to devote three-quarters of my effort to research in my current setting.

Since most of my current efforts focus on people who live with cystic fibrosis (CF), a few words about CF may be a useful backdrop for some of the examples which follow. It is a life-shortening disease, and is the most common genetic disease among Caucasians. A failure to transport sodium molecules in cells leads to a buildup of mucus, leading to lung infection and blockage, as well as intestinal malabsorption. To slow disease progression, daily airway clearance treatments to clear mucus are required, as well as inhaled medications. A high-calorie, high fat diet may be prescribed, as well as supplemental enzymes or insulin (Wilfond & Taussig, 1999). All of this requires time—frequently one to two hours per day, which can be difficult to integrate into a family lifestyle. Unfortunately, anywhere from 22-93% of the prescribed treatments are not being completed (Modi et al., 2006). I wondered if there might be spiritual beliefs which might affect how many treatments people completed. If so, that might point a way forward for developing chaplaincy interventions, and contribute to improved child health.

What is the nature of a researchable question?

Feasible and Meaningful

One of the most useful distinctions my research mentor taught was to refine my research question so that it was both feasible and meaningful. Feasible means it's small enough that I can carry out the study with the amount of resources that I have available to me.

Meaningful means the question is big enough so that my results contribute enough new knowledge to make a change—in my clinical practice or to expand on those results in a new study exploring a deeper aspect of the questions. Feasible and meaningful sound easy in an office conversation; carrying out those principles is more difficult.

As I began to develop my research interests in pediatric chronic care, I heard psychologist of religion Annette Mahoney talk about a construct she had been exploring, known as “sanctification,” which was defined as “perceiving aspects of life as having divine significance or character” (Mahoney et al., 2005). Sanctification had initially been studied in relationship to marriage and was being broadened to viewing one's body as having sacred qualities. College students who sanctified their bodies reported increased levels of pro-healthy behaviors; that is, they exercised more, and reported lower levels of alcohol and drug use, as well as fewer unhealthy eating habits (Mahoney, et al., 2005). I saw the potential link between a theological concept (sanctification) and my research area in cystic fibrosis. Treatments were burdensome and extensive—and not all recommended treatments were being completed each day. What if people who got the recommended treatments done were those who endorsed the idea of body sanctification? The beginnings of a study began to form in my mind.

I raised the idea with my mentor, who began asking questions. Did I think this applied to completing all daily cystic fibrosis treatments—airway clearance, inhaled nebulized medications, insulin, enzymes, vitamins, high-calorie high-fat diet? Did I really plan to study all of those treatments in a single study, and how did I plan to do that? Taking oral medications can be tracked by giving them to participants in special pill bottles with a computer chip in the cap that records a date-time stamp when the bottle is opened. When the bottle is returned to the researcher, the data in the cap's chip is uploaded to a computer and the researcher knows how often the bottle was opened (although not whether pills were actually taken). That could work for enzymes and vitamins, if I could afford to purchase enough bottles for everyone in my study. I could ask people to record what they ate and drank each day and track calorie intake that way. Of course, what was to prevent participants, who knew their diet was being studied, from creating fictitious meals in their food diary to make it appear they were consuming what they should be? Similarly, how was I to know whether someone did their airway clearance twice a day for 25-30 minutes each time? Or inhaled antibiotics or other drugs? It would be an ideal study to include every aspect of one day's treatments, but it simply wasn't feasible to carry out with 120 parents spread over six states and not unlimited resources in funding and staffing. The question was how close to an ideal study could I come that was feasible for me to carry out with the resources available to me?

I knew that there would have to be more to getting treatments completed than simply having a particular psychological or theological belief. What about major depressive disorder? People who have depression (or even dysthymia) lack motivation to do even formerly enjoyable activities, much less completing repetitive treatments that have relatively little immediate benefit. Since I was proposing to look at younger children, that meant I'd need to be studying their parents, who would actually be ensuring that treatments were completed. What if the parents' marriage was conflicted? Might that not have an effect on their abilities to do the daily treatments? Were moms better than dads at getting treatments done, or older parents better than younger parents? I could theoretically show that one or two psychological/spiritual constructs related to parents' treatment completion, but that wouldn't mean very much. People are influenced by many factors, and for any study to be meaningful to clinicians, I would have to include enough variables that either had already been shown to affect parents' abilities to get their child's treatments done, or those which plausibly might play a role. To be a meaningful contribution of new knowledge, I had to expand—by including novel concepts from theology and chaplaincy—what was already known to affect adherence to recommended treatments.

Every research question must be honed down from its ideal state to one which is small enough to be feasible in the hands of the researcher, and large enough to make a meaningful contribution of new knowledge to the field. Striking that balance is part of the art of developing a research question, and it will look different in the hands of every researcher based on their experience, funding, and the availability of staff to help with the research.

“Why” Rather Than “How”

Conceptual Model

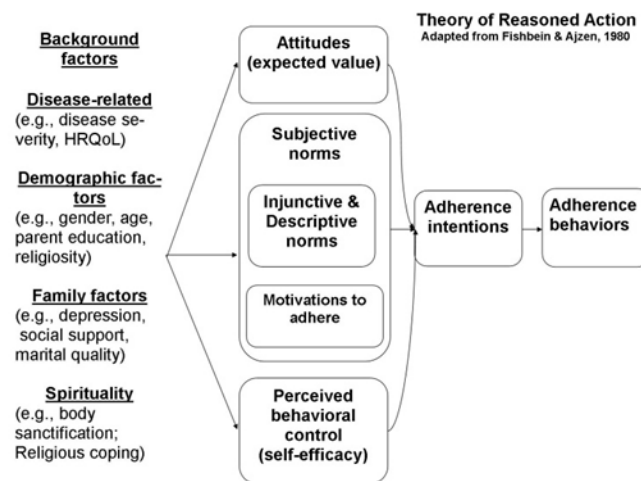
A research question is part of something larger. Just as the individuals we serve as chaplains do not exist in isolation, but live in a network of relationships with others, research questions also do not stand alone. One may spontaneously think of a testable question (Does writing a prayer every day to God in a private notebook help persons with cancer who are estranged from God, to reconnect with God?) to which the response is, “what makes you think that writing a prayer would work?” How would you explain the importance of that question to a skeptical physician—that writing would have any relationship with health outcomes? Being able to discuss your work in the context of a larger theory or what is known as a “conceptual model” of how people think, feel or behave is important.

Having a conceptual model does several things. First, it adds to your credibility in the eyes of established clinicians and researchers who may initially be skeptical of a chaplain doing research. My research mentor, himself a religious person from a different faith tradition, was intrigued by my notion that religious or spiritual beliefs might influence the ways in which people acted—and he was by no means willing to assume that such a relationship

might exist simply because I proposed it. At the very least I needed to show him first that my thinking rested on a foundation of a conceptual model and how the concepts I was interested in could be integrated into an existing model.

I wanted to explore the role of religious and spiritual beliefs and how they affected the care people with CF took of their bodies (or their children's bodies): did they adhere to the prescribed therapies? Many conceptual models for health behaviors exist. How was I supposed to select one on which to build my own thinking? I decided on two criteria: a conceptual model either had to have religious or spiritual concepts explicitly integrated (and in a way which made sense); or it had to have constructs sufficiently similar that I could map religious or spiritual concepts onto it. None of the health behavior models I looked at met the first criterion. I decided I could integrate religious and spiritual concepts along with other psychosocial concepts onto an adapted version of the Theory of Reasoned Action (Ajzen & Fishbein, 1980). The diagram below shows how I explicitly integrated the religious and spiritual factors of interest into the other "background factors" which were part of the original model.

Figure 1
Conceptual model example



This model says that the best predictor of a behavior is one's intention to do the behavior, and that intentions are predicted by three determinants. The determinants are attitudes towards the expected value of doing the behavior; subjective norms (the interaction of motivation with one's sense of other's expectations of our behavior); and self-efficacy. These determinants are in turn predicted by "background factors", including disease-related issues such as severity, health-related quality of life (HRQoL), demographic factors, family factors such as depression and marital adjustment, as well as spiritual and religious factors.

The second benefit of having a conceptual model is that it helps clarify your thinking by helping to define what factors, other than the variable you are measuring, might also be affecting the outcome you're interested in, and ways in which you might go about studying them. Referring to my conceptual model above, it was immediately clear that I had not considered how people's attitudes towards the treatment's value might influence their behavior, and that I would need to measure this. After all, if they didn't see any value in the treatment they were supposed to do, it was reasonable to expect that someone might not do their treatments. It was also clear that I would have to think about ways to measure treatment adherence: how, in fact, was I going to know if a person did their airway clearance as prescribed (usually twice a day for 24-30 minutes each) every day? A third benefit is that a conceptual model can help clarify your question development by providing opportunities to think about causality. Did I think that religious or spiritual concepts caused people's adherence behaviors, or did I think that religious or spiritual concepts affected people's motivation to do the treatments, and that any change in their adherence behavior was really more of a "downstream" effect?

How do I know if this question is significant enough to warrant research?

What would it take to make you change your clinical practice? Or what would you turn to if you had to demonstrate to an administrator or skeptical physician the basis for continuing to do what you do? I often begin my first didactic on chaplaincy research to the CPE residents at the institution I serve with the question, "How do you decide who to visit on your floor?" The answers are the ones you might expect: people who ask for a chaplain, people with high acuity or relatively long lengths of stay, or who have been referred by a staff member. My next question is, "What if I told you that you're likely visiting the wrong people?" I show them a study by Fitchett and colleagues (Fitchett, Meyer, & Burton, 2000) who demonstrated that people with spiritual struggle, who are at greatest risk of poorer health outcomes, don't ask for chaplaincy care. Instead—and the authors use the phrase, "to those who have will more be given"—the people who ask for chaplains already have a great many spiritual or religious resources and may well be been visited by their clergy or a member of their congregation. Yet these are the people we tend to visit: confronted by limited time and a large number of inpatients, it's easy to prioritize on those who have asked for a chaplain. The problem is, the study suggests, the person who is spiritually "bleeding out" is doing so silently and is likely to escape the busy chaplain's notice because they don't ask. So I encourage the residents to develop a means of screening everyone for risk of spiritual struggle and prioritize visits based on that. A research question is significant "enough" when having the answer would make you reflect on your clinical practice, and whether or not you are justified in continuing or changing what you do. A "significant" question is one which is likely to have a positive effect on the field of inquiry, whether that is an improved clinical practice, demonstration of current practice as "best practice," questioning the continuation of a standard practice, or the generation of new knowledge.

How do I avoid repeating the research of others?

A colleague relatively new to research was struggling to apply a particular model of how people learn and was becoming disillusioned with the model as originally described; it just didn't fit with her experience and her conversations with mentors and mentees reflecting on their educational experiences. In conversation with an experienced researcher in the field of learning measurement, she wondered aloud if she could modify the model based on what she had learned. The elder researcher responded, "That's what all research does. It builds on, or modifies, someone's prior research based on new information." So the starting point for developing new research questions has as one of its first tasks a solid grasp of others' prior research in this area. This means newly developed questions extend our knowledge in some way, and at the same time do not waste effort duplicating existing knowledge. This is another way in which grounding your question in a conceptual model is helpful: you will come to understand what is well-known about aspects of the model, and those places where there is still much to discover.

Learning what others have already done happens through a process known as a "literature search" or "literature review." Without unduly anticipating the next section about who a chaplain might consult with in developing their research question, I encourage developing a relationship with the medical library staff at your institution. Although much of the literature review process can now be done by any chaplain with internet access, professional medical librarians can provide invaluable assistance. My experience is that they are often intrigued by the questions and problems I've brought, because my questions have been outside the bounds of what they are typically asked, and are very engaged in assisting me.

There are two primary online databases of published research articles where a chaplain developing a question might begin their literature search. The first of these is the National Center for Biotechnology Information, an arm of the National Institutes of Health, popularly known by its url name of "PubMed" (www.pubmed.gov). The second database is PsychInfo, and a medical librarian may need to help you access this. While there is often some overlap in the results from searching both databases, there are enough unique articles that I normally search both databases as a matter of course. Both databases allow for customized searches, allowing the researcher to limit the scope of the search. When possible, I tend to limit searches to those in which the keywords of interest appear only the abstract (or in the case of PubMed, the Title/Abstract). The assumption I am making here is that if my keywords don't appear in the brief summary of the article, the article is probably not close enough to my interest to warrant my reading it. That assumption works well for most searches but it breaks down when the topic is very narrow or when I expect only a few articles to be identified. In other words, the more specialized your field of interest, the less limited your search should probably be.

Once you have your list of articles, you can download many of them directly from the internet. Others you may have to work with the medical librarian at your institution to obtain. A third option is to identify the e-mail address of the first author and contact them directly requesting a copy of their work. This may be necessary when your literature

search provides you with a reference published within the past twelve months; such articles are frequently unavailable for downloading from online sources. At this point, then, you have a stack of articles which relate to your developing research question. Synthesizing the content can appear daunting. I want to suggest that rather than begin with the first article and read through each one in its entirety, what is called for at this stage is a limited, focused reading. To help maintain the focus, I suggest creating a grid with the following column headings: authors/dates; population; sample size; analytic method; results; limitations and future directions; and comments. For each article, fill in each column; the author(s) names and publication year is self-explanatory. “Population” is a brief description of the participants (e.g., “Men with prostate cancer less than one year post-diagnosis”). Sample size is the number of participants (you might include a breakdown by gender or age if the articles gives one). Analytic method summarizes how the data were analyzed (e.g., “grounded theory methodology”, “Chi-square and ANOVA” or “correlations and regressions”). In the Results column, summarize the findings in 1-3 phrases. Under “limitations and future directions” list in bullet-point format any items mentioned by the authors. The Comments section allows you to enter any remarks or impressions you have about each article. Utilizing a grid helps guide your reading so that you are pulling out the same kind of information from each article, and assembling it in a way that makes comparisons easy and allows patterns to emerge.

As you pick up each article, you are reading for the specific information you need to fill in your grid. You will get the overall gist of the article as you work through it in this process, and as you develop your question, you’ll find yourself returning to read particular sections more deeply. Once your grid is complete, look at it in terms of how it can help clarify your question. Do any of the “future directions” that the authors suggested relate to your question (or did they even suggest your question)? Are there limitations in a study which you think you have the resources to overcome? For instance, the article by Piderman and colleagues on factors identifying patient expectations of hospital chaplains (Piderman et al., 2010) utilized a relatively older sample. They noted that their study provides “limited information on...patients younger than 35 years”. Working in a pediatric facility, with a potential sample rich in adolescent and young adult patients, as well as parents who are young adults, such a comment might well suggest that I contribute new knowledge by developing a research question focusing solely on persons under 35 years. When you look at the analytic methods, are there patterns there which suggest that your question might advance the field because your method of analyzing the results is novel? Or perhaps the reverse is the case—the analytic methods used by others suggest to you that your question will be best answered by following the example of others.

It is possible that as you read through the articles, that you’ll discover that someone has already asked and answered your question. If this were to happen, then you have a choice. You can accept their answer and give up your budding research effort, or you can take a more critical stance. Do the results make sense to you, or persuade you to accept them? If not, you may want to revise your question rather than abandoning it. What limitations and

future directions do they describe—and do these offer you a new starting point from which to pose a new question?

Who can I consult with to assist in developing the question?

A common aphorism in the research community is, “we stand on the shoulders of giants.” All good research builds on the previous works of others, and moves forward in collaboration with others. Admittedly, my initial effort studying written prayers didn’t include others—and it might have had a more significant impact if it had. Identifying people who can provide assistance in developing and refining the research questions is very important. The perspective of others can save you time from pursuing fruitless ideas and can enhance your question by opening up new aspects of the topic and ways of exploring it. You’ll want to develop relationships with others who can provide you with helpful feedback from different perspectives.

The obvious potential consultant is another chaplain, and they don’t need research experience to be helpful to you. They should be able to read your question and understand what you are trying to understand and why it’s important to explore that question. If any aspect of what you show them isn’t clear to them, then you’ve learned some useful information. Inviting them to explain what is unclear can lead to an improved articulation of what you are trying to do and why. They may also direct you to additional resources you were unaware of, or broaden your awareness of the research literature in their field.

It is also very helpful to seek feedback during the development stage from researchers and clinicians who are not chaplains and who work in the area in which the question is situated. In my current setting working with people who have CF, that means turning to pulmonologists or to social scientists with experience with this population. These “subject matter experts” can offer feedback on several aspects of my developing question. The first is whether or not the question is clearly formulated and is worthy of study. They can also respond to requests for feedback couched in terms of, “How might I revise this to produce information that you would find helpful to learn?”

An additional benefit of seeking feedback from or collaboration with clinicians from other disciplines than chaplaincy is that doing research together becomes a form of chaplaincy care for them (Grossoehme, 2011). A colleague doing a qualitative study focused on mentoring found that the interview process itself raised topics for subsequent care that she was convinced would not have arisen otherwise. Perhaps because they are already working collaboratively with a chaplain, they are more comfortable engaging us in such conversations rather than asking us for care directly—even if they have worked side by side with us knowing we are chaplains for years.

If you want to pursue research as a collaborator or co-investigator, and most especially if you want to pursue research as a primary investigator, seek out and develop a relationship with a mentor. This relationship is built around the idea that you bring raw questions and refine them over time based on your discussion. Later you’ll bring preliminary data and

results and develop your interpretation of them, and develop the next research question. A suitable mentor should be an experienced researcher and investigator and have a record of successfully mentoring others and of having their own research funded. They should be supportive of your efforts and be able to challenge your assumptions. The most important criterion for a mentor is also the one that is frequently the most difficult to attain: a good mentor will make time for you. They are sufficiently willing to invest in you that they will give you their time, as scheduled, hear what you have to say or ask, and encourage you in your search for knowledge and answers.

Levels of research and involving others

The Association of Professional Chaplains (APC) published a set of Standards of Practice for Acute Care Chaplains in 2009 which included research as a standard that all acute care chaplains would practice ("Standards of Practice for professional chaplains in acute care settings," 2009). Similar standards for chaplains in long-term care and hospice/palliative care settings followed (copies of those standards are available at APC website: www.professionalchaplains.org). The research standard has three levels, recognizing that chaplains will function at different levels of practice regarding research. The first level is research literacy—reading and understanding published research findings and how they apply to one's clinical practice. All board certified chaplains should function at this level. If you're reading this book, you are most likely either practicing or wanting to practice at the middle level—collaborating with established investigators—or becoming one of the few who choose to practice at the third level of being an independent investigator.

This second level, in which chaplains collaborate with established investigators, provides multiple opportunities for involving others. As noted above, other clinicians who have research experience are your go-to people for feedback in developing your question and articulating the impact of exploring your question. One or more of these people may also be real or potential collaborators in your work. Perhaps you sought them out initially for feedback alone and they were intrigued enough with your question that they suggested you might want to submit your questions and have your work included in one of their ongoing or developing studies. Or you may have already decided to collaborate on your question and you are seeking their feedback because they are stakeholders in its outcome.

A chaplain colleague of mine was clinically attached to a particular oncology subspecialty and was part of a qualitative study about how adolescents' spiritual or religious beliefs had impacted their oncology experiences. She was approached by an NIH-funded investigator focusing on psychosocial factors in the treatment process, and asked my colleague if she would suggest some religious/spiritual items to include in her quantitative study. My colleague was interested in religious coping and submitted items from the Brief R-COPE (Pargament, Koenig, & Perez, 2000). When data collection is completed, my colleague will be given the results about types of religious coping in this sample, and how religious coping relates to the study's primary outcomes. She can also expect to be included in discussions about the implications of the results and eventual authorship of a manuscript presenting these findings.

How will I measure my results?

Just as it is important to know when to say good-bye and terminate a chaplain's clinical visit, there is a need to know in research how you'll know if you're done—if you will have what you need to answer the question. In fact, the more clarity you have initially about what you want to end up with, the better off you will be. You'll wind up with a better result if your research question has been shaped from the beginning so that it yields a measurable result. The result might be quantitative data or qualitative; in any case your ability to describe what you want in advance will increase the likelihood of your attaining that goal. There are numerous questions which might be interesting to pursue, such as "Does prayer work?" or, "How does prayer work?" but neither question will yield a measurable result in the end. "To whom do people pray?" on the other hand, could yield the percentages of people who address prayers to God, or to Jesus, or to Allah, or "El buen Pastor." This data, in turn, might begin to inform how you pray with people at the bedside. And such data might be generated from a research question along the lines of, "How do people writing prayers in an open notebook in a pediatric hospital chapel address the Holy One?" As written, this question doesn't reach the level of significance to warrant research—by itself. As part of a larger inquiry into the use and theology of prayer as it might inform clinical chaplaincy care of hospitalized parents, it could be a secondary aim. Well-written research questions do not speculate. They have a very clear point (or multiple clear subpoints), and are specific in terms of who they describe and what results they will yield. Note that in the example above, the research question was limited to, "people writing prayers in an open notebook in a pediatric hospital chapel." Already I have limited the scope of question to a particular population. The words, "How do people...address the Holy One?" already suggest that the answer to the question will be limited to some form of count data, or percentages, or possibly a list of names.

Conclusion

Writing a good research question is an art. Yet it is not very different from the types of clinical goals many of us develop to document in the "plan of care" section in a person's medical records. Many of us are taught to write individualized goals for the patients and parents that we provide care to, which are "SMART": specific, measurable, attainable, relevant and time-bound. Such goals communicate what is important enough to this person's well-being that you are going to do it, in what time frame, and how you will know when you're finished. In a similar way, research questions should be "smart." They need to be specific about what sample of a population you are going to study; be meaningful enough that you're going to do it; feasible and attainable for you to carry out with limited resources of money and time; relevant to be potentially significant contributions of new knowledge; and have sufficient clarity about the outcome so that you can design a study to produce an answer to the question. Grounding your research question in a conceptual model will help you focus your question, suggest possible methodologies for carrying out your study, and enable conversations with colleagues by giving you a common language and concepts with which to talk.

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Chapter 5

Choosing Research Methodologies

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Once you have identified a research question, the next task is to pick an appropriate methodology. Methodology has been defined as “diverse principles, procedures, and practices related to the conduct of research,” (10, Kazdin, 2002). For the purposes of this chapter, we will be focusing on methodology as it relates to the *procedures* of research.

One way to categorize methodologies is by the purposes that they are meant to serve. These purposes include exploration, description, prediction, and determining cause and effect. Because programs of research often culminate in testing causal questions, we will begin by carefully describing the designs that are suited to such questions and the rationale behind their key components. Then we’ll move on to correlational methods, which are designed for the purposes of explanation or prediction. Finally we will review methods best suited to description and exploration—surveys and qualitative research. We’ll close by reviewing the considerations that factor into your choice of methodology and comparing key characteristics of each type of methodology.

To Examine Causality: What is an Experiment?

Some research procedures are designed specifically to answer questions about causality—that is, whether changes in a given variable of interest *cause* changes in another variable of interest. To answer a question of cause, the ideal procedure is an *experiment*, a carefully designed procedure in which the researcher deliberately manipulates one variable of interest in order to examine the effect of this manipulation on some other variable or variables of interest. The technical definition of an experiment in research methodology is actually somewhat more complicated than this, but we will get to these details after providing some background and defining some important terms.

Designing an Experiment

Let’s consider a question about cause that is relevant for hospital chaplains. A chaplain or a hospital administrator may wonder, do visits from chaplains cause patients to feel more satisfied with their overall care in the hospital? Knowing an experiment is the ideal procedure here, we could design a study in which we deliberately manipulate chaplain visits—that is, having chaplains visit some patients but not others—and then examine patient satisfaction in our participants at discharge.

One of the first decisions we would have to make in designing this study is how to choose which patients will receive a chaplain visit and which patients will not. This is a very crucial matter in the design of experiments. To illustrate, imagine we decide that an expedient way to choose which patients receive chaplain visits is by using the hospital floor, with all the patients on the second floor of the hospital receiving chaplain visits and all the patients on the third floor of the hospital receiving no chaplain visits. This seems

like a perfectly good design at first. But perhaps we come to find out that there are some especially kind, energetic, and dedicated nurses on the second floor, and they have no similarly dedicated counterparts on the third floor. At the end of our study, if we do indeed find that patient satisfaction is higher on the second floor than on the third floor, how can we be sure it is the chaplain visits that made the difference and not the nursing staff? Because of the way we designed our study, we simply cannot be sure that it was the chaplain visits that made the difference.

Back to the drawing board then: how should we decide which patients receive chaplain visits and which do not, such that at the end of the study we can have reasonable confidence that it was indeed the chaplain visits which caused the difference in patient satisfaction? Research methodology has an answer for us: *random assignment*. In order to rule out the interference of some confounding variable (like nursing staff quality), we must *randomly* choose which patients will receive chaplain visits and which will not. In this case *random* does not mean haphazard. Instead it means that each patient has an equal likelihood of being assigned to receive a chaplain visit. One way to achieve this is by flipping a coin: each time you flip a coin, the chance it will land heads is always the same—50%. So, to assign chaplain visits, we could flip a coin for each patient. If the coin lands heads, that patient is assigned to receive a chaplain visit. If the coin lands tails, the patient will not receive a chaplain visit. This procedure ensures that some other important variable (like nursing staff dedication) is not confounded with chaplain visits. This procedure also transforms our study design into a *true experiment*.

We are almost ready to give a technical definition of a *true experiment*. But first, we must introduce some important terms.

Important Terms

In research methodology, we refer to the variable we manipulate, the possible cause, as the *independent variable*. In this case, the independent variable is chaplain visits. We have two *conditions* of this variable in our study—a condition in which the patient receives a chaplain visit, and a condition in which there is no chaplain visit. It would be customary to call the condition in which the patient receives a chaplain visit the *experimental condition*. The condition in which the patient does not receive a chaplain visit would then be called the *control condition*.

The term *dependent variable* is used to identify the variable we are measuring, the variable we presume to be dependent (hence the term) on the independent variable. In this case, the dependent variable is patient satisfaction.

The term *units of assignment* is used to refer to the units which are assigned to one of the conditions of the independent variables (Cook & Campbell, 1979). Units of assignment could be almost anything, depending on your research design. In this case, the units of assignment are patients, since we will be assigning patients to different conditions. Note that the term *units of assignment* is not commonly used in research literature, but rather, serves an important purpose in describing what makes an experiment a *true experiment*.

Box 1: Example of a true experiment.

Research Question: Do visits from hospital chaplains improve patient's satisfaction with their overall care in the hospital?

Independent variable – chaplain visits

Levels/conditions of the independent variable

- *experimental condition:* chaplain visit during a patient's stay

- *control condition:* no chaplain visit during a patient's stay

Dependent variable – satisfaction with overall care

Units of assignment – patients

Method of assignment – random (coin toss)

With these terms we can now define a *true experiment* (based on Cook & Campbell, 1979)

1. There is an independent variable, with at least two levels/conditions.
2. There is a dependent variable.
3. There are multiple units of assignment.
4. Units of assignments are randomly assigned to each of the levels of the independent variable.

A Published Example

A study by Kristeller, Rhodes, Cripe and Sheets (2005) serves as an illustration of the implementation of an experimental methodology in a published study. In this study, Kristeller and her colleagues were interested in the following question: *does briefly discussing spiritual concerns with a physician positively effect a patient's care satisfaction and quality of life?* To study this question, every other patient in a set of 118 consecutive patients presenting for care at hematology/oncology practices was assigned to have a brief conversation about spiritual concerns with his/her doctor in addition to routine treatment. The other patients did not have a conversation about spiritual concerns and simply received treatment as usual. Results showed that patients who talked about spiritual concerns with their doctor reported greater satisfaction with care and improved well-being three weeks later relative to those who hadn't had this conversation with their doctor.

Let's examine how this study meets our criteria for a true experiment.

1. There is an independent variable, with at least two levels/conditions. The independent variable is *conversation about spiritual concerns during a visit to the physician*. The two levels/conditions are a) having a conversation about spiritual concerns with the physician, and b) no spiritual conversation.
2. There is a dependent variable. The dependent variables are patient satisfaction and quality of life.
3. There are multiple units of assignment. Units of assignment are *patients*, of which there are 118.
4. Units of assignments are randomly assigned to the levels of the independent variable. Every other patient was assigned to have a conversation with the physician about spiritual concerns. This procedure is not technically random assignment. However, since we have no reason to suspect that there should be

systematic differences between every other patient presenting consecutively, we may conclude that this procedure adequately approximates random assignment. This criterion is therefore met.¹

Box 2: Published example of a true experiment.

Research Question: Do conversations about spiritual concerns with a physician improve patient satisfaction and quality of life?

Independent variable – conversation about spiritual concerns with a physician

Levels/conditions of the independent variable

- *experimental condition:* conversation about spiritual concerns

- *control condition:* no conversation about spiritual concerns

Dependent variables – patient satisfaction and quality of life

Units of assignment – patients

Method of assignment – random (every other patient)

To Examine Causality: Quasi-Experiments

Quasi-experiments are very similar to true experiments, with one important difference—assignment to conditions is not random. Regarding our study of chaplain visits, if we had stuck with our original plan of assigning patients to conditions by floor rather than by coin toss, our study would then more accurately be called a *quasi-experiment*, rather than a *true experiment*.

Recall the concerns described above about assigning patients to conditions by floor—that nurse dedication might be higher on the second floor and might account for improved patient satisfaction on that floor relative to the third floor. This is a concern in *any* quasi-experiment: if we find that a variable is significantly associated with both our independent and dependent variables, we cannot confidently rule out the possibility that this third variable better accounts for our results than the independent variable. However, when quasi-experimental procedures are designed carefully, we may successfully use *statistical control* in such a way that it approximates the experimental control we otherwise would achieve through random assignment (see Shadish, Clark & Steiner, 2008).

Designing a Quasi-Experiment

To illustrate why and how we might use a quasi-experimental design, let's return again to our experimental study on chaplain visits and patient satisfaction. Imagine we were discussing such a design with our colleagues. While understanding that random assignment is an ideal procedure for addressing our research question, our colleagues might have some practical and ethical concerns that make random assignment less appealing. For instance, what if a participating patient assigned to not receive a chaplain visit specifically requests a chaplain visit? And what are chaplains to do if a concerned

¹ Being careful researchers, Kristeller and her colleagues verified that patients in the experimental and control groups did not differ on important variables prior to the experimental manipulation – i.e., no significant differences were found between groups on demographic variables, religious affiliation, diagnosis or illness severity as measured at prior to the experimental manipulation.

nurse makes a referral to a chaplain for a patient who has been assigned to not receive a chaplain visit? Is it ethical to deny that person a chaplain visit in order to maintain the integrity of the random assignment procedure?

So we may begin discussing a quasi-experimental design. Instead of assigning patients to receive or not receive a chaplain visit, we may decide to allow participating patients to receive care as usual from hospital chaplains. We could plan to then retrospectively “assign” or categorize patients into different levels of the independent variable in the following way: patients who receive just one chaplain visit will be categorized as control patients, and patients who receive two or more chaplain will be categorized as experimental patients. Knowing we want to use statistical control, we’ll also plan ahead of time to assess important variables upon admission of the patient to the hospital—for instance, gender, severity of illness, and religiousness. We’d also probably want to measure some important variables upon discharge—for instance, length of stay.

Once we conduct our study we have lots of data to analyze. As with a true experiment, we have data regarding our dependent variable—patient satisfaction. In addition, we have data about other important variables we thought might be associated with both chaplain visits and patient satisfaction—i.e., gender, severity of illness, religiousness, and length of stay. Perhaps through initial analysis of our data we come to find that patient satisfaction is indeed higher among patients who were in the experimental condition (i.e., received multiple chaplain visits) relative to those in the control condition (i.e., received just one chaplain visit). We also come to find that, in our sample, religiousness is higher in our experimental group relative to the control, and that religiousness is associated with higher ratings of patient satisfaction. The simultaneous association of religiousness with our independent and dependent variables means that religiousness is an important variable to statistically control. Through procedures you’ll learn about in more detail in the next chapter, we can adjust our statistics in such a way that it is as if the experimental and control conditions had identical average scores on religiousness (even though in actuality this is not the case). This adjustment allows us to reasonably infer that differences in patient satisfaction between our experimental and control conditions are due to differences in the number of chaplain visits, rather than to differences in religiousness.

Box 3: Example of a quasi-experimental study

Research question: Do visits from hospital chaplains improve patients’ satisfaction with their overall care in the hospital?

Independent variable: chaplain visits

Levels/conditions of the independent variable:

- *experimental condition:* multiple chaplain visits during a patient’s stay
- *control condition:* one chaplain visit during a patient’s stay

Dependent variable: satisfaction with overall care

Units of assignment: patients

Method of assignment: non-random (chaplaincy services provided as usual)

Control variable: religiousness

A Published Example

Let's look at a published example of a quasi-experimental design. Researchers Alexander and Orme-Johnson (2003) wanted to assess the effectiveness of a form of mantra meditation called Transcendental Meditation (TM) for reducing anxiety and aggression in inmates at a maximum security prison. Pre-test measures of anxiety and aggression were administered to inmates interested in the TM program and inmates not interested in the TM program. Training in TM was offered at different time points over the next several months. An average of 15.7 months after pre-test, post-testing was then administered. Those who completed the TM program were compared to a) those who were interested in the TM program but had been wait-listed for later participation, b) those who were uninterested in the TM program, and c) those who dropped out of the program.

Analyses revealed the TM-completers showed diminished levels of aggression relative to comparison inmates, even after controlling for pre-test aggression, as well as demographic and criminal history variables. However, anxiety was not significantly different among TM completers compared to other groups when pre-test anxiety was controlled for. Therefore, though assignment to the TM program or comparison groups was non-random, the statistical procedures used allowed the authors to conclude with some confidence that TM is effective in reducing aggression, but not anxiety, in inmates at a maximum security prison, and may be likewise effective in related samples.

Box 4: Published example of a quasi-experimental study (Hood, 1978)

Research question: Is Transcendental Meditation (TM) effective in reducing anxiety and aggression in prison inmates?

Independent variable: participation in the TM program

Levels of independent variable:

- *experimental condition:* completion of TM program
- *comparison conditions:* wait-listed, uninterested in TM program, dropped-out of TM program

Dependent variable: anxiety and aggression

Units of assignment: inmates

Method of assignment: non-random (determined by inmates' interest in the program and whether they signed up in time to attend the program before post-test was administered)

Control variable: pre-test scores on anxiety and aggression, as well as demographic and criminal history

To Explain or Predict: Correlational Designs

While questions of cause typically require an experiment or quasi-experiment, correlational design² is more appropriate for questions about relationships between variables which may or may not be causal. In a correlational design, there is no attempt to manipulate an independent variable and the focus is to measure an association—or *correlation*, to use statistical terminology—between two variables of interest; in other words, to predict or explain one variable by using another. Even though the relationship may not be causal, the terms *independent variable* and *dependent variable* are sometimes used to describe the predictor variable and predicted variable, respectively.

Designing a Correlational Study

Returning to our study of chaplain visits and patient satisfaction, if we currently had few resources and little time to begin addressing this question, we might take a step back from our original causal question and ask instead, “Is greater use of chaplain services associated with improved patient satisfaction?” Alternate ways to phrase this question include, *Can use of chaplain services explain differing levels of patient satisfaction?* and *Does use of chaplain services predict higher patient satisfaction?* We could draw on data already collected by the hospital on use of chaplain services and patient satisfaction at discharge and examine the strength of the association between these variables. If we did find a significant correlation between chaplain services and patient satisfaction, we might then use this information to persuade colleagues to help us pursue an experimental or quasi-experimental design to determine whether this relationship is indeed causal.

Again a published example will be useful here. Researchers McConnell, Pargament, Ellison and Flannelly (2006) were interested in a construct called *spiritual struggle*, which refers to distress and discord stemming from religion or spirituality. To give you an idea of this concept, one measure of spiritual struggle (the negative religious coping subscale of the Brief RCOPE; Pargament, Smith, Koenig & Perez, 1998) includes items such as *wondered whether my church had abandoned me; questioned the power of God; and felt punished by God for my lack of devotion*. In light of previous smaller-scale studies showing that spiritual struggle was associated with higher levels of psychopathology, McConnell and colleagues set out to test the strength of this association in a large national sample.

Consistent with the researcher’s hypotheses, higher levels of spiritual struggle were associated with more psychopathology. Next McConnell and her colleagues wanted to be sure that the association they found between spiritual struggle and psychopathology was not an artifact of gender or another demographic variable. Put another way, they wanted to be sure that the correlation between spiritual struggle and psychopathology could not be explained by the fact that—for example—women had both higher levels of psychopathology and higher spiritual struggle. Therefore, the researchers used statistical

² As you’ll learn in the next chapter, the term “correlational design” can be a bit misleading. Correlations can be calculated with any number of study designs, including experimental designs. But it is a good short-hand for a study in which there is no attempt at experimental control and the goal is simply to examine associations (correlations) between variables.

means to “control for” gender (and other demographic variables), and then they reexamined the correlation between spiritual struggle and psychopathology. This relationship remained significant after adjusting for demographic variables, indicating that the relationship between spiritual struggle and psychopathology was not simply an artifact of gender (or another demographic variable).

Designing a Longitudinal Correlational Study

Notice that in the above example, the researchers were looking at relationships between variables measured at the same point in time. For this reason we could further describe this design as a *cross-sectional* correlational study, so called because it is as if we have taken a cross-section of our sample, a small slice of a set of individuals’ experience at one point in time. A variation on this design is a *longitudinal* correlational design. In longitudinal correlational design, we examine the strength of the relationship between two variables that are measured at *different* points in time. This design helps us identify important predictors of a given variable of interest over time. As you may have already noticed, longitudinal correlational design and quasi-experimental design share a lot in common.

To illustrate, consider a longitudinal study on spiritual struggle by Pargament, Koenig, Tarakeshwar and Hahn (2001). In this study, the researchers wanted to know whether spiritual struggle would predict subsequent mortality among the elderly. To examine this question, they assessed spiritual struggle in a sample of elderly patients at one time point (Time 1) and returned to the sample two years later (Time 2) to examine mortality rates among their participants. Then they examined the strength of the association between spiritual struggle at Time 1 and mortality at Time 2 and found that higher levels of spiritual struggle predicted higher mortality. Next, the researchers wanted to be sure that the correlation between spiritual struggle and mortality was not an artifact of differing physical health or mental health at Time 1. So the researchers statistically controlled for physical health and mental health at Time 1, and then re-examined the relationship between spiritual struggle and mortality. After this adjustment, the association between spiritual struggle and subsequent mortality remained significant, indicating that spiritual struggle was an important predictor of mortality in this sample.

To Describe: Survey Research

If questions about associations and cause are not the focus and you simply want to be able to describe a group of people or a phenomenon in quantitative terms, survey design is an appropriate methodology. In survey research, measurements are taken not to examine relationships between variables, but to get at descriptive questions such as *How common is it to struggle spiritually? How frequently do hospital patients pray? What do hospital chaplains commonly do in their work?*

For questions like this, *sampling* becomes an important concern. Sampling refers to how we recruit individuals to participate in our study. Ideally, we want participants in a given study to be *representative* of the larger group or *population* that the study seeks to describe. For instance, if we wanted to estimate with some confidence about how often the average

American prays, we shouldn't survey only university professors. Instead we should survey a variety of different individuals that represent the range of circumstances, professions and personalities within the American population. The ideal way to achieve this is through *random sampling*. Here the term *random* means that every member of the population is equally likely to be included in the sample. Something very close to random sampling of the American population may be achieved by, for instance, using a computer program to randomly select addresses of people who will receive survey materials.

Random sampling can be logistically very difficult for a variety of reasons. So, in place of this, there are other ways to recruit a sample of participants that is roughly representative of the population of interest. For instance, in their study of spiritual struggle and psychopathology, McConnell and her colleagues (2006) obtained their data from a sample of individuals recruited with banner ads on a wide range of websites. To verify that the sample was indeed roughly representative of the American population, the researchers compared their sample's demographic data to that of the United States Census and found that their sample's demographic data did in fact reflect census data.

Serving as an example of survey research, Fogg, Weaver, Flannelly and Handzo (2004) designed a survey study to find out how frequently and for what reasons various health professionals refer patients to hospital chaplains. They examined data collected between 1994 and 2000 on the referrals to hospital chaplains at a suburban acute care facility in Bronxville, New York. They found the following: most referrals were from nursing staff (about 80%); about 75% of referrals were requests for a chaplain to visit a patient; and about 25% of referrals were requests for a chaplain to counsel a patient's family or friends. The researchers calculated the rate of referral as well: for every 1,000 patients who stayed at the hospital, 39 were referred for chaplaincy service.

To Summarize: Meta-Analysis

Meta-analysis is a research method used to systematically compile and summarize the research findings across many similar studies (Glass, 1976). A meta-analysis answers questions about findings from a body of research on a particular topic. For example, suppose you are interested in whether spiritual struggle is associated with psychological distress, and you look to the published studies on this topic for guidance. Let's say after looking at several studies, you notice that some studies find that spiritual struggle is associated with greater distress, some find that spiritual struggle predicts *less* distress, and some find little association between spiritual struggle and distress. On the whole, you may wonder, does the literature support an association between spiritual struggle and greater distress, or not? To answer this question, you could compile results from all known studies that measure statistical associations between spiritual struggle and distress and then calculate an average association across these studies.

This is exactly what Ano and Vasconcelles (2005) did in their meta-analysis. First they used a comprehensive article search strategy in an effort to obtain all published results on the relationship between spiritual struggle and distress. They developed and adhered to

criteria regarding whether or not to include an article in the meta-analysis, in order to minimize the possibility that their own biases would influence whether they saw a study as appropriate or inappropriate for inclusion in the meta-analysis. Then they carefully coded all of the studies and extracted quantitative data needed to calculate a measure of the average association between spiritual struggle and distress across these studies. After all of this work, they found that spiritual struggle is modestly tied to higher levels of distress across a range of circumstances and samples,

To Explore or Describe: Qualitative Designs

Up until this point, we have been considering only quantitative designs. While quantitative designs predominate in the psychological and medical literature, *qualitative* designs are common in related research areas, like nursing, social work, and education. Similar in some ways to survey research, qualitative methods can be used to answer descriptive questions. They are useful for exploring a phenomenon about which little is known and developing theories that can then be tested through quantitative means. Qualitative methods are also useful when trying to understand something from someone else's perspective (Bradley, 1991). Finally, qualitative methods can be valuable for bringing quantitative results "to life." It can sometimes be difficult to appreciate the significance of a numerical finding without human stories behind it, and qualitative findings address this need.

In general, qualitative designs involve categorizing narrative material and then looking for important patterns in the material. In addition to this "generic" design (Edmonds & Kennedy, 2012), there are more specific methodologies that have been developed to systematize the process of collecting and interpreting narrative data. Below we provide an overview of qualitative methods—content analysis, phenomenology, grounded theory, and ethnography—providing a definition and a published example for each. Note that some of the illustrative studies discussed below involve the calculation or inclusion of quantitative data to complement qualitative findings or to facilitate the interpretation of qualitative findings. These mixed-method studies illustrate ways that researchers can profitably combine qualitative and quantitative designs.

Content Analysis

Definition. Content analysis refers to a systematic procedure for interpreting narrative material. First categories or codes are developed, often by examining a subset of the narrative material. A coding system is established which provides a set of rules to categorize the remaining material. Next the materials belonging to each category are examined in turn in order to find patterns and draw conclusions.

Example. To explore the kinds of questions that palliative care patients ask hospital chaplains, Strang and Strang (2002) sent an open-ended questionnaire to a nationwide sample of Swedish hospital chaplains. The questionnaire asked respondents to "list the most frequent questions posed by patients," (p. 859). Through content analysis of the responses to this question, the authors identified five categories of questions: meaning,

death and dying, pain and illness, relationships, and religious issues. A quantitative summary of results indicated that questions of meaning were the most frequent category. Examples of questions reported by respondents that belonged to this category include: “Why did I get sick? What was the meaning of my life? Was this all there is?” (p. 3). Interestingly, questions about religious issues were relatively infrequent. The authors conclude that the hospital chaplain role in Sweden has shifted from a focus on religious concerns to a broader focus on existential concerns.

Phenomenology

Definition. Phenomenology is used to understand in depth how individuals interpret their own experience of a phenomenon of interest. First, participants are selected and recruited who can report in detail on their experience; next, one-on-one interviews are conducted with these individuals; and finally the transcripts of these interviews are reviewed closely for themes and patterns (Smith & Shinebourne, 2012).

Example. Researchers James, Cottle and Hodge (2011) conducted a phenomenological study to explore nurses’ and chaplains’ understanding of the role of the Family Support Person (FSP), a staff member present with the patient’s family members if or when they witness resuscitation of the patient. The researchers (based in the United Kingdom) selected four nurses and three healthcare chaplains who were experienced in the role of FSP to be interviewed on this topic. One-hour interviews were conducted with each participant and then the interviews were transcribed. Each of the three researchers read the entirety of the scripts and identified themes. Through discussion, the researchers agreed on the following as common themes;

- 1) Assessment: determining the patients’ and families’ wishes regarding family presence during resuscitation ahead of time, and monitoring of how the family is coping during resuscitation;
- 2) Managing choice: deciding whether or not to honor a family member’s wishes to remain present during resuscitation;
- 3) Navigating the setting: helping manage how physically close family members can be to the patient during resuscitation;
- 4) Ongoing commentary: explaining the medical procedures occurring during the resuscitation to family members;
- 5) Coming to terms with death: helping the family cope if resuscitation was aborted and the patient died;
- 6) Conflict: difficulty gaining respect as an important member of the medical care team;
- 7) Support: the FSP’s need for support from peers and their own family members after a difficult experience.

The researchers conclude that the information gathered supports the crucial role played by FSP’s, and they highlight the need for better support for current FSPs and better training for those new to this role.

Grounded Theory

Definition. Grounded theory is a procedure used to generate theory from qualitative data (Glaser & Strauss, 1967). First, the qualitative data are examined and categorized. During this process, each new instance of a particular category is continually compared to the previous instances of that category in order to reassess the nature of the category and the need for another category. As the researcher continues to carefully review the data, at some point comparison of new instances to previous instances yields little new insight, at which point the categories are considered “saturated” and the data analysis is complete. The researcher may then reflect on the categories to identify themes and patterns and formulate a theory.

Example. Alcorn, Balboni, Prigerson, Reynolds, Phelps and others (2010) set out to study the role of religion and spirituality in the experiences of advanced cancer patients, with an eye towards the development of spiritual care interventions for this population. They randomly selected 68 patients with advanced cancer from four medical hospitals in Boston, Massachusetts. After filling out questions regarding demographics and religious background, each participant was asked whether religion or spirituality had been “important to your experience with your illness,” (Alcorn et al., 2010; p. 582). Those who answered yes to this question were asked to describe how. These responses were recorded and transcribed. The transcripts were reviewed using grounded theory methods to identify themes and to create a coding scheme for these themes. Then the transcripts were reviewed again and coded by two investigators. This process yielded five primary themes, listed in order of prevalence (determined quantitatively) among the participants:

- 1) Coping through religion/spirituality (e.g., “... religion and spirituality keeps me going”; Alcorn et al., 2010, p. 584);
- 2) Religious/spiritual practices (e.g., prayer);
- 3) Religious/spiritual beliefs (e.g., “It is God’s will, not my will...”);
- 4) Religious/spiritual transformation (e.g., seeking out information about one’s own religious traditions and others);
- 5) Religious/spiritual community (i.e., turning to one’s spirituality or religious community for support).

The authors conclude by describing how their findings may inform the development of spiritual interventions for advanced cancer patients.

Ethnography

Definition. Ethnography involves the observation of a culture or group by a researcher who seeks to “embed” him or herself in that culture or group (Edmonds & Kennedy, 2012; Fetterman, 2009). The goal is to develop in-depth understanding of this culture or group, with particular focus on in-group members’ perspectives of their own experience. This methodology was originally developed to understand other cultures, but can be applied to other contexts or groups as well.

Example. Cadge and Sigalow (2013) were interested in how hospital chaplains from a range of religious backgrounds negotiate religious differences between themselves and the

patients they serve. To explore this, the first author, Cadge, spent a year doing fieldwork with hospital chaplains, which chiefly involved shadowing chaplains as they carried out their duties and conducting semi-structured interviews with chaplains. She found the chaplains dealt with religious differences between themselves and their patients through 1) if requested, referring to a chaplain of the patient's religious background when possible; 2) *neutralizing*, defined as "us[ing] a broad language of spirituality that emphasizes commonalities rather than differences"; and 3) *code-switching*, defined as "us[ing] the languages, rituals, and practices of the people with whom they work," (p. 146). Cadge and Sigalow (2013) describe neutralizing and code-switching in detail, using key examples to illustrate use of these strategies among chaplains from a range of religious backgrounds. The authors conclude by suggesting these strategies are likely used by chaplains in other healthcare sites besides the particular hospital that was the focus of this study. They recommend further research on how individuals handle religious and spiritual differences in a variety of settings.

Case Studies and Small-n Studies

The last categories of methodologies we will introduce to you are case studies and small-n studies. In case studies and small-n studies, an individual or small group of individuals are studied closely. The small size of the sample makes possible the collection of many qualitative details, though quantitative information can be gathered as well. This design may be used to describe or explore a phenomenon of interest that a particular individual or small group uniquely demonstrates.

There are also quantitative case study designs that address questions of cause—usually regarding the effectiveness of an intervention for a particular individual or small group of individuals. In these designs, careful manipulation of the independent variable and measurement of dependent variables of interest can provide initial support for a causal role of the independent variable under study. Because they involve small samples, these methodologies are limited in their generalizability to larger populations. Below we've provided an example of a qualitative case study and a quantitative small-n study.

Qualitative example. In order to better understand what may help individuals recover resiliently from stroke, researchers Price, Kinghorn, Patrick and Cardell (2012) conducted two in-depth interviews with an elderly man who was identified as particularly resilient in his post-stroke adjustment. The interviews were transcribed and analyzed using a number of qualitative techniques, including content analysis and narrative analysis. These processes revealed the way social support, spirituality, internal locus of control, and an action-orientation, among other strengths, helped him recover from his stroke with resilience. The authors particularly emphasized his shift from anger at God to reconnecting with the goodness of God revealed to him in nature's beauty.

Quantitative example. Murray-Swank and Pargament (2005) used a small-n methodology called *interrupted time-series design* to conduct an initial evaluation of a spiritually-integrated intervention for sexual abuse. Two clients participated in the 8-

session intervention, and data were collected on patients' day-to-day functioning over the course of their involvement in the intervention. Time-series Auto-Regressive Integrated Moving Average (ARIMA) analyses were used to test for significant changes in functioning over time. Findings from these analyses provided support for the effectiveness of this intervention in enhancing positive religious coping and reducing spiritual distress. The small sample size of this study allowed the researchers to complement these quantitative analyses with rich narrative data about the therapy process for each of the individuals involved in the study.

Summing Up: Choosing a Methodology

There are several categories of considerations that will influence which methodology is most appropriate. As we've highlighted, a chief consideration in choosing methodologies is the kind of question you are asking—whether it is about cause, prediction, explanation, or description. Another consideration would be the phase of a research process: more specifically, qualitative, case, and small-n studies may be appropriate in the beginning phases when little is known about a topic; whereas, in later phases of a research process, we may have causal hypotheses we can test through experiments, quasi-experiments, or longitudinal studies. A third consideration is how much funding and time you have at your disposal. When funding and time are limited, experimental designs, longitudinal correlational, or work-intensive qualitative research may be impractical, while survey designs, case studies, small-n designs, or correlational designs may be more appropriate.

Finally, consider the audience for your research project. For an audience oriented towards quantitative results, such as psychology researchers or hospital administrators seeking information about cost effectiveness, a quantitative design is often needed. For an audience not accustomed to interpreting quantitative findings, anecdote and narrative data provided in qualitative designs can be crucial for motivating your audience to support further research on a topic or the implementation of practical solutions to problems.

Chart 1. below provides a snapshot of the various methods we have covered in this chapter. This is not a comprehensive chart, but instead is meant to provide you with initial guidance as you consider which methodology or methodologies to further explore as you design a study for a given topic or research question.

Chart 1.

Methodology	Key components	Purposes	Drawbacks
True experiment	Manipulation of an independent variable; measurement of a dependent variable; random assignment	To address questions of cause	Can be logistically difficult or expensive; may be ethically problematic or impossible to randomly assign treatments
Quasi-experiment	Similar to an experiment, but assignment is non-random	To address questions of cause	Support for causal role of a variable may not be as strong as in a true experiment
Cross-sectional correlational	Measurement of the strength of the relationship between two variables measured at the same point in time	To address questions about relationships between variables that may or may not be causal	Provides only weak information about cause
Longitudinal correlational	Measurement of the strength of the relationship between two variables measured at different points in time	To test for predictors and sequelae of variables of interest; may be used to support the causal role of variables measured earlier in time	Can be logistically difficult or expensive
Survey designs	Questionnaires assessing variables of interest in a given population; no effort to relate one variable to another	To describe a population of interest	Sampling method becomes crucial
Meta-analysis	Compiling quantitative results across multiple studies	To summarize a body of literature	Work-intensive
Qualitative methods	Collection and careful review of narrative data for patterns and themes	To develop theories; to gather information about a new research area; motivational value	Work-intensive; Researcher bias may influence results to a greater extent than in quantitative methodologies.
Case study/small-n designs	In-depth qualitative and/or quantitative data collected on an individual or a small number of individuals	To study rare phenomena; to provide initial support for treatment effectiveness	Can be difficult to generalize to other cases and/or to draw confident conclusions about cause

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Chapter 6

In Pursuit of the Truth: Statistical Tools

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In this chapter, we discuss the topic of research statistics with the goal of helping you to be an informed consumer of statistical tools. It is typical that when we utter the word, Statistics, it is associated with a mix of repulsion, anxiety, confusion, fear, and avoidance. In fact, we would be willing to hypothesize that some readers saw this chapter title and skipped right over to the next section!

For those who have remained curiously intrigued, let's start our chapter with a "Crucial Conversation" (Patterson, Grenny, McMillan, & Switzler, 2013). Statistics IS NOT mathematics. You do not need to know algebra, calculus, or trigonometry to be an informed consumer of statistics. Therefore, the negativity that frequently accompanies math need not enter. Statistics IS more akin to philosophy and logic, fields of which chaplaincy is quite familiar. Statistics IS a set of tools that allow consumers to make decisions based on observation with an indication of how much confidence they can have in their decision.

Q: How is a statistician like an auto mechanic?

A: They are alike in many ways, they both: have specialized tools to apply in precise applications, assist you in making sure that your project/vehicle runs smoothly, and help you to be an informed consumer.

With your indulgence, we use this analogy throughout the chapter in pursuit of its goal of assisting you in becoming an informed consumer of statistics. It is essential to focus on a well-designed study and hypothesis as described in chapter 5. Statistics are tools that help you answer a question, but they cannot help if the question is not the right question to elicit the data you need or the data collected are poor. This would be equivalent to an auto mechanic being asked to fix a helicopter engine or to resurrect a 1971 Ford Pinto from the junk yard. Moreover, as in the case of a driver describing the car problem to the mechanic as my car is "acting funny," if the research question or hypothesis is likewise poorly articulated, the study will suffer. It is a good idea to meet with your statistician during the design phase to ensure that you understand how your question/hypothesis and design will be analyzed; what data are needed to answer your questions, and what answers can be provided. Statistical results may not be reliable if there is poor questioning, design, or data collection.

Goal of Research (The Garage)

Similar to the study of philosophy and to the mechanic's garage, the goal of research or scientific method seeks to discover truth. Within their garage, auto mechanics seek to discover the truth about a vehicle's performance by using various tests, tools and techniques. In research, we use hypothesis testing as a general framework in pursuit of "the Universal Truth," hereafter referred to as the Truth. Table 1 provides a summary of the hypothesis testing framework. As you can see in the columns under Universal Truth, the

hypothesis is either true or false. However, we have no tangible way actually to know the Truth so we conduct studies in an attempt to gather evidence about the Truth. Statistics are used to help us make reasonable conclusions from studies. In Table 1, we have represented Study Conclusions in the rows, where there are only two results—fail to reject the hypothesis or reject the hypothesis. These are similar to the hypothesis being true or being false, respectively; however, the field uses different terms since we can never really know the Truth. As you can already tell by this nuance, the scientific method is very conservative. Therefore, the outcome of a study will determine that conclusions are either congruent with the truth or not. When a study's conclusions do not correspond with the Truth, we call that an error. Errors can take two forms: Type I and Type II. As seen in Table 1, the field of research is much more tolerant of making Type II errors (20% tolerance) than Type I (5% tolerance). In Type 1 errors, there is a false positive assessment, so the hypothesis appears to be true when it is not. In a Type 2 error there is a false negative assessment, so the hypothesis appears to be false when it is not. There is a great debate; however, among statisticians about whether this difference in tolerances is appropriate—some statisticians argue that they should be equivalent (Lipsey & Hurley, 2009).

Table 1.
Hypothesis Testing Framework

		Universal Truth	
		True	False
Study Conclusion	Fail to Reject	Correct! (Power)	Error! (Type 1 or alpha) Tolerance usually at 5%
	Reject	Error! (Type 2 or beta) Tolerance usually at 20%	Correct!

Understanding Types of Data (The Vehicle)

A basic understanding of statistical tools requires an understanding of types of variables or data. This is similar to a mechanic knowing to use metric tools on imports and standard tools on domestic vehicles. Data collected through the experimental design and in response to the research hypothesis or question are what statisticians “work on.” Knowing about the different types of data helps to know how to apply and interpret various statistical tools appropriately.

In general, there are two kinds of variables: **discrete** and **continuous variables**. Discrete variables represent an underlying construct that can only be measured in mutually exclusive categories. One example of a discrete variable is board certification in healthcare chaplaincy, either a chaplain is board certified or not. These are mutually exclusive, similar to being pregnant or not—there is no almost pregnant. When statisticians work with these data, they will commonly assign a whole number to the category. For example, non-board

certified may be coded with a zero and certified with a one. This is primarily for convenience as it is easier to perform analyses on numbers rather than text. However, to the uninitiated this can be confusing as they look like numbers but are really categories. In contrast, continuous variables have an infinite range of measurement between whole numbers. This means that it is possible to have as many decimal places represented as your measurement is sensitive enough to detect. Weight is an example of a continuous measure because the distance between one pound and two pounds can be measured to several decimal places if the scale is sensitive enough to measure at that level.

Understanding your data types is essential to understanding which statistical tools to use because choosing the appropriate tool depends on the question that you are attempting to answer and the type of data collected for each variable. Statistical tools applied to discrete variables typically use **frequencies** (i.e., the number in each category or level) for computation while tools applied to continuous variables often use the **mean** (i.e., average) and the **variability**, which is a measurement of how each score differs from the mean.

Seeking answers using statistical tests (The Tools)

Statistical tests are the tools that allow statisticians and researchers to evaluate the results of the study based on the question asked (What kind of problem does my care have?) and the type of data (noises, sparks, lack of function, conditions when problem appears, etc.) collected. The majority of statistical tests used in research are ultimately interested in using a sample to make inferences about the population from which the sample was selected, which is why these statistics are called **inferential statistics**. Because inferences are made, there are many ways to ensure that the inferences are as accurate as possible. Some of these methods were presented in chapter 5 for methodology and some relate to statistics as well. The type of statistical test used depends on whether the variable is discrete or continuous and if the data meet certain conditions that are associated with the specific test.

These conditions are known as **assumptions** and they are beyond the scope of this chapter (for further study see [Introduction to Statistics](#)). The purpose of this chapter is for general understanding, not computation, of these statistics, so it is important to consult with a statistician rather than trying to perform analysis yourself without the proper training and background. Most people would not attempt to replace the transmission in their car! Finally, every statistical test or tool provides a **test statistic**. Moreover, each test statistic has an accompanying **probability value (p-value)**, which, again, is dependent on various characteristics of your design and data. The values of test statistics can vary widely across the many tests available to researchers; however, the *p*-value is standard and ranges from 0.000 to 1.000. In other words, every data analysis will provide two values that are used for determining whether the data supports the hypothesis. But, the *p*-value provides the clearest guidance in interpreting the results because it is standard. The *p*-value is the probability that you have rejected the [null hypothesis](#) due to error or chance (see chapter 5 for hypothesis testing and sources of error/chance).

In general, most professions use a *p*-value of ≤ 0.05 as a mark of confidence that the null hypothesis can be rejected which is referred to as “statistically significant.” A *p*-value of \leq

0.05 means that there is a 1-in-20 possibility or less that your results could have occurred by chance or error alone. In the proceeding sections, we will present a few of the more common statistical tools with examples that will include both the test statistics and p -values.

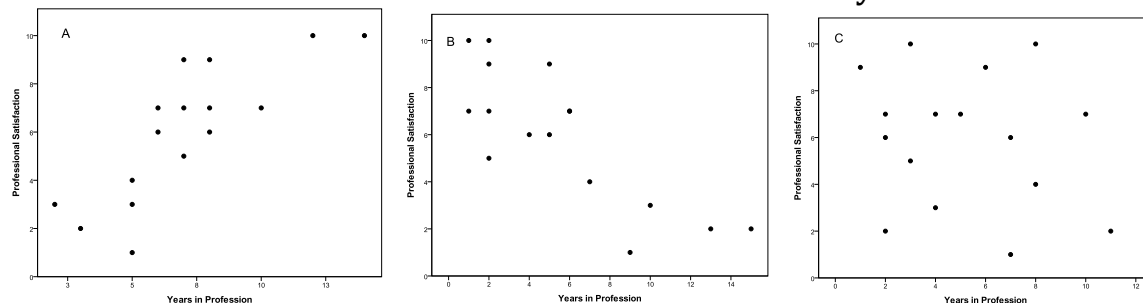
The following sections outline two types of tests: **tests of association**, or how variables are associated/ related, and **tests of differences**, or how groups differ on some variable. Each section provides a brief explanation of the statistical test and an example for conceptual purposes. In the “tests of association” section, **correlations** and **regressions** are presented. In the “tests of differences” section, **chi-square**, **t-test** and **ANOVA** are presented.

Tests of Association: Correlation & Regression (Red Toolbox)

Correlation

One of the most widely used statistics is the correlation and the most common is the **Pearson’s correlation coefficient** (Pearson, 1895). A correlation is index of strength of association, which has wide-ranging use but many limitations. Correlations analyze two variables looking for tendencies in those two variables to vary or change together. The test statistic is r . For example, years in a profession and professional satisfaction often are correlated. If you were asked to test this assertion in health care chaplaincy, you might collect data on both of these domains in a sample of chaplains, then work with a statistician to determine if they were correlated. Figure 1A-C displays the three potential outcomes of that analysis with the correlation test statistic (r) and the associated p -value. Figure 1A depicts a **positive correlation** because both variables increase in unison and the r has positive value. In other words, professional satisfaction tends to increase the longer the chaplain is working in the profession. If one variable decreases as the other increases, the correlation is **negative correlation** (as depicted in Figure 1B) and the r will have a negative value. The more correlated two variables are, the more they will approximate a straight line when plotted. Note that Figure 1C looks more like a circle than a line and that the correlation is not statistically significant (p -value is $>.05$).

Figure 1A, 1B, 1C
Possible Results of Correlation Analyses



These figures display the correlation between the number of years a chaplain has been employed in the profession (horizontal axis) and the corresponding Professional Satisfaction score vertically (on a scale of

1-10 with 1 representing the least amount of satisfaction and 10 representing the highest amount of satisfaction. Figure 1A is a positive correlation ($r = 0.814$, $p < 0.001$) or the longer in the profession, the more satisfied. Figure 1B is a negative correlation ($r = -0.801$, $p < 0.001$) or the longer in the profession, the less satisfied. Figure 1C displays a lack of a statistically significant correlation ($r = -0.202$, $p = 0.452$)

Although correlations are widely used, as mentioned, they have limitations. First, correlations do not allow for causal inferences. In other words, correlation does not equal causation. In the previous paragraph, the correlation between years in a profession and professional satisfaction (Figure 1A) was used as an example of a positive correlation but being a professional chaplain for many years does not necessarily mean that a person will be more satisfied with the profession than a chaplain new to the profession. Many factors relate to professional satisfaction such as salary, the setting where a chaplain ministers and so on. Variables that can impact the relationship between the two variables of interest (satisfaction and years in profession) are referred to as **confounding variables**.

Regression

Because so many variables can be inter-related, a more sophisticated form of correlation analysis known as regression often is used to determine the association between variables. Regression has many advantages over correlation in that the relationship between two or more variables can be assessed and that how the variables tend to vary can be assessed more thoroughly to allow for prediction. In regression, change in one variables of interest (**the dependent variable** or **outcome**) is predicted by one or more other variables (**the independent variables** or **predictors**).

Regression analysis is a more sophisticated analysis in that it controls for other variables that might confound the relationship between two variables as previously discussed. Controlling for a confounding variable is a mathematical way to remove the effect of one or more variables on the relationship between the variables of interest. In the satisfaction and years in profession example, a regression analysis could be performed that includes each subject's salary and ministry setting that would allow for a statement such as "regardless of salary and ministry setting, a chaplain's years in profession can predict his or her professional satisfaction" within a certain degree of accuracy. In fact, regression analysis provides values that specify how much change in the independent variables predicts change of one unit in the dependent variable. Notice that the inference does not include a statement of causality.

There are many types of regression but the most commonly used are **linear regression** and **logistic regression**. In linear regression, the dependent variable (outcome of interest) is continuous and in logistic regression, the dependent variable is categorical.

Tests of Difference: Chi-square, t-test & ANOVA (Gray Toolbox)

Chi-square

Chi-Square (χ^2) tests are used to determine if two groups differ on a particular variable that is dichotomous and are displayed in a **2x2 table**, as shown in Table 2. The table is referred to as a 2x2 table because each variable has two levels, or categories, such as hospital or hospice for setting and yes or no for board certified. Chi-Square tests can be used with variables that have more than two levels, but the concept is easier to understand in the 2x2 design.

If you were asked by your supervisor to determine if there was a difference in board certification across various service settings, you might collect information on a sample of chaplains in various settings and their board certification status. In the table, one variable is represented in the rows (Service Setting) and one variable is represented in the columns (Board Certified) and each variable is divided into the different levels of the variable represented. Each cell within the table displays the number ("count" or "frequency") and percentage of subjects within a specific row and column. If we want to know how many subjects minister in a hospital and are BCC (the upper left cell), we move across the 'setting' row to the 'yes' column and find that 44 subjects are in a hospital setting and are BCC, which represents 22% of the sample.

The question that a chi-square test answers is "Do the cell frequencies differ from what is expected?" and in most cases, the expectation is that all cells have an equal chance of occurring. In other words, the expectation is that all cells will be equal and this is the null hypothesis that is being tested. The alternative hypothesis is that the cells will not be equal. In this example, the cells are similar but not exactly the same and subjective evaluation of their similarity will differ by evaluator, so we need an appropriate statistical test to help us decide which hypothesis is supported by our data. For this example, the difference in the number of BCC between settings is not statistically significant as determined by the test statistic χ^2 and its corresponding p -value which is greater than 0.05.

Table 2.
Results of Chaplains by Setting and Certification

		Board Certified		Total
		Yes	No	
Setting	Hospital	44 (22%)	54 (27%)	98
	Hospice	40 (20%)	62 (31%)	102
Total		84	116	200

Chi-square test 2x2 table for group comparison of the number of BCC by Service Setting ($\chi^2 = 0.66$, $p = 0.42$).

t-test and ANOVA

While chi-square tests are used to compare groups on a categorical variable, a family of tests known as the Student's t -test and Analysis of Variance (ANOVA) are used to compare

groups on a continuous variable. In the chi square example, we were interested in determining if the board certification (yes/no) differed by service setting (hospital/hospice). Now, in this example, we are interested in determining if the number of years as a chaplain (continuous variable) differs by setting (categorical variable). The t-test is the appropriate test to make this determination.

T-tests are analyses that compare the mean (or in lay terms, the average) of one group to the mean of another group to determine if the groups differ. Both the means and the amount each individual score varies from the mean (known as the **standard deviation**) are used in the calculation of the *t* statistic. This is known as a **between-group**, or **between-subjects**, analysis because each subject provides data to one group only. Standard deviations, as mentioned, describe how far each score varies from the mean and are standardized so that one unit of standard deviation added and subtracted from the mean will represent 68.2% of the scores, adding and subtracting two standard deviations from the mean will represent 95.4% of the scores, and adding and subtracting three standard deviations from the mean will represent 99.6% of the scores.

In our current example, the null hypothesis is that the mean number of years as a chaplain will not differ by setting and the alternative hypothesis is that the mean number of years as a chaplain will be different by setting. Table 3 shows the means and standard deviations for our sample. Hospice chaplains have been in their practice slightly longer than hospital chaplains by almost three years on average and the difference is statistically significant as determined by the test statistic *t* and the corresponding *p*-value which is less than 0.05.

Table 3.
Results of Chaplain Years of Experience by Setting

		Mean (years)	SD
Setting	Hospital	4.25	2.32
	Military	7.13	2.9

Means and standard deviations (SD) for group comparison of the number of years as a chaplain by ministry setting ($t = -2.19$, $p = 0.046$).

One strength of this statistical tool is that it allows for **within-group**, or **within-subjects**, analysis, which allows you to compare a person's score at one point to another score at a second point. All of the statistical tests presented before this do not allow for this type of analysis. Because a person's measure will be correlated to that person's measure later, the scores are considered to be **dependent**, namely, the result of the second measure for a person depends on the result of the first measure.

An example will help clarify this. Many readers will be familiar with the Scholastic Assessment Test or SAT college entrance examination. If Sally takes the SAT in April and then re-takes it again in June, it is highly likely that her score in June will be related to her score from April. If she scored high in April, it is unlikely that she would score low in June. These two measures for Sally would be dependent on each other. Of course, statisticians have a tool for this. The **dependent samples t-test**, or **matched samples t-test**, is

designed to accommodate the correlation or relationship between the measures. A common use of this t-test is for before and after designs such as surveys taken before and after an educational seminar.

The ANOVA tests are similar to the t-tests in that they also compare means between groups on continuous variables and allow for within- and between-group designs. The fundamental difference is that t-tests are only used for categorical variables with two levels whereas ANOVA is used for more than two categories. Suppose we are still interested in determining if the number of years as a chaplain differs by setting but now we want to compare hospital, hospice, and military settings. The table would be similar to the ones provided for the t-test with an additional group for military but with a fundamental difference. In this example, the p -value tells us that there is a statistically significant difference between the groups, but the difference may not be between all groups. It is common to run **post-hoc**, or follow-up tests, between each group pairing to determine which groups differ from each other.

Another key difference is that while the t-test allows for between-group comparisons and within-group comparisons, these are two separate tests. ANOVA allows for between- and within-group analysis in one test. ANOVA also has tests that allow for within-subjects measurements across time similar to the t-test but the difference is that two or more time points can be analyzed in one test (called **repeated-measure ANOVA**). For example, the dependent samples t-test only allows for analysis of a pre- and post-test score while the repeated-measure ANOVA allows for pre-test before the education seminar, post-test one week after the seminar and post-test one month after the seminar. Another advantage of the ANOVA test is that a variant called the **Analysis of Covariance** (ANCOVA) allows for controlling for confounding variables, similar to regression.

Drive Safely!

In this chapter, we presented basic statistical concepts framed in the analogy of the mechanic (statistician) with an informed driver (you, the research chaplain) in a garage (goal of research) operating on a vehicle (data types) using toolboxes (statistical tests). This chapter was not meant to be a comprehensive tutorial on statistics but rather an accessible introduction. Often, mechanics apprentice with an expert mechanic previous to entering or at the start of their profession and this is true for novice researchers as well. Most people take courses in statistics and work with a more experienced statistician before opening their own “garage” or using specialized “tools” and we recommend the same to you. However, it is important to be an informed consumer and develop a good relationship with a statistician.

We would like to offer a few suggestions for driving safely with your statistician. Our first recommendation is to bring the statistician into the process early. Statisticians can and should be included in the development of the research design and methods to ensure that the design used and data collected can provide the answers to the research question. In

other words, statisticians will provide guidance on what types and how data are collected¹ to ensure that the desired analysis can be performed. We have had a few instances where the researcher did not involve us until after data collection. We had to deliver the difficult news that they had not collected the data in a way that could be analyzed and that their data were unusable. We have also had to inform researchers that they needed to spend hours reorganizing their data for their analyses. This not only is disappointing and time-consuming but also increases the likelihood that mistakes will be made. Again, these types of situations can be avoided by partnering early in the development of the research project. Another suggestion for working with a statistician is similar to working with any colleague: develop timelines and accountabilities. This will be helpful to develop for all members of your research team but is especially important with your statistician as this person probably is involved with multiple projects for multiple other researchers.

Finally, statisticians do not expect you to be as knowledgeable as they are in statistics just like you do not expect statisticians to be able to perform chaplain duties. Expect the statistician to ask you questions about what you want to accomplish. Similarly, you should ask questions, become familiar with what they are doing with your data and why. Remember that you will someday be presenting your results in front of a group and you cannot always bring your statistician along to explain what was done or why.

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¹ This sentence is grammatically correct, “data are”. The term “data” is actually plural. The singular form is datum.

Chapter 7

Evaluating Research

Part A: Qualitative Research

Shoshanna Sofaer, Dr.P.H.

A. The Question And The Method

The first and most significant decision that a researcher makes is “What’s my question?” All the other decisions a researcher makes should be driven by the nature and content of the question. So the first thing to look at in evaluating either qualitative or quantitative research is whether the researcher has clearly identified her question. Ideally, the question will have a clear focus. Take two questions about chaplaincy:

1. What do chaplains do?
2. What do chaplains do when working with patients and families when the patient is facing death?

Both of these are reasonable questions, but the second has more focus. That doesn’t mean it will be easier to answer, but it will be easier to know if you have arrived at an answer, and easier to develop the details of your research plan. Note, by the way, that both of these are “descriptive” rather than “explanatory” questions. For example, an explanatory question might be: “What difference does it make to the work of chaplains when they have multiple visits with a patient and/or family rather than just one visit?” Here you are trying to explain the consequences of multiple visits. You are also comparing; questions can also be “comparative” in nature. For example, “How does the work of chaplains in ICUs differ from their work in regular medical/surgical units?”

In evaluating any kind of research, you should look for the investigator to provide a strong rationale for their choice of question (indeed for all the choices they make). Have they reviewed the existing literature and identified that their question has either never or rarely been addressed, or never or rarely been addressed using strong methods? Have studies been done, but with very different samples?

Why worry about the investigator’s rationale? Well, resources for research don’t grow on trees and we want to make sure they are not being wasted. In addition, if a person has not gone to the trouble of doing a solid literature review, it makes us wonder if she knows enough to design and conduct a good study. Remember, however, that a very important factor in choosing a research question is that the researcher really cares about the answer, or that her colleagues and organization really care. The choice of a research question inherently involves values, even passions. That’s fine. Can passion about the question lead to bias? Certainly, but not inevitably. If the researcher seems to have a preferred answer to the question, that’s a real problem, and one important reason that you need to look carefully at all aspects of a study’s methodology. However, a good researcher will care

passionately about getting a well-founded answer, and will be more likely to design a rigorous as well as relevant study.

If you are looking at a qualitative study, you also need to ask whether the question chosen is appropriate for qualitative work. If an enormous amount is already known about a topic, if strong quantitative measures of key variables already exist, then it may not be appropriate to do qualitative work. If, on the other hand, little work has been done, and that work is inconclusive, it's good to at least consider qualitative approaches. Here are two ways to think about this. One is philosophical. The philosopher Abraham Kaplan (1964) distinguishes between what he calls the "context of discovery" and the "content of justification." I believe he is thus distinguishing between qualitative work, where little is known and there is much to be discovered, and quantitative work, where you often have a specific hypothesis that you are trying to test (justify). The second way to think about this is more concrete. The hallmark of qualitative work is that it asks "open-ended" questions, while in quantitative work you need to ask "closed-ended" questions. As you see in the examples below, it is possible to "quantify" the closed-ended questions in some way, so when you analyze your data you will be working with numbers. The "raw data" you get from asking qualitative questions is typically "text," i.e. what people said. That requires, as we will see, a wholly different approach to analysis, and quantification is rarely the immediate goal.

Examples of Closed and Open Ended Questions

Closed ended question: Did you feel more at peace after you spoke with the chaplain?:

Yes/No or Much more at peace, somewhat more at peace, about the same, somewhat more distressed, much more distressed

Open ended question: How did you feel after you spoke with the chaplain?

Closed ended question: About how long did you spend with the chaplain: five minutes, ten minutes, fifteen minutes, half an hour, more than half an hour

Open ended question: How did you feel about the amount of time you got to spend with the chaplain?

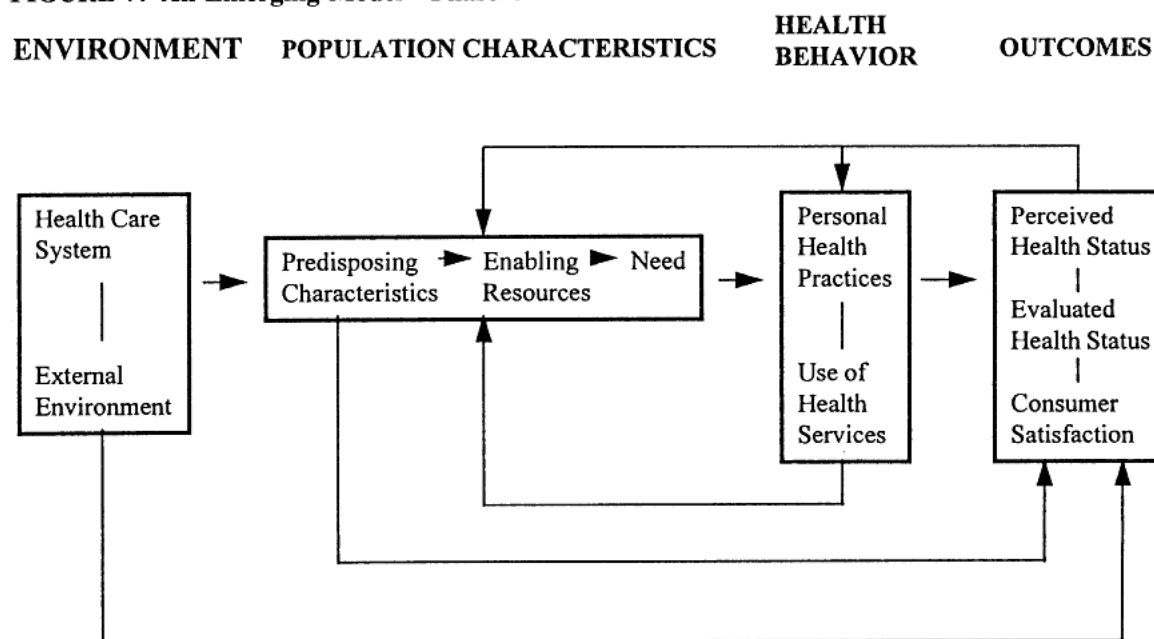
What does it mean to ask an open-ended question? First, it means you do not know, at the outset, the full range of responses to your question. You are ready, willing and able to be surprised by the answers you get. Second, it means you are giving more power to your respondent: s/he can say anything s/he wants, and does not have to be limited by the range of "response options" you have provided.

B. Conceptual Underpinnings

One question often, but not always, asked of a piece of research is whether it is guided by a theoretical or conceptual framework. Such a framework can be helpful in identifying the issues to look at around a particular question. Questions and hypotheses can be derived from a strong framework. In qualitative work, there is some disagreement about whether or not you need a framework. One school of thought says the researcher should go into the field with a completely open mind and believes that adopting a theoretical or conceptual framework inherently makes that impossible. Another school of thought notes that it is pretty difficult to not have any thoughts or ideas about a subject, particularly if you care a lot about it. In that school of thought, having a conceptual framework is not required, not forbidden, but optional. If you are evaluating a piece of research, your primary question should be this: if there is a conceptual framework (1) does it make sense (not is it “correct” but might it be correct); (2) is it actually used to guide the research; and (3) does the investigator link the study’s findings back to the conceptual framework, either indicating how it is supported or how it is not.

Let’s look at two existing conceptual frameworks that are used in studying aspects of health care delivery. The first, the Andersen-Aday Behavioral Model of Health Care Use was first published in 1974 (Aday, LA and Andersen, R.). Over time, Dr. Andersen, often with colleagues, has revised the framework, as he and others conduct research. What he terms the “emerging” model (Andersen, 1995) now has four major elements: the environment (including the health care system itself and its external environment); population characteristics (including what he terms predisposing characteristics, enabling resources and the need for services); health behavior (including personal health practices and the use of health services); and finally, outcomes (including people’s perceived health status, their evaluated (by others) health status, and their satisfaction). The key elements of the original model was the distinction between “predisposing” factors, most of which are hard to change, and “enabling” factors, which are more mutable.

This framework has primarily been used to understand why people do, and do not use health services, and to identify what can be done (for example by increasing the number of people with health insurance or the availability of needed services in a convenient location) to support appropriate access to and use of health care. Over time, however, Andersen recognized that using health services, by itself, is not enough – we must examine the results of using services, thus the addition of “outcomes” to the model. From the perspective of chaplaincy research, this model can help us understand what influences the extent to which chaplains provide services to patients and their families, as well as to health care professionals, and in the “emerging” model, what results from these interactions.

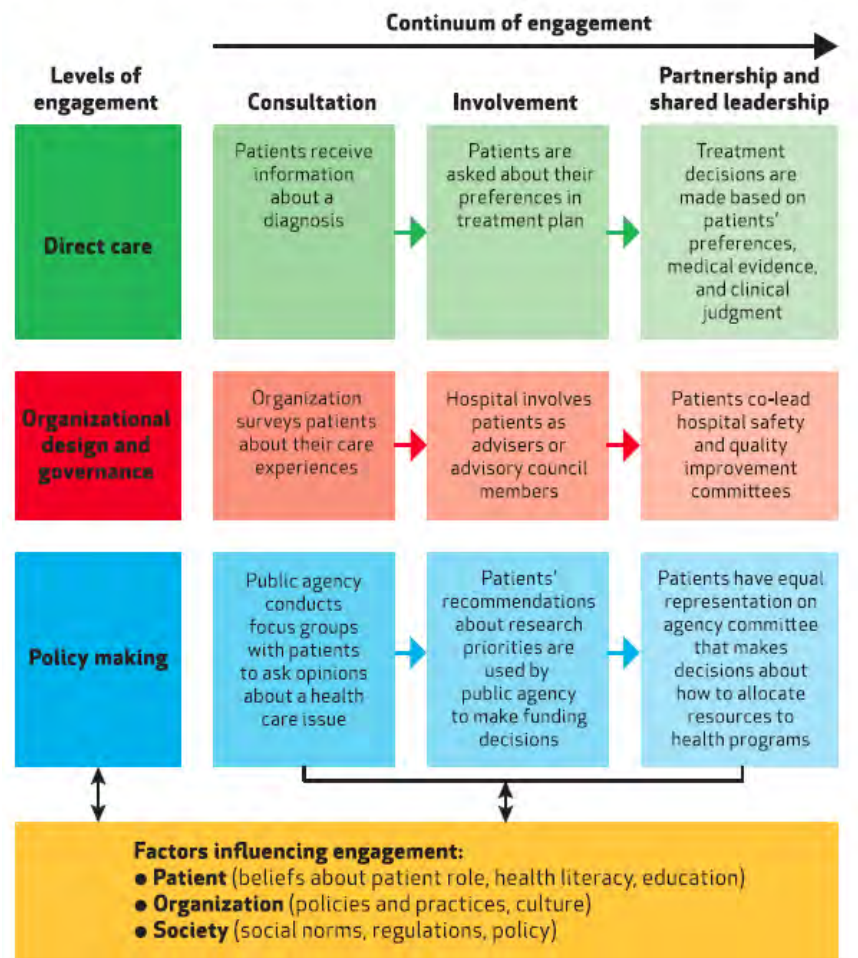
FIGURE 7. An Emerging Model—Phase 4

The second is a very recent conceptual framework developed by a team of researchers and practitioners who are interested in patient and family engagement (Carman et al., 2013); these authors are hoping that this framework will be used both to carry out research and to develop interventions to increase engagement.

The framework identifies three levels at which patient and family engagement can occur with respect to health care delivery: (1) the “direct care” level, of interactions between patients and family members (broadly defined to include close friends as well) on the one hand and clinicians on the other; (2) the “organizational” level, where patients and family members work to support changes in hospitals, medical practices and other health care organizations; and (3) the “societal” level, where they participate in making policy decisions or working on community projects. It also notes that there is a “continuum” of engagement, that goes from simply being consulted, through surveys, focus groups or on advisory boards; to more active involvement, for example as part of a quality improvement team, to partnership in decision-making.

Finally, it notes that the extent of engagement depends on factors within the individual participants (patients, family members, clinicians, leaders), organizational factors, and the environment, in particular including the social norms that speak to the roles of patients on the one hand and clinicians, especially physicians, on the other. The implications of this framework are that whether and how patient engagement happens depends not just on patients themselves, but on health care professionals and organizations, and perhaps even how the media present patients on TV or in the movies. Descriptions of the PFE framework make it clear that these authors, too, are concerned about outcomes, in particular the achievement of the “Triple Aim” of improved population health, reduced costs, and improved patient experiences of health (Berwick, Nolan and Whittington, 2008).

As a “nascent” rather than “established” framework, it is likely it will change over time, most probably by becoming more specific and detailed, but perhaps by becoming still broader. From the perspective of chaplaincy research, this framework would see involvement of patients and families with chaplains as not just the use of a service but a way of engaging with their health and health care in quite a different way. Here, too, we would want to understand whether and how chaplains help patients and families become more engaged in their health and health care, and with what results.

EXHIBIT 1**A Multidimensional Framework For Patient And Family Engagement In Health And Health Care**

SOURCE Authors' analysis. **NOTE** Movement to the right on the continuum of engagement denotes increasing patient participation and collaboration.

There are many existing frameworks in health services research and more broadly the social sciences. Models and frameworks are in the process of being developed for chaplaincy research in particular. Note, however, that some researchers create and then

use, even test, their own conceptual frameworks, which can contribute to intellectual progress.

C. Research Design

Any research study has a design, and this includes qualitative research. The elements of a research design are:

1. A description of your “unit of analysis”
2. A description of your sample, including whether you are comparing samples
3. The time frame for your research

The methods used for data collection and analysis are sometimes thought of as part of the broader “design,” but it is best to hold off on those issues for now to make sure that these elements of the design get the attention they need.

1. Unit of Analysis

This somewhat odd term is more commonly used in quantitative studies, but it has been my experience that you really need to be clear about it no matter what kind of study you are doing. Does the study examine how different chaplains do their work? Then the unit of analysis is the *individual*. Does the study examine the dynamics within families as they respond to the work of chaplains. Then your unit of analysis is the *family*. What if the study compares how the chaplaincy service is organized across many different hospitals? Then the unit of analysis is the hospital, i.e. the *organization*. And so forth. Why is this important? Again, it is a matter of focus, and keeping focus. When people are unclear about their unit of analysis, they get confused, and confuse the reader. They come to conclusions about individual chaplain leaders rather than talking about different hospitals, or they pay attention to patient characteristics instead of family dynamics.

2. Sample

Again, this term seems to come from quantitative work, but it is critical in qualitative work, because the whole approach to sampling in qualitative work is so different. When you read any piece of research, you want to know “Who was studied?” That’s the sample. Going back to the unit of analysis, you may be studying a sample of chaplains, of families, of hospitals, of whatever. But the researcher has to make very clear the characteristics of their sample and why they were selected. Important terms here are “inclusion” and “exclusion” criteria. In one of my recent studies, I was trying to learn from hospital patients how they viewed the role of nurses in the coordination of their care, using focus groups. We had to recruit people to participate in the focus groups, and we therefore had to identify who we wanted to include and who we didn’t. We could have decided that we would choose the same type of people for all the groups. So we would have told the recruiters that people in the group had to (1) be at least 18 years old, since we did not want to study children; (2) have been a patient in a general hospital for at least one night in the last year; and (3) be able to speak and read English and have no visual or hearing impairments. These are inclusion criteria.

The exclusion criteria we used were that each person could not (1) be a nurse themselves or have a close relative who was a nurse; and (2) have been in a focus group related to health care within the past year. The first exclusion is to avoid having a “professional” drown out the voices of the patients; the second is to avoid people who sign up for focus groups because of the incentive alone, since they tend not to contribute much of value. In actuality, we chose to “stratify” our sample. We had nine groups; three were made up of people who had been maternity patients; three who had been surgery patients; and three who had been medical patients. Why did we do that? We thought, but were certainly not sure, that there might be differences in perception and experience across different kinds of patients.

Notice something about these samples. They are not “random.” Instead, they are what qualitative researchers call “purposive” or “purposeful.” If you are doing a survey, i.e. a largely or entirely quantitative study with just closed-ended questions, you typically want to choose a sample that is “representative” of a larger general population. To do that, you have to choose people at random from the population. In almost all qualitative work, you are picking and choosing people *on purpose* to vary in specific ways. These specific ways are reflected in your inclusion and exclusion criteria.

We have given an example of how this works with individuals, but there are other approaches. For example, go back to the question about how hospitals vary in the way they structure their chaplaincy service. You could, actually, take a list of all the hospitals in a community, or state, or country, depending on the size of your study, and just randomly select hospitals and do qualitative data collection. No problem. You also have the option, however, to try to look for particular kinds of variations. So you could try to get information on something like the number of full-time equivalent chaplains they employ per 100 hospital beds. You could then make a list that goes from the highest to the lowest chaplain to bed ratio. You could then choose to study the five hospitals with the highest ratios and the five with the lowest ratios. This is emphatically **not** a random sample, but it is a purposive one.

When evaluating a qualitative study, therefore, look for a clear and detailed explanation of the study sample, going beyond just size, into inclusion and exclusion criteria, any stratification that was used, and most important, the rationale for the particular approach used. Why did they choose the highest and lowest ratio hospitals? Why did they exclude professionals from the focus groups?

A last issue about the sample is whether there are “comparison groups.” In the design of quantitative studies, this question is critical. Without what are called “equivalent” comparison groups, a study cannot unequivocally conclude that a particular intervention resulted in a particular outcome. That is rarely if ever an issue in qualitative work, but if comparisons are being done, the investigators need to make that clear. For example, in our focus groups that were stratified, we were in fact comparing the responses of the maternity, surgical and medical patients, but we were not trying to do what is called

“causal attribution¹.” We nevertheless had to make our intended comparisons clear and give a rationale for making this particular comparison.

3. Time Frame

Finally, the investigators need to indicate the time frame of the study. Is this, as is common, a “cross-sectional” study, where you are just looking at your sample at a given point in time, or is it “longitudinal” in which you may be following your sample over time. The key here is that the time frame and the research question have to match. In some cases, a study might be “retrospective,” that is it is investigating events or experiences from the past. There is nothing wrong with this, except that typically in a qualitative study, that means you need to ask people to bring things up from their memory bank, and we know that our memory of events in the past can be either quite exact, very fuzzy, or just plain wrong.

D. Data Collection

I bet you were wondering when we would get to this! Data collection does seem, and actually is, a critical part of any research project, including qualitative research. If the data for a study have not been collected properly, you simply cannot have faith in their conclusions. So what do you look for when assessing a research study’s data collection methods? First, what specific method(s) of qualitative data collection did they use and why did they use them? The most common methods are focus groups and individual interviews, often called key informant interviews. Less common but entirely legitimate methods include observation and document analysis. Studies may use only one of these methods or combine methods. By the way, when people use the term “mixed methods” they are actually not talking about a study that uses more than one qualitative method, they mean a study that combines qualitative and quantitative data collection.

The keys to assessing data collection methods are determining (1) if the researcher describes the data collection process in enough detail for you to see whether it was carried out systematically and rigorously and (2) if the researcher explains, even in a sentence or two, why she chose the method(s) she used.

What do you want to see in a description of methods? Answers include the particular topics that were examined using each method; how much freedom the data collector had to probe, add questions, drop questions, reorder questions; how long each focus group or interview took; in the case of interviews whether they were in-person or by phone; whether there was a formal instrument (focus group moderator guide; key informant interview protocol; observation protocol) used and if so whether it is available on request; who carried out the data collection (how many different people, their level of previous experience; whether and how they were trained for this specific data collection effort); any unforeseen events that led to changes; and any changes that were made over time. You are

¹ Causal attribution involves creating a design that lets you, with great confidence, attribute the results of an intervention to the intervention itself, rather than to anything else. The most commonly known studies of this kind are randomized control trials to assess the safety and efficacy of new prescription medications. It is essential that we know that what happened to patients happened because of the medication and nothing else.

looking, first, for transparency, and second for clarity. If you get the sense that something is not being shared, worry about it. It might be an oversight or inexperience, but it is really not acceptable. .

Here are some “rules of thumb” about when to use what method:

- Use **key informant interviews** when you want to discuss personally sensitive information; with subjects who are likely to be shy or quiet if anyone else is present; when you want to reduce people’s tendency to “play to an audience” and when you want to go as deep as possible into a topic. When doing interviews, the researcher needs to be sensitive to the relative power and social class of the interviewer and the interviewee. Especially with vulnerable people, the researcher has to be quite protective.
- Use **focus groups** when the topic is not all that sensitive (although extremely experienced researchers have done small focus groups with people facing death, or people who have relatively recently had a loved one die); and when you think the interaction among the participants will actually yield richer information, as people react to each other’s comments as well as to the moderator.
- Use **observation** when you want a chance to have a relatively “unfiltered” experience of an event. That is, you observe something rather than ask people about it. This is an underused and highly valuable method, great for looking at educational and training sessions, and a huge range of meetings, like meeting of staff, boards, community groups, etc. You can also observe interpersonal interactions – watching a chaplain work with a patient, or a family, or with her staff colleagues. People worry that observers will have an impact on the natural dynamics of a situation. A good observer makes herself invisible quickly and many are surprised by how easily they are ignored. In smaller interactions, however, this is more of an issue; this is one reason people often audio- or video-tape interactions and then play them back later on.
- Use **document analysis** when, well, you have a lot of highly relevant and potentially revealing documents available to analyze. Note that this is not medical chart review, where you are typically looking for a specific, pre-determined set of items. The use of this method, again, is based on the nature of the research question, and also the material to which the researcher gets access. Documents might include proposals, annual reports, minutes of meetings, transcripts of meetings, letters from patients, process notes from clinicians, etc. This option is too often overlooked; using it can be a sign of real creativity.

E. Data Analysis

One of the major changes in qualitative research over the last twenty years has been in how data are analyzed. This has been a technological revolution, i.e. the use of special software programs that take a lot of the drudgery out of the analysis process and make it easier to be rigorous as well as creative. Two of the most commonly used programs are NVivo and Atlas.ti. With the availability of these tools, the bar has gotten higher for evaluating qualitative data analysis. In the past, all too often, people simply reported their findings without saying a word about how they got to them. At its worst, people did not even record notes from their interviews, either by hand or using a tape recorder – this meant there was no “raw data” to which one could refer to validate the conclusions. These practices undermined the value and reputation of qualitative research.

Today, when you are evaluating a piece of qualitative work, you need to find explicit information of the following:

1. How were the data captured (e.g. audio-tape, video-tape, structured notes)? Were transcripts made?
2. If there are a lot of data, i.e. many interviews or focus groups, how were the data “managed” and “stored” so they could easily be retrieved?
3. Were the data coded? Coding is the core of qualitative analysis; it involves tagging pieces of text (sometimes a phrase, but usually a sentence or a paragraph) with a specific term that represents an idea of some kind. For example, in a current effort to code interviews with the parents of young children with asthma, we have codes that represent different reasons for using the Emergency Department instead of going to one’s regular physician (e.g. convenience, cost, anxiety about symptoms, etc.) Software programs make it easier to code, but more important, easier to gather all the pieces of text that have been tagged with a given code, or a given pair of codes, etc. Several questions are important about coding. Did the researchers come up with some codes ahead of time, based on their questions, their hunches, their conceptual framework, etc.? Or did they generate codes “inductively” by multiple readings of the transcripts? Some of the best analysts do both – they create “*a priori*” codes at the outset, and then add “emergent” codes, and sometimes remove or revise the earlier codes.

The authors also need to tell you who did the coding, their level of experience and/or their training for this particular effort. Ideally, at the outset, or throughout the coding process, two people will code the same material. The software programs can then generate an “inter-coder reliability rate,” which should be reported. Typically, people vary in their coding, and a critical element of analysis is to resolve these differences by clarifying the meaning of the codes, or by revising them as needed. Discussions among the research team are critical here.

Coding is not the end of the process. The next phase is where creativity and clarity come in. In qualitative analysis you are typically looking for themes and variations that emerge from the data. Coding, and then looking at text with the same or different codes helps you identify those themes and variations. As an evaluator of a study, you want to see a clear description of how people went from their codes to their themes. Keep in mind that this is

about “making meaning.” It is here that qualitative work becomes so different – numbers and statistics are not there to give you meaning – the investigator has to find it. Ask yourself, are the identified themes explained clearly? Do they make sense or seem unlikely or implausible? Do you get the feeling that the researcher had already decided on them ahead of time and forced the data to fit her preconceived notions?

Finally, does the researcher acknowledge other potential interpretations of the data? Did she test for any of these? And does she clearly state the limits of the study? For example, a big issue for qualitative work is the extent to which the sample chosen actually provided the information desired. Did she reach the right folks? Enough of them to get a reasonable degree of certainty that a wide range of perspectives was captured? To what, if anything, can the findings be generalized? Given that qualitative work is not about random sampling, generalizability is inherently questionable. This means you have to be careful about saying that what you found in your study is what will always, or almost always, be found in studies of the same research question. The investigator needs to “fess up” about limits to generalizability.

F. Wrap Up

One of the biggest problems with all kinds of research studies is that the investigators do not clearly, and creatively, describe the implications of their research. There can be implications for practice, for policy, for theory and for future research. All too often, future research and perhaps theory are mentioned but practice and policy are not. People in practice and policy find this frustrating, and over time they begin, therefore, to pay less attention to research in making their decisions. This is exactly what we need to avoid and overcome. So the final step in evaluating a study is to see if meaningful implications were drawn, and if they are consistent with the findings as presented. Last but not least, ask yourself: did the research question get answered and if so, to what extent?

Checklist for Evaluating Qualitative Research

- [] There is a clear research question that is best answered through the use of qualitative methods (e.g. there is little high-quality previous research, we are still in the “discovery” phase, the range of possible answers to the question is mostly unknown).
- [] The investigators have clearly reviewed prior relevant research, and has presented a rationale for the importance of their question(s).
- [] If a conceptual or theoretical framework is presented as the basis of the research, it is clearly presented, actually used, and the study’s findings are linked back to the framework.

- [] The “unit of analysis” of the research (e.g. individual, family, community, organization, nation) has been clearly specified and makes sense given the research question.
- [] The study sample has been described so that it is possible to know what kinds of people, organizations, families, etc. are included in the study and what kinds are excluded. The basis on which research subjects/objects are selected into the sample is clearly described, and may be “purposive” rather than only “random.”
- [] If different samples are being compared, this is indicated, and the comparison makes sense given the research question.
- [] The study clearly describes the time frame for the research, e.g. whether phenomena are being looked at in the “present” or the “past;” or whether the study is intended to be long-term in nature, looking into the future.
- [] The study uses one or more primary data collection methods that are qualitative in nature, e.g. key informant interviews, focus groups, observation, gathering and analysis of documents.
- [] The investigators provide a reasonable rationale for the selection of their data collection method(s).
- [] They describe the data collection process in enough detail to permit an assessment of whether it was carried out systematically and rigorously. For example, if key informant interviews are used, the investigator does the following:
 - Describes how structured the interview was, i.e. how much latitude the interview had to add, drop, re-word or re-sequence the questions
 - Describes the topics covered in the interview and/or provides a copy of the interview protocol; indicates any suggested probes.
 - Describes whether interviews were done in person or by phone or some other way, and about how long they lasted
 - Tells you how many interviews were conducted, overall, and if there are multiple settings for interviews, in each setting; it is admirable but not essential that a profile of the people interviewed is presented.
 - Indicates if there was difficulty getting permission to interview certain people, or as many people as desired.
 - Indicates the number of people who conducted each interview and the number of people who were typically interviewed
 - Indicates whether/how the interview was recorded (e.g. video-tape; audio-tape, notes).
- [] The investigators describe the data analysis process in enough detail to permit an assessment of whether it was carried out systematically and rigorously. This includes:

- Indicating that what people said in interviews or focus groups was transcribed
 - Describing the process used to identify patterns and themes in the data: in particular, saying whether the transcribed data were “coded;” if coded, how and by whom the codes were developed; by whom the coding was done; and what checks were used to ensure that coding was accurate and consistent.
 - Indicating whether or not a qualitative software program was used in coding and which one.
 - Describing how the coded data were organized for in-depth examination and interpretation.
- [] The study articulates its conclusions; those conclusions are consistent with the results of the analysis.
- [] The study discusses the implications of the research for policy and/or practice and for future research. These implications are also well grounded in the findings, backed up by the background literature and previous research.
- [] The limitations and inherent weaknesses of the research are acknowledged and it is clear that conclusions and implications are defined in the context of those limitations.

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Evaluating Research Part B: Quantitative

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Although original empirical quantitative research may sometimes be reported in books, it is most often published in peer-reviewed journal articles in print or online. This venue is preferable to researchers because the results appear more quickly – both because the article is a shorter format to write and because the time from review to publication should be much quicker. The peer review process for journals is not perfect, but it provides a level of oversight, and allows editors making decisions to accept or reject manuscripts with the benefit of several perspectives and types of expertise.

The following is intended for chaplain researchers working in numerous capacities. All chaplains who read the quantitative research literature need to be able to evaluate the research. Chaplain researchers who are preparing manuscripts for publication can benefit from the following guidelines on what the peer reviewers and editors who are judging their work will be looking for. Some chaplain researchers who begin publishing quantitative research may eventually be asked to serve as peer reviewers themselves.

The Peer Review Process

For those who are submitting manuscripts for the first time, the peer review process can seem quite daunting. And in fact it is true that the majority of manuscripts submitted to many journals are rejected the first time, so a rejection letter shouldn't feel like the end of the process – it is really the beginning of improving the paper.

When an article is submitted to a journal, the editor may decide to send it out for review, or it may be rejected immediately if he/she feels it is inappropriate for the journal. If the paper is sent out to reviewers (often three), they will be given several weeks to respond. The reviews will contain comments on the paper written for the author(s), as well as a confidential recommendation about publication for the editor. The editor will evaluate the reviews, which may or may not agree with each other, and make a decision. There are three basic possibilities: a paper may be accepted (this almost never happens with a first round review), or rejected, or the author(s) may be asked to “revise and resubmit” the paper. A cover letter from the editor giving the decision and the reviews themselves will then be returned to the author(s). If invited for an “R&R”, the editor will often give a deadline for receiving the resubmission.

When revising a paper, close attention should be paid to every comment. Besides revising the paper itself, the author(s) should write a response letter detailing how they have handled the critiques. The revised version of the paper will again be sent out for review, usually to the same reviewers. At that point it may still be rejected, or accepted, or get another R&R, on its way to eventual publication in this or some other journal.

In the following sections we discuss some of the markers of quality research that a reader of the journal, or a reviewer of manuscripts, or an editor will be looking for. The discussion will focus on observational (as opposed to experimental) research, because that will be more relevant to chaplain researchers. Experiments would require patients to be randomly assigned to “treatment” and control groups, and measuring any difference in outcomes for the two groups. Observational studies, on the other hand, record the behaviors, perceptions, and feelings of participants as they occur naturally.

Introduction and Literature Review

The beginning of the paper should quickly convince the reader that the subject of the research is important and should motivate him or her to read further. One good strategy for introducing quantitative research (and qualitative research as well!) is to cite data showing the magnitude of the issue at hand. For example, a paper on the chaplain’s role in counseling about advance directives might cite the proportion of adults in the United States who do not have an advance directive. Even better, data on the recent *trends* in the issue in question can lend a sense of urgency.

When providing data from other studies, it is important to choose only those from trusted sources, such as peer-reviewed journals, or US government or research foundation data. Cite the source the data come from, and provide the context the reader requires to appreciate the importance of the information. The text should not just summarize the research, it should convey to the reader *why* this study is important to the present project.

The structure of literature reviews will vary. An ideal structure will begin with a classic or well-known study, then bring the reader up to date with more recent research. The structure is like a funnel – the opening situates the research in a broad and historic context, then previous studies that contribute to the research question are discussed, and at the narrowest end, the review should conclude with a close look at just one or two studies that most closely approximate the new research that will be reported in the paper.

Research Question

Every researcher should be able to state clearly what it is that he or she wants to know. Research is the process of generating new knowledge. The research question is the entry-point into the territory beyond what is presently known. The literature review should have led right up to the edge of “the known” and the research question will follow naturally to ask about “the unknown”. Some studies may not articulate their research question directly, but they should. To take our example of the chaplain’s role in the completion of advance directives again, we might ask “How frequently do chaplains discuss advance directives with patients and families?”

Hypotheses

Hypotheses, on the other hand, are not always required in a quantitative research paper. A hypothesis is the statement of an expectation about what the data in the study will show. It must identify the independent (exposure) and dependent (outcome) variables, specify the

direction of the association, and include the comparison group. An example of a hypothesis would be: "Patients without an advance directive who have discussed their end of life plans with a chaplain will be more likely to complete an advance directive than patients who did not have such discussions." In many cases, however, the research on a particular topic is not sufficiently developed for specific hypotheses to be formulated.

Sample

The sample is the "who" of the study. The paper should report the number of persons providing data for the study and how they were chosen. A sample can be said to be representative of some larger population only if every individual in the larger population initially had an equal chance of being chosen, and if that probability can be defined. Usually this means that a complete list, or sampling frame, was available to the researchers, and that the participants for the study were chosen from it with some probability method. If, as is often the case in clinical settings, patients are recruited as they are available and willing to participate, the sample cannot be said to be generalizable to any larger group of patients, even at that institution; the study participants represent only themselves.

An important measure of the quality of a study is the response rate, or the proportion of individuals who were approached about the study who agreed to participate. A response rate above 70% would be considered very good; below 50% would likely be questioned by reviewers. There are certainly exceptions for hard-to-recruit populations, particularly if little is known about them, and that would include palliative care populations.

Human Subjects Research

Research with living individuals is subject to review to ensure their protection from adverse consequences of participating in the research. The lead researcher must notify his/her Institutional Review Board (IRB) of the protocol of the study before it is performed, and be declared exempt from review, or receive an expedited or full review and be approved. If confidential medical records will be studied, or sensitive topics included in a questionnaire, subjects in the research will most often be asked to sign a consent form. The paper should report that the study was approved by the relevant IRB.

Study Design and Data Collection Methods

This is the "how" of the study. The data for quantitative studies could come from already-existing data, such as from the archives of institutions, or medical records, or government sources. Many studies utilize data from surveys that have been made publicly available by the original researchers, through the Inter-University Consortium for Political and Social Research (ICPSR) or the Association for Religion Data Archives (ARDA). Secondary or archival data sources should be fully cited.

Other researchers will collect their own data. Quantitative data are most often collected by surveys administered face-to-face, or over the phone, by mail, or over the internet. The responses to questions are frequently entered directly into the computer, which is much more efficient and less prone to error than paper and pencil questionnaires that must be entered later by hand.

If a study consists of survey responses taken at one point in time, it is a cross-sectional study. Although the researcher may identify independent and dependent variables, the direction of causality cannot be determined since all variables are measured simultaneously. A longitudinal or follow-up study requires re-contacting the respondents after a period of time for a second interview or to ascertain their status; time order of the measures can then be determined, although researchers should always be cautious about making causal statements.

Measures

This is the “what” of the study. Much of the information the researcher wants can be obtained by using the questions or groups of questions that other researchers have published previously. This is not cheating or taking a shortcut, it is a desirable way to have the new research project be directly comparable with existing research. Using standard measures for a phenomenon such as depressive symptoms, for example, provides the reader with confidence that the construct, or variable being measured is both reliable and valid. Reliability means that a measure performs consistently over time, and that the items that make up an index or scale are correlated with each other. Validity means that a question or scale actually measures what it says it does; there are various types of validity, such as face validity, construct validity, concurrent validity, and predictive validity.

The researcher who has a novel research question, however, may find that there are no studies that have collected data on the topic of interest; or that existing questions from interviews in other studies are flawed. If a new measure or construct is proposed, care should be put into developing the items that will measure it, and it will be important to demonstrate its reliability and validity. For example, if the researcher wants to measure chaplains’ reactions to their interactions with patients, he/she should read the related literature, and spend time talking with chaplains when writing the items to be used. The responses should then be carefully analyzed for their patterns of correlation, and only those items that best represent the construct should be chosen. Focusing on a new construct and developing a way to measure it can be a real contribution to the research literature.

In addition to the independent and dependent variables, other measures of the sample’s characteristics, including gender, age, race/ethnicity, education, marital status, and income should be included as control variables.

Analytic Methods

Survey data can be analyzed with computer programs such as SAS (Statistical Analysis System), STATA (Data Analysis and Statistical Software for Professionals), or SPSS (Statistical Package for the Social Sciences). The research will examine the single variable, two-variable, and multi-variable patterns, or associations between the variables. The research question and/or hypotheses will determine the order and structure of the analyses. The types of variables – categories such as race/ethnicity or gender, variables with ordered levels such as ratings of health, or continuous variables such as a score on a

depression assessment – will determine which statistical tests and procedures are appropriate. To go back to our example, the hypothesis concerning the likelihood of a patient signing an advance directive could be tested with a chi square table or logistic regression analysis, because the dependent variable is a category (yes/no). For explanations of chi square and logistic regression analysis see chapter 6 of this Handbook, “In Pursuit of the Truth: Statistical Tools.”

Results

The results section should begin with a description of the characteristics of the sample being studied, including age and gender make-up, and other demographic characteristics. These data, reported as means or proportions, and ranges, would appear in a table, which sometimes also contains [bivariate associations](#). In our example, this table would show the proportion of the sample that did not have an advance directive and the proportion that discussed the subject with a chaplain. If a new construct such as chaplain feelings is being developed, a second table would report a factor analysis of the components. A final multivariate analysis would test the hypothesis and show whether there was a statistical association between chaplain discussions and advance directive completion.

Tables and figures should be carefully prepared. The title should accurately describe the type of statistical analysis, the independent and dependent variables, and any subgroup analyses that are stratified by gender, race/ethnicity, etc. The columns and rows should be self-explanatory phrases, and not simply the brief variable label. Be sure that the units of measure (dollars, means, percentages, raw numbers, or regression coefficients) are labeled.

When describing the content of a table, always begin with the big message or the overall pattern. Then give an example using numbers from the table: “...the proportion of patients who completed an advance directive was 50% higher among those who discussed it with a chaplain than among those who did not.” Finally, if there are any exceptions to the overall pattern, note them: “...this proportion was similar among all gender and race groups, but did not hold for the small number of younger patients, for whom there was no difference.”

Discussion

The structure and composition of discussion sections differs from one discipline to the next. All will contain a brief summary of the findings, a frank enumeration of the limitations of the study, and an underscoring of the study’s innovations, contributions, and strengths. In some disciplines it is the norm to introduce new research literature in the discussion section; in others this is unusual. Overall, however, the discussion section offers the author(s) the opportunity to reflect on and interpret the meaning of the findings for the audience.

Abstract

A good abstract will tell the reader quickly the basic facts of the study. The requirements for the abstract for any particular journal are very specific as to word count, and whether it should be structured with subheadings or in a paragraph form.

Composition and manuscript preparation

It is very important to follow the submission guidelines, which are different for every journal. The style of references and citations, the structure of sections, and the word length requirements must be followed closely. Sloppy writing and careless copy-editing can negatively influence reviews, even if the content is good.

Summary check list for evaluating quantitative research:

1. The *literature review* should provide a well-referenced rationale for the study.
2. The *research question* should state the purpose of the study.
3. The *hypothesis* (if included) should state the researcher's expectation of what the findings will be.
4. The *sample* and *method of sampling* should be described clearly so that the reader will know how generalizable the findings are.
5. The *method of data collection* should be described clearly so that another researcher could potentially replicate the study.
6. The *measures* used to capture key concepts in the study should be clearly described if originally developed for the study, or referenced if available in previous publications.
7. The *data should be analyzed* with methods appropriate for the sampling and measures.
8. The *results* should be presented in tables and described in text, beginning with single variables and ending with multivariable analysis.
9. The *discussion* should summarize the findings, acknowledge the limitations of the analysis, and speculate about the meaning of the overall findings.

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Chapter 8

Quality Improvement

An Invitation to Chaplaincy Research: Entering the Process

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Key Concepts:

- Competent, compassionate health professionals are needed to more efficiently and effectively provide comprehensive person-centered and family-focused care quality care to our rapidly aging population.
- This offers opportunities for chaplains to contribute to the development of a collaborative healthcare system that provides accessible, quality, comprehensive, culturally-congruent, biopsychosocial-spiritual support to all those in need.
- Chaplains are needed who have the quality improvement skills to develop, evaluate and replicate a wide range of services to address these needs.

Key Words: Quality Improvement; Leadership Development

Introduction

In 2001, the Institute of Medicine released an influential report calling for a transformation in the delivery of healthcare in America (IOM, 2001). This report highlighted existing deficiencies in service and called for improvements to ensure that our healthcare system would be reliably safe, effective, patient-centered, timely, efficient and equitable. Improvements were called for, but unfortunately, there is ample evidence that healthcare in the United States continues to be both unsustainable and untenable, with disturbing gaps in the delivery of care and disparities in access to quality care (IOM, 2013; IOM, 2008).

This has resulted in a window of opportunity to influence the delivery of healthcare and created a sense of urgency regarding the development of new programs to better meet the needs of our increasingly aging population (Fletcher & Panke, 2012; Moy, et al, 2011). There is tremendous tension to both improve the delivery of healthcare and manage the costs associated with that care (Patient Protection and Affordable Care Act, 2010). A more nimble healthcare system is needed that systematically evaluates practice to continuously improve the delivery of care (IOM, 2012).

Therefore, data matters. In an ideal world, data provides the evidence that drives practice, with findings from effective practice transmitted through quality educational programs and resulting in evidence-informed policies that improve the delivery of quality services to all of those in need. You may have noticed that we do not live in such an ideal world, but nonetheless data matters. Data matters to patients as it provides the evidence that allows practitioners to select interventions that have the highest likelihood of success for the individual receiving care.

As our healthcare system becomes ever more complex, more technologically-driven, our population ages and our workforce shrinks, we have to become better able to tailor interventions to those most likely to benefit. Evidence is urgently needed to determine the quality of care and the added value that a service provides. Data matters to those who pay for care and to those who provide it. Data helps us to discern more wisely. But historically, psychosocial-spiritual professionals have not been well prepared to contribute to the evidence base, resulting in limited data supporting the efficacy of many social work and chaplaincy interventions. As healthcare resources continue to shrink, difficult decisions about staffing levels will need to be made. Institutions will be increasingly accountable to justify expenditures as good stewards of limited funds. If we as psychosocial-spiritual professionals are not able to demonstrate our effectiveness and increase our role in the development of a robust evidence base, our continued existence in healthcare is in jeopardy. And *meaningful* data matters most. We need to be innovative in our selection of metrics if we are to measure the complex and multi-dimensional work that we do. This chapter explores the concept of quality improvement and strategies to generate data that is meaningful with additional resources to guide further learning.

Clarification of Terms

There is much written about the quest to provide quality care (Abernethy, 2014), but it can be challenging to identify what constitutes “quality” healthcare and who decides how we determine it has been achieved. Do we measure *quality* in terms of *quantity*, focusing upon numbers of patients seen, rapidity of “throughput” and cost containment curves? Or is it defined by adherence to established “best practices” and increasing patient satisfaction scores? Should it include patient safety or employee retention rates?

Batalden & Davidoff (2007) define quality improvement:

“... as the combined and unceasing efforts of everyone-healthcare professionals, patients and their families, researchers, payers, planners and educators- to make the changes that will lead to better patient outcomes (health), better system performance (care) and better professional development (learning).... This definition arises from our conviction that healthcare will not realize its full potential unless change making becomes an intrinsic part of everyone’s job, every day, in all parts of the system.”
(Batalden & Davidoff, 2007, 2).

If we believe that quality healthcare is person-centered and family-focused and includes attention to the biopsychosocial-spiritual domains of care - such as is recommended in the provision of quality palliative care (NCP, 2013), we have an obligation to be part of the team that attempts to define and measure these factors through research and quality improvement activities. Efforts to systematically improve care become essential to our daily work and no longer optional. If we believe that attention to patient spirituality as a foundational element of quality care – we have an obligation to demonstrate this with evidence. We are fortunate that the founders of palliative care shared this belief and have incorporated spirituality into the quality indicators for palliative care (De Roo, et al, 2013).

Palliative care is here understood as care that is focused upon improving patient function and quality of life and is inherently collaborative in nature. Palliative care is appropriate from the moment of diagnosis of a serious illness onward and across settings. It strives to deliver care that is culturally congruent and respectful of diverse spiritual, existential and religious perspectives (NCP, 2013).

Although many in healthcare embrace the concept of evidence-informed practice, this belief is not universal. Indeed we should recognize that until recently the fields most associated with psychosocial-spiritual care were the least likely to be a part of the collection of “evidence” related to their provision of care. It is not uncommon to find chaplains and social workers who completed their formal professional education with only the briefest of an introduction to research and who see the concept as “optional” to their practice.

This has not served our fields well and has allowed the perspective of other disciplines to dominate many policy decisions. As a palliative social worker, I’m involved in educating my colleagues on the importance of evidence-informed practice and encouraging them to make data their friend. A key element of this is recognizing that at its most fundamental level, “research” is critical thinking. Clinicians are needed who are curious and who wonder why an intervention worked better for one person than it did for another. From this perspective, the development of a critical mindset is key. What is needed are healthcare providers who are reflective about what they do and why they do it, who question outcomes and who are committed to the provision of highest quality care possible. Practitioners from every discipline are needed who are willing to learn the skills necessary to determine what works best for whom and how can we continuously improve the delivery of our care?

The federal government distinguishes “research” from “quality improvement” to clarify which activities will require approval from an institutional review board (IRB). Research in this context is systematic investigation designed to contribute to generalizable knowledge (typically through publications shared externally). Quality improvement (QI) activities are also a form of systematic investigation, but the goal of a QI project is to evaluate the service in context (sharing findings internally with the intent to improve the delivery of care provided within a particular institution or agency). If an activity is determined to be research, there are a number of additional institutional obligations (related to the protection of human subjects, etc) that need to be met prior to proceeding (more detail on research activities can be found in other chapters of this text).

QI projects typically focus upon optimizing effectiveness, addressing deficiencies in a service and/or increasing the value of a program to its customers. Continuous quality improvement is considered the goal, with staff engaged in on-going efforts to improve the delivery of care across all aspects of the institution.

Quality Improvement Frameworks

Determining the appropriate quality indicators for a particular project can be intimidating. It is easy to be tempted to “throw the baby out with the bathwater” and argue that what we do as chaplains or social workers is primarily relational and therefore not easily measurable. But just because a task is difficult doesn’t mean it shouldn’t be done. We need the providers of these services to be part of the teams who are engaged in the collection of evidence if we are to create the kind of nuanced tools that are necessary to move our fields forward. Collaborating with our colleagues in active and productive discussions can generate new ways of thinking that can open doors to measure “success” and “quality” in the psychosocial-spiritual programs and services we offer.

A popular framework for evaluating quality comes from the Donabedian framework of structure, process and outcomes (Donabedian, 1988). This framework offers the opportunity to measure structural characteristics of programs, providers or tools (for example, availability of services to other-than-English-speaking populations); processes (that might include policies for referral to chaplaincy, or timely documentation of a spiritual care assessment) and outcomes (that might consider satisfaction with care delivered by chaplains in the critical care unit).

Determining what to evaluate requires consideration of many factors. A needs assessment might provide clues regarding areas of dissatisfaction that can guide next steps. It’s important to define the purpose of the QI project so that consideration can be given to what data will be collected and what audience will receive this information (Dy, 2013). Prioritizing activities with key stakeholders will help to formulate this process. Agreeing upon a vision statement (for example: *To integrate spiritual care into our provision of comprehensive, person-centered care to the oncology patients in our hospital*) can help provide clarity moving forward. In our work with the *ACE Project* (a National Cancer Institute-funded leadership-skills building program for 300 psychologists, spiritual care providers and social workers), we asked participants to frame their institutional change projects as S.M.A.R.T. goals (Otis-Green, Yang & Lynne, 2013; Otis-Green et al, 2009). S.M.A.R.T. is an acronym for goals that are Strategic, Measurable, Achievable, Realistic and Time-framed (Conzemius & O’Neill, 2002).

Decisions need to be made regarding what population will be evaluated and what setting used. It’s important that the project is strategically selected to be manageable in scale and achievable within a given timeframe with the available resources. Careful consideration of competing priorities and limited time commitments for accomplishing the project is necessary for the success of the project.

It can be useful to think in terms of “steps” or “phases” of a project. An example of an initial S.M.A.R.T. goal derived from the vision statement above might be: *Over the next year, our palliative care service will increase the number of referrals to chaplaincy for patients in the Critical Care Unit over three days by 10% each quarter.* A concrete and measurable goal such as this provides structure for the team to proceed and can be easily expanded (to other

units or to other populations) as the targets are met. For many, the identification of appropriate metrics is a stumbling block. Whenever possible, the use of validated measures is ideal, but many QI projects can be measured through less formal means. A goal such as this would require a baseline measurement that could be achieved through a chart review, with a quarterly count of chaplaincy referrals to determine progress toward the goal.

Quality Improvement Models

There are a variety of QI models available to guide your team. Your institution may have a preferred model, and it may be wise to work within the system that has administrative support. The following table provides an overview of several popular models currently in use. There are many similarities between the models, and they can be combined and adapted to best serve the needs of your QI program.

Table 1.
A Comparison of Quality Improvement Models

QI Model	Description
PDIA	Plan: Plan a change or test of how something works. Do: Carry out the plan. Study: Look at the results. What did you discover? Act: Decide what actions should be taken to improve.
FADE	Focus: Define and verify the process to be improved Analyze: Collect and analyze data to establish baselines, identify root causes and point toward possible solutions Develop: Based on the data, develop action plans for improvement, including implementation, communication, and measuring/monitoring Execute and Evaluate: Implement the action plans, on a pilot basis, and Install an ongoing measuring/monitoring (process control) system to ensure success.
Six Sigma	A set of tools and techniques (DMAIC = define, measure, analyze, improve, control) for process improvement developed by Motorola in 1986, and popularized by Jack Welch at General Electric in 1995. Focus: Eliminating errors and minimizing variability.
Continuous Quality Improvement	Focus upon the “process” rather than the individual.
Root Cause Analysis	A retrospective approach to error analysis
Lean	Developed by Toyota to increase efficiency within their production system

(Adapted from: U.S. Department of Health and Human Services: Health Information Technology and Quality Improvement *Health Information Technology Toolbox* Website:
<http://www.hrsa.gov/healthit/toolbox/HealthITAdoptiontoolbox/QualityImprovement/whatisqi.html>)

The Quality Improvement Team

As important as determining what you want to change and which change model you intend to pursue is the selection of who will be on your QI team. Palliative care projects will typically be interdisciplinary in composition. This inter-professional perspective provides greater insight into the complex and multidimensional aspects of care that you are likely to be seeking to improve. It's wise to identify champions of your project and give thought to the stakeholders who will be impacted by your efforts. Consider who stands to lose from your change activities and how you might mitigate their losses. How might you minimize their resistance? What skill set will you need to accomplish your goal? How might you expand your team to include those from outside of your immediate group? Is there a role for patients or family members in the project? Would the inclusion of community clergy offer additional diversity in perspectives that would be of benefit? Do you have representatives from differing genders and ethnicities on the team?

It is likely that staff education will be an aspect of your QI project. Preparing colleagues for the changes that you expect from them often requires professional education, yet few clinicians have received training in adult learning principles or feel confident in creating educational programs (Otis-Green & Ferrell, 2010). Failing to support others in understanding their new roles will likely have negative consequences for your program. Are there resources that you can access to support your team in educating your colleagues?

Who on your team will be accountable for what aspects of the work? Although collaboration is key, there needs to be someone who acts as the leader of the project and with whom "the buck stops." Does this person have the necessary authority to hold others accountable for their contributions to the success of the project? Are they sufficiently invested in the project? Do they understand the problem and the challenges you face? How will you know you've achieved your aims? What metrics will matter to your colleagues when you are implementing the proposed changes? Do you have access to those with skills in more sophisticated evaluation and data analysis should it be needed?

Do you have administrative support for your proposed changes? Will there be expectations that additional costs or additional personnel will be needed? How might these concerns be met? Is there the possibility of expanding the impact of your work through partnerships with others, both inside and outside of your organization? Who can support you as you leverage your work to maximize momentum for change?

Coping with the Challenges of Institutional Change

It's important to be mindful of the challenges inherent in organizational change. As with recommendations to patients for behavior change (for example to stop smoking), we can expect organizational resistance to change even when we have evidence in justification of why this is necessary. It's helpful to be mindful that systems are designed to maintain the results that they have always gotten, and resistance to change is to be expected. Organizations are made up of people who become comfortable in routine and who may fear change. Identifying strategies to help you cope with resistance will keep your QI team from

becoming dispirited when others resist your improvement efforts. You may find that colleagues misinterpret your motives and challenge your authority to expect them to behave differently. Using your clinical skills to work with resistance can be helpful when encountering organizational challenges. It's important not to take these this personally and to develop plans and back-up plans that can be applied when you encounter resistance.

Organizational change requires persistence and a commitment to improve care. If you have selected your QI project wisely, you are clear about why it matters and that clarity will help you maintain your motivation. Adapt your clinical skills in supporting patient behavioral change to manage challenges you face with institutional change.

Lessons Learned from Work with the *Transitions Program*

Earlier in my career, I had an opportunity to develop and pilot a series of psycho-educational support services under the umbrella of what we called the *Transitions Program* (Otis-Green, 2006). From the outset, we were committed to developing services that were evidence-informed and outcomes-oriented. We knew that we had to rigorously evaluate the impact of the work and were exquisitely conscious that we had limited resources at our disposal. Our program initially consisted of me and two chaplains.

To begin, we identified an institutional gap in bereavement services through a needs assessment of clinical staff. Interested colleagues from nursing, medicine, patient education, social work and chaplaincy joined a planning committee that met for nearly a year prior to launch of the project to review the literature, identify internal “change-champions” and to strategize initial services to be offered. We were acutely aware that staff “buy-in” would be necessary if we were to be successful in changing the culture of the facility toward how it cared for the dying and bereaved, and we worked very hard to ensure that we were not invading anyone else’s “turf.”

Initial activities included the development of bereavement support services that included bereavement mailings and support groups for the bereaved. We immediately discovered how difficult it was to obtain timely and accurate information about the deceased at our institution. Folks who died outside of our hospital might not come to our attention for many months. We needed to work with our nursing, health records and bio-stats people to create and streamline procedures that would more quickly route decedent information to our program. Using the “Plan-Do-Study-Act” cycle, we would make a series of micro-changes, evaluate the results and adjust our strategies accordingly. We used process metrics for much of this work, evaluating numbers of people identified and tracking the timeliness of the information. Subsequent measures included “satisfaction” surveys from those who received services, as well as the number of attendees at differing activities.

From our data, we quickly realized that we needed to expand our services further “upstream.” We recognized that the best way to improve the experience of the bereaved was to ensure that we provided the very best possible care at end of life. This meant that we needed to think of *Transitions* as a three-legged stool, with services for the bereaved,

the dying and those who cared for them (both personally and professionally). We conducted focus groups with staff from each shift and unit to clarify concerns so that we could develop tailored educational interventions to better prepare healthcare providers to address the needs of the dying and the family caregivers, as well as to support staff in developing healthier self-care strategies.

This led to a launch of targeted staff education sessions in a variety of venues. We integrated palliative and end-of-life education into the hospital's existing grand rounds schedules and developed stand-alone unit-based supportive programs. We offered nursing staff opportunities to participate in customized "de-griefing" sessions following periods of intense patient deaths (as often occur in critical care units and oncology floors), and created quarterly memorial services for the supportive care staff. *Transitions* chaplains also conducted institution-wide memorials following the deaths of healthcare staff who had died at the hospital.

In keeping with the principles of quality improvement, we were committed to continuously identifying gaps in service delivery. This led to the creation of a parallel program for our Spanish-speaking patients and families. *Proyecto de Transiciones: Enhancing End-of-Life and Bereavement Support Services for Latinos Within a Cancer Care Setting*, was funded by the Open Society Institute, with a Project on Death in America Grant. This allowed us to partner with a community hospice to develop culturally congruent support services in Spanish facilitated by a bi-cultural and bi-lingual professional bereavement facilitator. The success of this program led to a partnership with colleagues in the Korean community to trial a Korean-speaking bereavement program.

We learned from those attending support groups of additional "gaps" and created a wide range of programs to support families caring for dying loved ones. Given the diversity of those we served, we built a "menu-approach" to services, attempting to create a variety of activities so that participants would be free to select those that best met their needs and interests at any given time. This allowed the program's services to be easily customizable and contributed to a person-centered and family-focused approach to care delivery. We quickly recognized the importance of minimizing "regret" and focused efforts towards improving goals of care conferences for those facing end of life, with targeted education and mentorship to staff to improve communication around difficulty issues to enhance family meetings.

We developed seasonal programs (such as "coping with grief during the holidays"), but these expanded quickly due to interest and we created all day grief workshops held off-site in the community. We tracked attendance and evaluated program satisfaction and donations from "grateful" participants to measure program success. Patient-volunteers offered journaling workshops and scrap-booking sessions, in addition to professionally-facilitated counseling sessions at bedside. We found that patients and families were eager for "legacy-building" opportunities and *Transitions* staff developed workshops and groups to assist people in creating personally-meaningful legacy projects for loved ones (Otis-

Green, 2003). An important outcome from this aspect of the program is that it offered people something tangible that they could *do*. This strengths-based perspective is well supported in the literature and was a key to the rapid expansion of expressive arts activities within the program. We began small, but expanded services as we identified need and soon had a robust series of activities that included: *Coping and Caring*, *Detours*, *Legacy Builders*, *Compartiendo Esperanza*, *Art for the Heart*, *Writing for Wellness*, *Expressions!*, *Reflections*, *Reflexiones*, *Grief Retreats* and *Hands on Harps*.

We were able to obtain institutional (and eventually community) grant support for the creation of the *Hands on Harps* program (Otis-Green, Yang, & Lynne, 2013) which supported our first Musician in Residence, Lisa Lynne. Lisa brought her collection of harps to the hospital and encouraged the audience (patients, families and staff) to join in the concert. She coordinated monthly sessions led by visiting “talent” who would play throughout the hospital and clinic and at the bedside of those who requested. We purchased several small harps and a lending music “library” for patient and family use. We were attentive to cultural and ethnic diversity in the purchase of musical selections and were fortunate to have musicians from a wide variety of backgrounds willing to share their talents with our program.

We tracked “penetrance” of the program based upon staff referral patterns. We monitored which discipline or floor referred patients to us and used that data to target future educational efforts. In addition to measuring attendance and “satisfaction,” an interesting metric for the integrative arts aspect of our program was media attention. We tracked how the activities of *Hands on Harps* were highlighted through multiple newspaper outlets, radio interviews and television segments. Not surprisingly, that exposure was important for the continued community grant support of this work (now lasting for over a decade). We also measured the number and kinds of publications and presentations made about the program, and prominently shared these in our annual reports. We maintained a log that recorded thank you cards and appreciative staff comments related to the work, and of course tracked donations and grant monies received.

Given our focus on end of life and bereavement, we also attended to one another’s well being and committed ourselves to mutual team support and professional growth. If the work was to be sustainable and of the highest quality possible, we recognized that we needed to care for one another. Members of the team were supported in efforts to expand their skills through outside educational activities and encouraged to develop their expertise. We were committed to a transdisciplinary team approach to meeting the multi-dimensional concerns of our constituents and were explicit about our passion for the *Transition Program’s* mission:

Recognizing death as a natural part of life and grief as a healthy response to loss...Our mission is to enhance end-of- life and bereavement care by ensuring the provision of comprehensive and compassionate biopsychosocial-spiritual and educational services

throughout the continuum of life to patients, their loved ones, the bereaved and the professionals who care for them.

Summary

As the United States continues its process of healthcare reform, we can anticipate that we will see a heightened interest in efficiency and a continued call for evidence-informed interventions. Chaplain leaders have an important role in all aspects of QI projects to ensure that there is evidence for the seamless integration of spiritual care in healthcare. Data matters - make it your friend.

Practice Pearls

- QI is a team sport. Engage with colleagues to identify areas for meaningful improvement. Collaborate in the process.
- Be creative. Align incentives to encourage momentum toward the goal. Make the process fun. Reward efforts. Celebrate your success. Share your findings.
- Reflect upon what you learn each step of the way. Expand your focus and leverage your results. Be generous with your time and talents – help your colleagues to improve.
- Be enthusiastic and optimistic. Change takes time. This is a process. Change what you can where you can and let it go.
- Be intentional as you create your legacy – you are making your institution a better place to work and a better place to receive care. Be proud of your accomplishments. You are part of a project designed to improve the delivery of care.
- Build your leadership skills – be open to learning all that you can and applying this knowledge in other venues.
- Make a difference. Life is too precious to waste time. Focus on what matters most.

Potential Pitfalls

- Tackling a project that is too complex for the time and resources that you have available.
- Losing momentum due to lack of accountability and differing degrees of commitment to the proposed project.
- Losing sight of why this project matters. Your project has to be worth the effort that your team will be investing in creating the change to maintain enthusiasm for the project.
- Lack of clarity regarding metrics to measure “success.”
- Becoming discouraged when faced with institutional resistance – expect this as a normal part of the change process. Change is difficult. The status quo is designed to maintain the results it has always gotten. Don’t take it personally. Be creative when you encounter a barrier and move forward. Right is on your side – you are seeking to improve care – that’s what matters. That’s what we’re here for.

Additional Resources and Suggested Readings

- City of Hope Pain and Palliative Care Resource Center: Contains a listing of publications and resources for addressing spirituality concerns:
<http://prc.coh.org/Spirituality.asp>
- Duke University Medical Center Department of Community and Family Medicine: Patient Safety and Quality Improvement Website:
http://patientsafetyed.duhs.duke.edu/module_a/introduction/introduction.html
- George Washington Institute for Spirituality and Health: SOERCE: The Spirituality and Health Online Education and Resource Center:
<http://www.gwumc.edu/gwish/soerce/about.cfm>
- HHS.gov: U.S. Department of Health and Human Services, Quality Improvement Activities – FAQs: <http://answers.hhs.gov/ohrp/categories/1569>
- National Quality Forum Endorsement Summary: Palliative Care and End-of-Life Care Measures:
https://www.qualityforum.org/News_And_Resources/Endorsement_Summaries/Endorsement_Summaries.aspx
- U.S. Department of Health and Human Services Health Information Technology and Quality Improvement Website:
<http://www.hrsa.gov/healthit/toolbox/HealthITAdoptiontoolbox/QualityImprovement/whatisqi.html>
- U.S. Department of Health and Human Services Health Resources and Services Administration: Quality Improvement Booklet:
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Chapter 9

Disseminating Your Research

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The Importance of Disseminating Research

Chaplains have an incredible trove of clinical knowledge, theory and theology about spiritual care that can be recorded into conceptual models, case studies, best practices, and other formats (HealthCare Chaplaincy, 2011). As chaplains become researchers, they also need to cultivate the knowledge, motivation, discipline, and skills necessary for disseminating their research. Dissemination is an essential part of conducting research. Chaplains' research—and research about chaplains' work—should be published, presented, or otherwise disseminated to help the field move forward. Dissemination of research enables colleagues' access to the momentum, creativity, and leadership provided by researchers, which can inspire them to try it out, to participate in others' research, and to stay up to date with new developments in the field.

Another important benefit of disseminating research is that it enlightens colleagues from other disciplines. Physicians, nurses, mental health professionals, and others who are searching the literature or attending professional conferences should be able to find chaplaincy research featured just as prominently as the work of other disciplines.

Publishing and presenting also are considered part of the ethical obligation of conducting clinical research. When research subjects volunteer to participate in research, they contribute to the welfare of others. Researchers demonstrate their respect for subjects, as well as their commitment to the field and research funders, through dissemination.

It is also important to reaffirm the assertion that chaplains have many assumptions and hypothesis that they have not tested, which could be crafted into important research projects (Jain, Steven, & Rosen, 2013; Thomas A. Smith, 1998; T. A. Smith, 1998). Elsewhere in this book, other authors describe strategies for initiating the process of research, and we encourage you to read those chapters.

Moreover, chaplains should remind themselves that they have the basic tools for dissemination already at hand: the desire to understand individuals at a deep level, the willingness to learn, and the ability to communicate. All chaplains have some experience writing. Chaplains write theological papers, verbatims, chart notes, case histories, and annual reports. In addition we also have experience in giving presentations to colleagues, students, professionals from other disciplines, and institutional administrators. Chaplains have been organizing professional conferences, days of learning, task forces, advisory groups, and even attending conferences of other disciplines that relate to our work for decades. Chaplains excel at getting together to schmooze and tell stories. Storytelling and critical reflection on our stories is foundational in our CPE training, a cornerstone of our work, and congruent with many of our personalities. Many chaplains possess great talent for one-on-one rapport building and collegial support. Reporting about our work and its impact on us, our patients, and our field can be viewed as simply an

extension of our interpersonal skills. Writing and presenting is an extension of our calling to share and give of ourselves. Chaplains are expert at this.

Finally, as all hospitals, hospices, and social service agencies move to value-based models, we are increasingly being asked to demonstrate both quantitatively and qualitatively the value of our work. The more we publish and share our work, the more widely available is the research that makes clear the value of our profession. By disseminating our work, we can help chaplains not only to keep their jobs, but also to expand their roles and reach.

Barriers to dissemination

There are many venues available for chaplains to disseminate their research contributions (A. Tartaglia, Dodd-McCue, & Derrickson, 2012). Before describing these venues and ways to approach the writing and dissemination process, however, we want to discuss common hurdles—both real and perceived—that chaplains may experience upon venturing into the waters of dissemination. These hurdles can be divided into internal barriers and external constraints. We address these head on at the outset, in the hope that doing so will encourage more chaplains to take the necessary steps to share their work and wisdom.

Internal barriers include lack of awareness of the many opportunities to write, publish, and present chaplain generated ideas and contributions. Fortunately, becoming aware of these opportunities is straightforward, and we discuss these later in this chapter. Another internal barrier involves a diminished sense of the value of our work. Many chaplains may not realize the value of their knowledge, skills, and perspectives. Therefore, some internal psychological work may be needed—including encouragement from one's peers and guidance from trusted mentors—to increase one's confidence in the value and importance of sharing one's work.

We would argue that it's important not to wait, though, for some lightning strike of confidence (e.g., "Once I feel confident in what I have to say, I'll start writing"). Rather, chaplains need to trust at some level that confidence builds through the work itself. Similar to CPE training (one does not become a skilled chaplain overnight), becoming more confident in the value of one's writing and presentation increases over time, and is nurtured by the experiences themselves.

External constraints on chaplains include the numerous time and energy limitations we all face. We will suggest strategies for tackling some of these constraints. Also, we hope that simply acknowledging that these pressures are common to all of us will help validate and normalize this sense of "How can I ever write anything? I never have any free time!" as well as come up with some creative work-arounds.

In addition, a clear-headed and honest examination of whether these external constraints are truly as "real" as we perceive them to be can be helpful. Are you getting stuck on assumptions about research needing to be technical and quantitative, when in reality you likely have rich qualitative material readily available? Is *every* minute of your day, *every* day really consumed by urgent and clinical or administrative responsibilities? Are there not particular hours in the week or days of the year that you know from experience offer more spaciousness, and would allow you to spend

half an hour in your favorite café—or in your favorite armchair—jotting down your thoughts? Are you really prevented from recording your thoughts into a voice recorder or a smartphone (many with free transcription software installed) that could be organized later into written form? Is “the administration” really dead-set against your taking a small amount of time to research and write about your topic, or is this an imagined barrier? By simply challenging our own assumptions, just as we challenge those of our patients/clients, we can work small miracles in reducing such external constraints.

A chaplain’s perspective on dissemination

As a chaplain (AK), I have found the chaplain meetings and conferences I attend to be invigorating and productive. And I enjoy reading the newsletters from chaplain organizations as a way of learning about the evolution of ideas in the field, about events, and the conclusions and theories that my colleagues draw from their clinical experience with patients.

Yet, when I leave these chaplain gatherings or finish reading these newsletters, I often feel that although so much has been gained that will persist and grow, there is also much being lost. Dissemination-worthy thoughts and ideas are not being written down. They are often not being presented to other disciplines, or to the chaplains who were unable to attend the conference, perhaps because of expense, proximity, or lack of interest. I believe that dissemination through more widely accessed channels would allow more conversation across geographic areas and cultures.

I have also noticed that most chaplain organizations restrict some of their best “scholarship” to “members-only access” as a member benefit. Often these articles are trapped in documents (like a PDF) that are not indexed or searchable as, unlike many medical and psychosocial journals. It seems to me it would be more beneficial to the memberships to disseminate our best work and most interesting conversations more widely. Publications that are accessible through searchable databases (e.g., PubMed or PsycINFO), or that can be freely accessed online, will pop up in results of searches done by individuals from other disciplines, or by chaplains who are not yet members of a particular chaplaincy organization. Unfortunately, we tend to protect our intellectual and experiential output as if it were treasure that could be stolen. Instead, we should think of our work as precious, yes—but precious because it has value that multiplies, informs, and inspires when shared widely.

Chaplains’ unique contributions to research dissemination

A chaplain coauthor can give authentic and enthusiastic voice to the passion and dedication that most chaplains feel for their work. In addition, chaplains collect in their memory a cache of concrete clinical examples and experiences. Not to mention the clinical material already in writing in some form, in personal journals, reflections for peer reviews or retreats, documentation in medical records and case presentations/pastoral verbatim reports.

Chaplain co-authors can also identify and articulate phenomena visible to them because of their unique training and professional viewpoint. These perspectives may be surprising and lead to new and important research questions. For example, as a chaplain who has worked for years at a teaching hospital, I have encountered dozens of frail and ill patients who report that they feel

pride, empowerment, peace and generativity by being able to participate in research, in the hopes of helping others. Many patients say that it is important for them to be able to contribute to others even while they are seriously ill or dying. I have discovered, albeit anecdotally, that many seriously ill patients engaged in research studies report spiritual benefits of participation. They generally do not state that they feel too vulnerable or exploited. This experiential finding illuminated a hypothesis about patients with life threatening illness that I can now test through research. The perspectives of the chaplain can add novel and important dimensions to the field of ethics of research.

A researcher's perspective on chaplains' contributions

My experience in working with chaplains on research and writing over the past several years has been nothing short of...well, a blessing. I have learned so much—not only about what chaplains do, how they are trained, and how they accompany patients at some of the most difficult times—but also about the incredible possibilities that exist to advance the field of chaplaincy through research and writing. Our discussions of our research, during which our team reviews transcripts of chaplain sessions with palliative care patients and discusses spiritual assessment and intervention, quickly became the favorite part of my week. As we started writing up our findings together, the opportunity to work closely with the chaplains to help them give voice to their unique perspectives and contributions similarly became a cherished part of my work.

During our team meetings, we often come up with new manuscript ideas—beyond those originally specified by our original aims. This is a common occurrence in qualitative research studies, but has also helped us develop ideas for highlighting additional unique aspects of chaplaincy and chaplains' work.

Dissemination: Getting Started

Some assert that many chaplains already possess skills or habits that can encourage us to make the leap to writing and submitting manuscripts. Many chaplains have a practice of journaling, or poetry or other writing. Most chaplains have had to prepare and deliver presentations or a sermon at some point in their training or career as a spiritual caregiver (A. D.-M. Tartaglia, Diane, 2012). Furthermore, the training received in clinical pastoral education to engage with critique and feedback is also an important skill for chaplains to draw on when they are overcoming the fears or concerns about writing manuscripts (Association of Professional Chaplains, 2009). My (AK) experience is that the editorial process has been extremely constructive, and quite validating at times.

Although not all dissemination of research occurs through written materials, writing a 100-word abstract, or proposal, to make a presentation or present a poster at a conference can feel daunting. Even for chaplains who enjoy writing, sitting down to write something to disseminate for research can feel loaded and overwhelming. Therefore, we felt it would be worthwhile to address the writing process itself before we discuss formats or venues.

My writing process has certainly evolved since my first experience of developing a chaplaincy research project. Early on in our group's weekly meetings, Laura introduced us to one of her

favorite writing books, *Writing with Power*, by Peter Elbow. He describes different types of writing, and provides practical tips about how to unleash one's creativity and "power" as a writer by decoupling the critical "editor" part of our writing from the creative "writer" part. This has been very valuable to me as: I have become much more comfortable spending time just jotting down my thoughts, brainstorming with my colleagues, worrying less about producing a perfect piece of writing, and focusing more on letting my ideas flow. I have found that even this new way of writing, however, takes a certain type of discipline—the discipline to restrain my inner critic, to give myself the opportunity to let my thoughts guide what I want to say without editing myself. I have found some ways to help myself develop this discipline, for example, setting a timer for 20 or 30 minutes and just typing up whatever comes to mind on a particular topic. I think about this as starting a conversation, as a way to share a unique area of expertise. The discipline to allow myself the freedom to do this has at its heart my feeling that we, as chaplains, have important things to say and contribute.

When I do turn to editing my writing, it is extremely helpful to have a collection of articles to cite from. This is now much easier, thanks to bibliography and reference management software that helps me to collect articles and quotations of interest and cite them easily. Examples of citation software are programs like [Endnote](#), [Refworks](#), and [Papers](#). There are even "free" programs, such as [Mendeley](#).

Importance of Colleagues

A key lesson for me has been the importance of having close colleagues with whom you can openly and honestly discuss your ideas—no matter the stage of development those ideas are in. Having colleagues with whom I feel comfortable sharing even ideas that are very "rough" has been invaluable, for this has given me added confidence that my ideas are worth disseminating. My colleagues help me shape my ideas, find what is most interesting or compelling in those ideas, and point out areas where I need to think more or support my statements in a better or different way. In addition, my colleagues have been critical for initiating new partnerships and collaborations, and finding new venues for dissemination (for example, Laura encouraged me to submit an abstract to the American Association for Geriatric Psychiatry, an organization she is very involved in and that she thought could benefit from hearing about the chaplain's perspective.)

Our team has found that several methods have been very helpful in moving our writing collaborations forward. First, we've scheduled several "writing retreats," – one to two full days where we have sat in a room (with lots of good snacks) and brainstormed manuscript ideas, begun the process of outlining manuscripts, and spent time on writing alone and together. This is a way to find those missing blocks of time and actually schedule them into our time together.

We also meet together on a fairly regular basis (the important part is actually dedicating the time and putting it into our calendars), usually two of our team at a time, in front of a large screen to work on our writing together in real time. We have found, particularly in the chaplain-researcher collaboration, that writing together in person has been very helpful. We may only work on one or two paragraphs in an hour, or we may make progress on brainstorming the rationale for a manuscript or the main discussion points we want to make. Whatever we get done is more than we would have gotten done otherwise, so "It's all good," as they say. We have also found that the

ability to talk out our ideas and having to respond to questions such as “What do you mean by that?” or “Can you give me an example?” has helped get ideas into a deeper, fuller, and more fleshed out written form.

Other ways to make time for writing include scheduling “writing dates,” e.g., meeting a colleague or friend somewhere, both bringing laptops and spending time working on one’s own writing, but in the company of another!

Written Forms of Dissemination

Journal Articles

There are so many academic journals that it is impossible to review the entire landscape here. Chaplains should familiarize themselves with the key journals in their field, and identify a few journals in related disciplines that have published research or other writing related to chaplaincy, spiritual care, or religion and health or social science. Our team has kept a running list of journals to which we are interested in submitting our work.

Journal articles come in many varieties. “Regular articles” in most academic journals (particularly in health care) refer to data-based papers. The data may be quantitative or qualitative, but it involves data collection, analysis, and interpretation. Some journals also accept “brief reports”—shorter data-based papers that may focus on only one or two findings.

Most journals publish a variety of non-data-based articles as well. These include commentaries (essentially, well-developed opinion pieces), conceptual papers, case reports, book reviews, and letters to the editor. Other less common types of articles include annotated bibliographies, consensus statements, and practice guidelines. Most journals now have a website that clearly lists the criteria for each type of article. It is important to read the instructions for authors carefully, follow all directions, and carefully proofread before submission. There are also e-Journals, such as [The Yale Journal for Humanities in Medicine](#).

Data-based research articles have a common structure. If you are unfamiliar with this structure, begin reading more data-based journal articles to acquaint yourself with this standard way of reporting research findings. Table 1 lists the purpose and key take-home points for each part of a research paper. This is of necessity an abbreviated overview. Readers are encouraged simply to explore the literature to appreciate the variety of flavors of research reports, writing styles, and ways of presenting different types of data. At the end of the day, though, there is no substitute for the actual practice of writing, submitting, revising, and—finally—publishing one’s ideas and work.

Book Chapters

Accepting or seeking out opportunities to contribute to books that are either chaplaincy-focused, or include a chapter on spiritual care provides an excellent venue for writing about chaplaincy. Although book chapters are not considered “peer reviewed” publications, they can still be very valuable for the field, the author, and the audience. They can also serve as important opportunities

to review the literature on a given topic, which may help you formulate research questions and identify important gaps in the research literature.

Other Forms of Dissemination

In addition to published articles and book chapters, chaplains have many other opportunities to disseminate their ideas and work. Chaplaincy and organizational newsletters provide a venue for sharing with interested colleagues. Webinars (seminars that occur online) can also be used to share research. Keeping a blog, posting to others' blogs, or "tweeting" (or using other social media) to notify interested parties about issues, events, updates in chaplaincy, and chaplaincy research can all serve as valuable modes of communicating to a more diverse or broader audience.

Presentations at National Meetings

Presenting at national meetings is another valuable way to share one's work and ideas. Presentations, like written forms of dissemination, also come in many varieties, and depend on the venue. Read "Calls for Presentations" or "Calls for Submissions" from organizations you attend or are thinking of attending to learn more about what forms of presentation their meeting will offer. Usually an abstract is required for submission. In some cases, work in progress can be presented. For chaplains, dissemination can occur at annual meetings of the various chaplain cognate groups, i.e. AAPC, APC, ACPE, CAPPE/ACPEP, NAJC, NACC.

Posters

While many academic meetings have one or more poster sessions, the chaplain cognate groups have not often implemented poster sessions at their meetings. These are worth considering, as they could be a valuable way for chaplains to gain experience in presenting their work. Having poster sessions give an opportunity to chaplains who may not feel comfortable or ready to offer an hour-long workshop or seminar. In fact, the format of a poster may be more comfortable for many chaplains who are most comfortable and talented at one-on-one conversations. At conferences for disciplines other than chaplains, this can serve as an important opportunity to connect with professionals from other fields for future collaboration.

Table 1.
Overview of Goals and Key Points
About Each Part of a Research Paper

	Goals	Key points
Abstract	Briefly present study purpose, methods, results, and implications	Write the abstract last. Follow journal's instructions for structuring Abstract
Introduction	Provide rationale for study. Why is study valuable, important, and/or novel? What gap in the literature does it fill? Brief literature review to justify need for study. Present study aims and (if appropriate) hypotheses.	Usually approximately five paragraphs. May be shorter or longer depending on journal's style and word limits. Need not do exhaustive literature review.
Methods	Describe study setting, participants, consent, procedures, measures, and data analysis	Must have adequate level of detail for reader to understand how study was conducted. Begin writing while study still ongoing.
Results	Present findings in logical order. Describes both significant and insignificant findings. For qualitative studies, describes main themes/codes and provides examples. Points to Tables/Figures as appropriate but does not repeat information provided in Tables/Figures. Does not interpret data.	May be relatively brief depending on the findings and the scope of what is being reported. Consider presenting findings in Tables/Figures for greater ease of understanding as well as greater impact. Seek help as needed from statistician for description of analytic methods.
Discussion	Briefly highlight each key finding. Interpret each finding in context to prior literature (if available). Are these findings consistent with prior literature? How do the findings add to the literature? Draw inferences. Suggest explanations for disparate findings. Describe study limitations.	It's okay if the findings are not statistically significant; this may indicate possible limitations of way study was conducted. Discussion should not stray too far into speculation or unrelated areas. Reviewers will be asked whether interpretation of findings is appropriate.

	Suggest areas that findings point to that are in need of further research.	
References	<p>Provide key references, throughout body of manuscript, for all primary sources.</p> <p>Follow journal's instructions exactly.</p> <p>Use a referencing software and develop a library of key sources.</p>	<p>Do not need to cite exhaustively, but rather representative sources.</p> <p>A common mistake is not to cite assertions (e.g., "Chaplains' work saves hospitals money" is an assertion).</p>
Tables and Figures	<p>Used to display data that is more easily understandable in Table format (e.g., demographic characteristics of sample) or Figure format (e.g., trends over time).</p> <p>Do not describe in detail in Results, but refer to appropriate Table or Figure.</p>	<p>Consider whether a Figure may be more visually appropriate.</p> <p>Experiment with both, and enlist help choosing which is most understandable and makes the strongest impact.</p>
Supplemental Materials	<p>Check whether journal allows "Supplemental Materials."</p> <p>These include documents, tables, figures, or other materials (e.g., presentations) that are not necessary to understand the paper, but that a reader who wants additional information could refer to.</p>	<p>Follow journal's instructions exactly.</p> <p>Supplemental Materials sections may be useful for presenting more in-depth qualitative data.</p>

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Chapter 10

Pursuing Additional Research Education

George Fitchett, DMin, PhD

Introduction

Chaplains have different levels of interest in research. Many chaplains will be satisfied when they have developed a basic level of research literacy. Some chaplains however, may find they have a strong interest in research and want to learn as much about it as they can. I was such a chaplain and I know how exciting, and daunting, learning about research can be for us. In this chapter I will provide you with suggestions for how to obtain additional education about research. Because many of these suggestions have been part of my journey to become a chaplain-researcher, at various points in the chapter, including this Introduction, I will share some of that story.

When I started out in chaplaincy I wasn't thinking of doing research. In high school I enjoyed science classes but I wasn't especially comfortable with things like probability and statistics. In college I was a sociology major. I enjoyed studying the social sciences but I didn't have experience doing social science research. During my theological education, and especially my clinical pastoral education (CPE) internship and residency, I became very interested in pastoral care and counseling. Among other things, I was attracted to the field's emphasis on integrating knowledge from the behavioral sciences. However, as was characteristic of that period (1970s), the behavioral science I was exposed to in my training was mostly psychodynamic theories (Myers-Shirk, 2009). I certainly wasn't exposed to any discussion of evidence-based practice; the term wasn't used in medicine or psychology until the 1990s (Claridge & Fabian, 2005. Huppert, Fabbro, & Barlow, 2006)

At the beginning of my career as a chaplain, I had mentors and colleagues who thought that people involved in pastoral care and counseling should be involved in research. In the early 1970s I worked for the Institute of Pastoral Care in Chicago whose Executive Director, Randy Mason, was the lead author of a much discussed study of the association between scores on a measure of acceptance (e.g., being optimistic about the results of surgery) and speed of healing among retinal detachment patients (Mason, Clark, Reeves, & Wagner, 1969). I read the study carefully and was intrigued by its finding that a psychological factor like acceptance might be related to a health outcome like healing after retinal detachment surgery.

Jim Gibbons, one of my CPE supervisors, and Dave Myler, a good friend, thought chaplains should know how to do research so beginning in the mid-1970s they required the residents in their CPE program at the University of Chicago Hospitals to complete a research project together (see Gibbons & Myler, 1978). Around the same time, the North Central Region of the Association for Clinical Pastoral Education (ACPE), in which I have always worked, began to offer a prize for the best CPE student research project. The Region also began offering small grants to support research. Many of these grants supported projects by

colleagues in the Region, but two grants supported larger research initiatives undertaken by professional chaplaincy organizations. I followed the development of both of those projects with great interest. A 1981 grant helped support an ACPE initiative to develop a tool, the Clinical Ministry Assessment Profile, that could be used to describe CPE students' learning needs and the extent to which they made progress with them during their training (see Fitchett & Gray, 1994). In 1984 and 1985 the Region made grants to support an effort by the College of Chaplains, one of the predecessor organizations to the Association of Professional Chaplains (APC), to study patient satisfaction with chaplains' care (Gibbons, Thomas, VandeCreek, & Jessen, 1991; VandeCreek, Thomas, Jessen, Gibbons, & Strasser, 1991).

Another important factor that contributed to my growing interest and eventual involvement in research is that I was trained at and have always worked at Rush University Medical Center, an academic medical center where research is valued. This meant there were regular grand rounds research presentations offered by many departments that were open to everyone. There was also an excellent library. As a new chaplain I took advantage of both and I still do.

Several things that are distinctive about Rush also made it an excellent environment to support the development of chaplaincy research. First, in addition to its medical school, Rush has an excellent College of Nursing whose faculty includes experienced nurse-researchers. Second, we have a strong Department of Behavioral Sciences (psychology). Faculty in both nursing and psychology were important supporters and early mentors for our research program. A third factor is that in 1975 Rush developed a College of Health Sciences. In part because we were educators, offering CPE, our chaplaincy department became a department in the new College. Being a College department meant the staff chaplains and CPE supervisors in the department held faculty appointments in the College. It also meant that, like other departments, involvement in research was encouraged. The first chair of our new department, Christian Hovde, was a former professor of neuroanatomy as well as an Episcopal priest. Chris was very supportive of chaplains doing research.

Here let me draw three general points from my story about chaplains and education in research. First, the institutional context in which you work will play a role in your access to opportunities for additional research education. If you work in an academic medical setting there will be a number of opportunities for research education that will not be as readily available if you work in other contexts. Second, regardless of whether you work in an academic medical center or not, it helps to be in a department with leaders and colleagues who share an interest in research. Third, whatever your context, if you are interested in additional research education there are now many ways to obtain that education, in many cases through online resources.

First Steps: Reading Research

The first way that chaplains can obtain additional education about research is to read research. This may seem like an obvious suggestion, but it is impossible to overstate the importance of reading research for chaplains at any level of research competence. Reading research is important for chaplains with advanced research training, as well as for research novices. Much of what makes me a well-regarded chaplain-researcher is not just that I have conducted several research studies of my own but that my reading has given me an in-depth familiarity with a wide body of chaplaincy-related research. Reading research is something that every chaplain can do, regardless of where you work.

Until recently, chaplains mostly read research on their own. Now, following the example of our colleagues in medicine and other fields, chaplains have begun organizing research journal clubs. These are groups where chaplains, and sometimes chaplaincy students, all read the same article and come together to discuss it (King, 2008). Regular participation in a research journal club can help chaplains who are developing research literacy gain a better understanding of the unfamiliar methodological details about an article. Taking turns summarizing an article or leading the critical discussion of an article are excellent ways for chaplains to develop the ability to read research critically which is a key component of research literacy. If you are new to reading research, you may find it helpful to use an outline to help you summarize key points in an article. An outline my colleague Pat Murphy and I developed is in the Appendix and also on the [ACPE Research Network](#) website. Chaplain Mark LaRocca Pitts has also written a helpful outline (2009).

Large chaplaincy departments can meet in person for their research journal club. In situations where many chaplains work in the same health care system, it may make sense to organize a journal club that meets via conference call or Skype. Other journal clubs might include chaplains who work in the same city. Since 2011, Pat Murphy and I have been leading a webinar-based research journal club. The webinar is sponsored by the APC but it is open to anyone. For further information about this, including recordings of past sessions, see the APC website (<http://www.professionalchaplains.org/>). In cases where all of the participants in the journal club are relatively new to reading research you should consider inviting a colleague with research expertise from another department to join your journal club and help explain difficult issues. This can also be a good way to build connections with researchers in your institution. Chaplains in several departments, who have done this, report that even busy research colleagues are responsive to these requests. They also develop a different appreciation of chaplains when they find chaplains are interested in research.

If you are ready to read research, your next question may be what should you read and where can you find it? I have two suggestions about what you should read. First you should read broadly. Be curious and read research articles in our chaplaincy journals but also read articles from other disciplines or articles about health-related research in the news. Second, focus some of your reading on research that is related to the work you do. For example, if you are a hospice or palliative care chaplain, read research in that area, if you

work in pediatrics read research in that area. You might consider using a bibliographic management program such as [Endnote](#) or [Mendeley](#) to help you collect, organize, and summarize your focused reading. At a later point, with help from a mentor, your reading could form the foundation for a review article.

An excellent place to find articles, for both your broad and focused reading, is the [ACPE Research Network](#) website. The website is free and available to anyone. It is maintained through the excellent work of John Ehman, a chaplain at University of Pennsylvania Medical Center-Penn Presbyterian who is also the convener of the ACPE Research Network. A wonderful feature of the website is the Article of the Month. Begun in 2002, there are currently over 100 article reviews archived on the site. Each review includes a summary of the article as well as a paragraph about using it with CPE students. The part of each review I find most helpful is called “Related Items of Interest” where John provides brief descriptions of important research. In some cases, there are links to a review of a related article in an earlier “Article of the Month” column. Not infrequently, the material John summarizes provides an excellent overview of research on a specific topic. A good example is the July 2012 Article of the Month. Here John reviews an article by Sharma, Astrow, Texeria, & Sulmasy, (2012), about their Spiritual Needs Assessment for Patients, and then provides rich additional information about other measures of spiritual needs. On the ACPE Research Network website, you will also find a link to the website of the University of Pennsylvania chaplaincy department and to John’s annual annotated bibliography of research about spirituality and health (<http://www.uphs.upenn.edu/pastoral/resed/bibindex.html>). The bibliography for 2013 has 325 entries. There are annual bibliographies going back to 1999 and they are wonderful resources.

Another way to find articles to read is to regularly check the contents of specific journals. For many journals you can sign up to receive email notification of the table of contents of each new issue. The main chaplaincy-related journal published in the US is the *Journal of Health Care Chaplaincy (JHCC)*. A subscription to the electronic version of this journal is a benefit of membership in the APC. Most of the articles in *JHCC* are research-based and beginning in 2014, to help advance chaplains’ research literacy, the journal will periodically publish introductory articles about research methods. The *Journal of Pastoral Care and Counseling* is also a place where some chaplaincy-related and pastoral care research is published. Fortunately, both of these journals are indexed in [PubMed](#), the database of health-related journals operated by the US National Library of Medicine. If you are unfamiliar with searching PubMed or other databases, Kevin Flannelly, the editor of *JHCC*, and colleagues have published a helpful introduction (2011). You should also check to see if the library of your hospital offers any workshops or tutorials on searching these databases.

There is strong interest in a research-informed approach to chaplaincy in countries other than the US, including Canada, the UK and Australia. Some of that international work is published in the two journals mentioned above, but important international chaplaincy-related research is being published in journals such as [Health and Social Care Chaplaincy](#).

Between 1998 and 2012 the APC published a journal called *Chaplaincy Today*. That journal published some important chaplaincy research, including the report of a randomized clinical trial of chaplaincy with chronic obstructive pulmonary disease (COPD) patients by Will Iler and colleagues (2001), as well as articles about research-related topics such as writing for publication (Tartaglia, Dodd-McCue, & Derrickson, 2012). The contents of those issues are available to members on the APC website.

In addition to these chaplaincy and pastoral care journals, you will find much interesting and helpful research in journals devoted to research about religion and spirituality (R/S). These include the *Journal of Religion and Health*, *Psychology of Religion and Spirituality*, the *International Journal for the Psychology of Religion*, the *Journal for the Scientific Study of Religion*, and *Mental Health, Religion and Culture*. Because of the growing interest in research about R/S and health you will also find research about R/S in health and medical journals. If you work in cancer care, you will find R/S-related research in journals like *Psycho-Oncology*, the *Journal of Clinical Oncology*, and *Supportive Care in Cancer*. If you work in hospice or palliative care, be sure to look at *Palliative Medicine*, *Palliative and Supportive Care* and *Pain and Symptom Management*. If you work in gerontology pay attention to *The Journal of Religion, Spirituality and Aging*, which is an APC member benefit, as well as *Psychology and Aging*, *The Gerontologist*, and the *Journals of Gerontology*. If you work in another area ask some of your clinical colleagues about the main journals in that area and which ones publish research about R/S.

Subscribing to journals can be expensive, as is purchasing copies of single articles. There are some ways to avoid these costs. Researchers whose work was supported by the National Institutes of Health (NIH) are now required to make a copy of any articles about that research freely available to the public. Check PubMed to see if the article you are interested in can be downloaded there for free. If you work in an academic medical center your library will have online subscriptions to many journals whose articles will be easily available to you for free. If you are looking for an article in a journal to which your library doesn't subscribe use the interlibrary loan service to obtain copy. In many institutions there is no charge for this service. Other hospitals usually have a medical library whose librarians will be happy to help you obtain copies of articles you are looking for. Writing to the author of an article and requesting a copy of their work is also an option. Their email addresses can be found in the PubMed citation of their article.

For your focused reading, keep in mind review articles and chapters in handbooks. Reading a review article about research in your area of interest is a great way to get an overview of the research in that area whether it is research about R/S or not. With the growth of research about R/S and health, review articles are becoming more common. For example, for R/S in adolescent health see Cotton and colleagues (2006), for R/S in oncology see Peteet and Balboni (2013). One of the great features of PubMed is that you can focus your search on review articles. Also, keep in mind the growing number of books that review a whole field or area of clinical interest. These books have one or more chapters that provide very helpful overviews of research. For research about R/S and health, an excellent place to

start is the second edition of Koenig and colleagues' *Handbook of Religion and Health* (2012), which has chapters on specific mental or physical disorders (e.g., anxiety disorders, heart disease), as well as helpful overviews.

The two volume *APA Handbook of Psychology, Religion, and Spirituality* (2013), edited by Ken Pargament and colleagues, is also a remarkably rich resource. Ask colleagues in your clinical area if there is a handbook or textbook which serves as an overview of that area. The chapters in such a book can give you a good introduction to the research in that clinical area. You might find the book has a chapter about R/S (e.g., for the field of psycho-oncology see Fitchett and Canada, 2010). If it doesn't, maybe you can partner with a colleague and contribute one to the next edition of that book. If you're interested in doing that try contacting the editor of the text directly with a brief outline of your proposed chapter to see if they are interested.

Another Initial Step: Attending Research Presentations

In addition to reading research, attending presentations of research helped me a lot as I was learning about research. As mentioned above, here at Rush many departments have weekly grand rounds presentations that frequently are research-focused. Currently, I attend rounds in Preventive Medicine where I have a faculty appointment. When the topics look interesting I also attend rounds in Gerontology and Psychiatry.

Conferences are also a good place to hear presentations of new and interesting research. For years, I have been in the habit of attending meetings of groups like the Society for the Scientific Study of Religion, the American Sociological Association, the American Psychological Association or the American Psychosomatic Society when their conferences are held in Chicago. The Society of Behavioral Medicine has an active R/S interest group, and those meetings always have several presentations about R/S research. Other groups, such as The American Psychosocial Oncology Society, have been welcoming of research and presentations on spirituality. Some conferences have excellent pre-conference workshops on research methods. Thankfully, the number of research-related presentations at our chaplaincy conferences is increasing, so those meetings provide an opportunity to hear research presentations and also to talk with the presenters. Whether it's at a chaplaincy conference or another professional meeting, you may hear a presentation that is especially interesting. A conversation with that speaker, or an email to them, may lead to a mentoring or collaborative relationship even if you don't work in the same institution or city.

Traveling to meetings is expensive and not everyone has the opportunity to do that. This is where web-based presentations are so helpful. Our professional chaplaincy associations are offering more and more webinars and more of these include research. But don't limit yourself to chaplaincy-sponsored webinars. Find out what kind of web-based continuing education and research presentations are being provided by the major professional organizations associated with the clinical area in which you work.

Second Steps: Doing Research with a Mentor

What are the next steps to consider if you want additional research education or you are ready to actively engage in research? One option is to begin doing research with a mentor. As my interest in research grew, I undertook several small projects without a mentor, something I very strongly advise against. I learned some things doing those initial projects, but I also wasted a lot of my time and the time of the students and colleagues I recruited to help me. In addition, the findings from the studies were of minimal value (e.g., the most common behavior of family members at the time of a loved one's death was to cry; Fitchett, 1980). If you want to get involved in research, the next step - while you are reading the existing literature about your area of interest and beginning to formulate a focused research question - is to find a mentor. A research mentor is a person with advanced training and experience in conducting research who is willing and able to guide you as you begin to engage in research. Research mentoring, such as occurs in doctoral studies and post-doctoral fellowships, can be an intense, extended relationship with well-established guidelines and expectations (Lee, Dennis, & Campbell, 2007). Research mentoring can also be more informal.

My early mentoring took the form of collaboration with other researchers. The research program in our department was formally started in 1990 with the commitment of fifty percent of my time to doing research. Here it is important to note that in our field, such "protected time" for research, whether it is ten percent, twenty-five percent or more, is currently quite rare. However, as other chaplains who have done research have pointed out that (Bay & Ivy, 2006; Piderman & Johnson, 2009), without some protected time it is very difficult to get involved and stay involved in research. When we started the department's research program I had no training in research. In light of that, the plan for our research program was only to do projects in collaboration with experienced researchers who could serve as my mentors and assure the quality of the project; at that time, Rush had a strong program of research in psycho-oncology led by David Cella. Dave and his colleagues saw the value of R/S in coping with cancer, and they welcomed the opportunity to work with me to investigate that. Working with this talented team was a great gift that tremendously increased my knowledge about psycho-oncology and clinical research. I was also fortunate to be a collaborator in several important studies about the role of spirituality in the quality of life of patients with cancer and HIV/AIDS (Brady, Peterman, Fitchett, Mo, & Cella, 1999; Peterman, Fitchett, Brady, Hernandez, & Cella, 2002).

During this phase in the development of our research program the [Fetzer Institute](#) announced grants for research about the role of R/S for medical rehabilitation patients. Our department had a good relationship with Bruce Rybarczyk, the psychologist in our medical rehabilitation unit, who was an experienced researcher. The combination of my knowledge about R/S and coping with illness and Bruce's expertise in rehabilitation research enabled us to write a successful application and receive one of the Fetzer grants. I learned a great deal about doing research from working with Bruce and our colleagues on this project. I was disappointed that our hypothesis, that patients with higher levels of R/S involvement would have better rehabilitation outcomes, was not supported. However, an

unexpected finding, that higher scores on a measure of religious struggle were associated with poorer recovery, led me into an important new area of investigation (Fitchett, Rybarczyk, DeMarco, & Nicholas, 1999). Not every project needs to bear out its hypotheses in order to be valuable or publishable.

How do you find a research mentor? As I mentioned earlier, working at Rush meant that there were experienced investigators close at hand who were accustomed to working with junior colleagues. My early mentors were also clinicians, known to my colleagues or me from that context, who recognized the value of R/S in the lives of their patients. When I approached them about working together, I brought something to the relationship, my knowledge about existing R/S research with patients gained from my reading and attending research presentations. My early mentors recognized my limited background in research and knew that working with me would take time and energy. At the same time, however, they recognized that our collaboration could lead to things that researchers value, namely publications and potential new grant opportunities, not to mention new insights.

One way to find a mentor is to learn about the people in your institution who are doing research. Maybe there are investigators who have not considered the role of R/S but from your reading you know that it could be relevant to their research. You could reach out to those investigators and see if they are interested in having a conversation with you. That is how I met Lynda Powell who came to be a very important person in my development as a researcher. I read an announcement about the appointment of a new chair for our Department of Preventive Medicine. The announcement mentioned his expertise in hypertension. I was familiar with the research that suggested there may be a relationship between religion and hypertension (Levin and Vanderpool, 1989) so I set up a meeting. The chair of the department wasn't interested in the role of religion in hypertension but he referred me to Lynda, a new member of his faculty, who had a very strong interest in psychosocial factors, including R/S, related to cardiovascular disease. This led to a very important relationship and eventually to Lynda's suggestion that I get formal training in research by applying for an NIH K Award (more on that below).

It is also possible that when you look into the research being conducted in your institution you will find investigators who are already doing work that includes attention to R/S as one component of their projects (e.g., Wall, Engelberg, Gries, Glavan, & Curtis, 2007) or as a central theme in their research (Astrow, Wexler, Texeria, He, & Sulmasy, 2007; Sharma et al., 2012). If that is the case, you should contact these investigators and see if they are open to developing a relationship with you. If you are still learning about research you might ask if you could sit in on the meetings of their research team to learn more about the nuts and bolts of running a project or developing a grant proposal. If you have more experience with research and are familiar with some R/S research related to their work you might see if they are interested in a more active relationship that included mentoring or collaboration. 'Team science,' the use of cross-disciplinary teams to address complex scientific questions, has become an important approach in some areas of health research (see

www.teamsciencetoolkit.cancer.gov/public/WhatIsTS.aspx). Many experienced investigators whom you approach will be aware of the importance of team science for their work as well as the preference frequently given to grant proposals that effectively employ team science. I hope the day is not far off when investigators who are planning a new study where R/S may be a relevant factor, will know of chaplains in their own institution who have the interest and knowledge to be helpful members of their research team.

There can be many types of mentoring relationships. As I mentioned, my early relationships were informal and focused on collaboration on specific projects. Whether your mentoring relationships are informal or more formal it is important for you and your mentor to be clear about your expectations of one another. This includes expectations about your goals, the tasks you have agreed on, and the mentor's availability. As you develop as a researcher it is not uncommon to have several mentors. Since 1990 I have had a number of different mentors including those with whom I worked before I did my PhD, while I was in school, and after I completed my degree.

What qualities should you look for in a mentor? Basic qualities include availability, accessibility, as well as an interest in your career. Ask around at your institution for the names of people who have good reputations as mentors. Generally it is best to look for someone with prior experience mentoring others. Look for a mentor who will foster your development and not just use you to do their own research. If possible, try to talk with current or former mentees about what it is like to work with the mentor. In looking for a research mentor it is good to find someone who will push you, who will provide critical and constructive feedback about your ideas and work. In my career, the mentor from whom I learned the most, Carlos Mendes de Leon, a social epidemiologist, is the one who provided me with the most critical feedback about my work. It wasn't always pleasant, but I am very grateful for all that I learned from him. Few mentors will have experience working with a chaplain. Be sure it is something your potential mentor is open to. Trust your instincts when talking with a prospective mentor—if the fit feels wrong for you, it probably is.

What qualities should you cultivate in yourself as a mentee? You should take initiative but also be prepared. When I approached Carlos to mentor me in relation to my application for the [NIH K Award](#) I had already studied the requirements for the Award and talked with people who had received one. Before our appointments, I sent him drafts of the section of the application we would be discussing. Be prepared to work hard. Most researchers work very hard, including evenings, weekends, and vacations, in order to meet deadlines for grants and manuscripts. Your mentor will assume you have a similar level of commitment. One of the most important characteristics of a researcher, and mentee, is curiosity. You will need to find a balance between confidence in what you know and openness to new ideas and methods.

In most cases, mentors are not paid for their mentoring. However, if you have a research idea you wish to pursue and you have the resources, another option is to engage an experienced investigator as a consultant or collaborator to guide you as you pursue your

project. As more chaplains gain research experience and education we can begin to mentor one another. Mentoring chaplains who are involved in research is an activity that is very rewarding for me. Most of the people I mentor do not live or work in Chicago. Working with a mentor in another city is quite common.

In addition to doing research with a mentor, another route to getting involved in research is through quality improvement (QI) or process improvement projects. While there are important differences between QI projects and research (Margolis, Provost, Schoettker, & Britto, 2009; Morris & Dracup, 2007) many QI projects, like research, involve the systematic gathering and analysis of data. In some hospitals every department, including the chaplains, are expected to conduct periodic QI projects (Berlinger, 2008; Lyndes, Fitchett, Thomason, Berlinger, & Jacobs, 2008). Most hospitals, not just academic medical centers, will have staff that help departments design and conduct QI projects. Some hospitals offer more extensive training for their staff, including chaplains, who are designing QI projects. A lot of my early experience with research came from designing and conducting surveys of patient/family satisfaction with the services provided by our department. Involvement in a process improvement project related to organ donation led to multiple publications by chaplain Lex Tartaglia and his colleagues at Virginia Commonwealth University (Dodd-McCue & Tartaglia, 2007; Dodd-McCue, Tartaglia, Veazey, & Streetman, 2005; Tartaglia & Linyear, 2000). Being involved in or leading your department's QI project can be a rewarding way to gain experience with research.

Third Steps: Some Formal Training in Research

What are your options if your involvement in your department's QI projects or in some mentored research has further stimulated your appetite for research training and engagement, but you aren't ready to pursue a research-intensive graduate degree? Auditing research methods or statistics courses or enrolling in those courses at a local educational institution is a good way to further your research education. You can also find good courses in research methods and biostatistics online. Schools of public health are a good place to look for such courses. You can find a list of accredited schools of public health on the website of the [Council on Education for Public Health](#).

During the time I was collaborating with the research teams described above, I realized that my ignorance about statistics limited my understanding of what my colleagues were discussing and my ability to collaborate with them. To remedy this I audited the research and statistics class that was offered for the students in our Masters in Occupational Therapy degree. I followed this by auditing the year-long course in biostatistics that was offered for our doctoral nursing students. Auditing these courses was an important first step in my understanding some of the basic statistics involved in health-related research.

For those who have more time and resources there are well-established summer institutes that offer excellent health-research education. If you are interested in qualitative research you should look into the summer intensive offered under the auspices of [Research Talk](#). Two well-known programs in epidemiology and biostatistics are the Graduate Summer

Institute of Epidemiology and Biostatistics offered by Johns Hopkins Bloomberg School of Public Health and the University of Michigan School of Public Health Graduate Summer Session in Epidemiology (biostatistics is included). Both schools also offer certificate programs for those who complete a sequence of basic courses which includes online courses. Another option to consider is the Program in Clinical Effectiveness offered by [Harvard's Medical School and School of Public Health](#).

If you are interested in a program that focuses on health-related R/S research then you should consider the 5-day Summer Research Course on Religion, Spirituality and Health sponsored by the [Center for Spirituality, Theology and Health](#) at Duke University. Harold Koenig, MD, one of the worlds' leading experts in research about R/S and health, is the course director. Presenters include noted religion-health researchers from Duke and elsewhere. The course, which has been offered for a number of years, provides an introduction to how to conduct research on religion, spirituality and health, and how to develop an academic career in this area. Chaplains who are interested in research have enjoyed taking the course. Koenig (2011) has also published a book based on the course. Many chaplains subscribe to *Crossroads*, the monthly newsletter from Dr. Koenig's Center for Spirituality, Theology & Health (see the URL above). Each issue contains summaries of important new studies of R/S and health, as well as announcements about conferences and other resources.

Fourth Steps: Getting a Degree in Research and Career Development Awards

If doing research is important to you and you want it to be part of your career, then at some point you will need to get a degree that includes substantial research education. Before I describe some degrees to consider, I need to mention the Doctor of Ministry (DMin) degree. Most DMin programs require a project in ministry which in many cases involves research, frequently qualitative or program evaluation research. However, in general, DMin degrees involve little research coursework and rarely any coursework in quantitative methods or statistics. That is to say, while there are a few exceptions, in most cases the DMin degree will not provide adequate training for doing research focused on chaplaincy or on R/S and health. Importantly, the DMin degree is not recognized by our health care research colleagues as a research credential, in the way that the degrees below are recognized.

If you are considering a research degree there are several options to consider: Master of Science (MS) in Epidemiology, Masters in Public Health (MPH), Masters in Clinical Research, or PhD. The MS in Epidemiology and the MPH degrees are usually offered by schools of public health or medical schools. Most chaplains are unfamiliar with the field of epidemiology, the study of the distribution and determinants of disease and other health-related phenomena in populations. Because of the rigorous research methods involved in epidemiology and because of its focus on health, an MS in epidemiology or an MPH with a concentration in epidemiology would provide you with a very solid foundation in research. Both degrees are usually completed in two years when pursued on a full-time basis. However, most schools that offer these degrees permit part-time study and many offer on-line options. Both degrees provide well-recognized research credentials.

The Masters in Clinical Science degree is frequently offered by medical schools and some schools of public health. Here at Rush it is offered in our Graduate College. This degree is designed to provide clinicians, especially physician fellows or junior faculty, with training to design and conduct clinical research. Courses include research design, statistics, and research ethics. A central component of the degree is the mentored completion of a publishable research project that is often based on data from the student's clinical practice or a departmental QI project. In many cases that research project provides pilot data to be used for the student's first grant application to the NIH or other major granting organization (e.g., American Cancer Society, American Heart Association). Part of what makes this an attractive option for chaplains to consider is that this degree is usually meant to be completed on a part-time basis by people who are also busy clinicians. Research chaplain Daniel Grosseohme, who works at Cincinnati Children's Hospital Medical Center, completed one of these degrees as part of his NIH K award (more on that below).

If you plan to make research a major part of your career, then you should give serious consideration to obtaining a PhD degree. It not only provides you with the most extensive research education, it also signals to your colleagues, including those with whom you might collaborate or who might review any grant proposals you submit, that you have the research credentials needed to accomplish the work you propose. There are a number of PhD programs that offer substantial training in research methods that are relevant for research about chaplaincy or the relations between R/S and health. My PhD is in epidemiology, so I am partial to that degree. As I mentioned above, epidemiology uses rigorous quantitative research methods to study the health of populations and the factors, such as R/S, that influence health. My PhD research examined the relationship between daily spiritual experiences and cardiovascular health, including blood pressure, among healthy midlife women (Fitchett & Powell, 2009). As part of my degree I took elective courses in survey design, qualitative methods, and gerontology, as well as a lot of biostatistics, which I came to enjoy.

There are many other fields in which a PhD would provide good education in research for chaplaincy or the relationship between R/S and health. One factor that should be considered in making a choice is your prior training. If you have an MSW degree, then a PhD in social work should be considered. If you have a degree in nursing you might consider a PhD in that area. Many gerontology PhD programs provide strong training in research. Judy Ragsdale, a chaplain researcher and CPE supervisor at Cincinnati Children's Hospital Medical Center, did her PhD in Leadership and Change. It provided her with very strong training in qualitative methods, which she has used to study CPE supervisory education (Ragsdale, Holloway, & Ivy, 2009; Ragsdale, Steele-Pierce, Bergeron, & Scrivener, 2012).

What about getting a PhD in chaplaincy? In the past few years colleagues in the chaplaincy department at Virginia Commonwealth University (officially the Department of Patient Counseling, which like our department here at Rush is also a department in their School of Allied Health Professions) have developed a chaplaincy track in their PhD in Health Related

Sciences (<http://www.sahp.vcu.edu/phd/>). This is an exciting new option for advancing a research-informed approach to chaplaincy.

For most chaplains, paying for a research degree will be a stretch—unless they win the lottery or have a wealthy benefactor. One option is the reimbursement program offered by many institutions for all or most of the tuition associated with earning a degree that enhances your professional skill. Those who are considering a PhD should keep in mind that there may be pre-doctoral fellowships available from your school or other agencies that can support part or all of your education. For further information, check with the school or the PhD advisor with whom you hope to work.

Another option for some chaplains are the NIH-funded Career Development or K awards which provide mentored, “protected” time for research career development. There are a number of different types of K awards. They are described on the K-Kiosk on the NIH website (<http://grants.nih.gov/training/careerdevelopmentawards.htm>). Most K awards have an educational and a research component. For the educational component of my K Award, I completed a PhD degree in epidemiology. My research component involved the study of daily spiritual experiences and health. K-awards were probably not originally designed with chaplains in mind, but both Daniel Grossoehme and I have received one. Our awards covered 75% of our time for 5 years and included additional funds to pay our tuition and support some of the costs of our research.

If you apply for a K award you will apply to one of the 27 institutes or centers of the NIH, selecting the one whose mission is the best match for your research. Because part of my research focused on aging, I applied to the National Institute on Aging (NIA). Because his research focused on children with cystic fibrosis and their families, Daniel applied to the National Institute for Child Health and Human Development. Writing a successful K-award application is a demanding undertaking. K-awards are competitively reviewed. My first submission received a good score but wasn’t funded; my revised submission was successful. There were four factors that contributed to my success in getting the award: 1) my prior publications indicated I had a serious interest in research; 2) I had a substantive educational plan, earning a PhD in epidemiology; 3) my two mentors were well-respected researchers (both had been funded by the NIA); 4) I wrote an excellent research plan. The first drafts of my research plan weren’t excellent but my mentor, Carlos Mendes de Leon, worked with me on many revisions and in the end it was very good. Other organizations (e.g., the American Heart Association, the American Cancer Society, the Department of Veterans Affairs) have grants for research education or that support education for young investigators. Again, it’s not likely any of them were developed with chaplains in mind, but if you can make a strong case for your work, and have good mentors, you just might be successful.

Summary

When I began my career as a chaplain I didn’t know anyone who was a chaplain-researcher and didn’t know I wanted to be one. Now I am a chaplain-researcher and I’m not alone. It is

work that suits me and I do it well. The people I work with, at Rush and around the world, are one of the great pleasures of this career. Being able to make a contribution to chaplaincy and to the care of patients and their families through research is a gift. I hope this chapter has provided helpful suggestions for how to get further education in research for those of you who think you would also like to be chaplain-researchers. Remember, it all begins with reading research.

Acknowledgments

I am grateful for the helpful feedback of the following colleagues on an early draft of this chapter: Judith Blanchard, John Ehman, Kevin Flannelly, Stephen King, Pat Murphy, Annette Olson, Katherine Piderman, Judy Ragsdale, John Salsman, and Lex Tartaglia. Laura Dunn and Daniel Grossoehme provided especially helpful feedback about mentoring.

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Chapter 11

Participating on Research Teams A Place at the Table

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Tammie Quest, MD**

To sit at the proverbial table with regard to healthcare research — joining a team — is a privilege granted to those who have an operationalized practice to investigate. As previously stated, professional chaplaincy is an established and respected discipline but is largely unknown as to its effects on the outcomes in a healthcare environment. At once there is a need to understand the activities of chaplaincy (chaplains as subjects) and also a need to investigate spiritual health writ large (chaplains as investigators). It is up to professional chaplains to ensure that chaplaincy has a seat at the table for both endeavors.

As the chaplain author of this chapter, I've had an interesting journey of getting to the table. I was "reared" in the traditional way through academic theology, religious formation/endorsement and clinical pastoral education—all of which were important passages in developing literary analytic skills, multicultural appreciation, ministerial identity and integration of personal narrative. I also went forward with psychological preparation, which required me to learn research methods and conduct an empirical study. In the advancement of my career, however, I chose to accept appointments that added to my expertise as a clinician, an educator and an administrator.

Like any language, what I may have acquired about conducting research from my education was mostly lost due to lack of exercise. I was fortunate in mid-career to be presented with the challenge of growing a research effort within a large chaplaincy department in an academic medical center environment. I was moving from leading an innovative chaplaincy department with service and education components to new adventure—it was like starting from scratch. Instinctively, and with the advice from trusted colleagues, I was encouraged to locate a wide circle of researchers who shared an interest in spiritual health and then my challenge was to join existing research efforts. If successful, this would lead to independent/team funding and enable me to circle back to chaplaincy research.

Incidentally, I started this new endeavor in the pit of the great recession. Nevertheless, I went forward to collaborate with colleagues writing grants for public health initiatives such as religious identity and reproductive health, cognitive disorders related to dementia and religious influences at end of life. Most of these projects, while interesting and important to fields of community health and nursing were not related in any direct way to my clinical context as a chaplain-related professional. I spent several seasons investing myself on "group" research projects where I would simply be responsive to one element of the project. Because of this spotty relationship with several projects at once, I was not in a good learning place for becoming a researcher. I was not connected to a mentor or a community of persons who were re-tooling for scientific investigation. I spent way too much time getting connected and not enough time reading and getting more familiar with

my own field. Being connected to several groups was good exposure but distinctive from a “team” project where all persons are devoted to the design, implementation and ownership of a study and its results. It was felt that the various “group” projects that I was connected to were not funded mostly due to the economic downturn, but looking back on it I can say that my lack of connection to the problem and my disconnection as a team member contributed to the lack of support generated. In some ways, I am now glad that these projects were not funded because I needed to learn the lesson that chaplaincy and a direct focus on spiritual health issues needed to be the domain of my concentration. Along came Tammie.

It was in just the past several years that the operationalization of palliative care at Emory became solid under the direction of emergency medicine and palliative care physician Tammie Quest. Along with establishing strong multi-disciplined teams that included chaplains, the Emory Palliative Care Center, began a research effort that was necessarily inclusive of the palliative components of physical, psychological, sociological and spiritual attributes. The situation was right for me to consider Tammie as my (our) mentor and colleague toward becoming a researcher(s) in spiritual health. The timing coincided with a funding opportunity that led to a major research project and the support of this very book. I was now on a team that was concerned with developing a project that investigated chaplaincy and was also invested in my training as a chaplain researcher. The project succeeded in developing an ongoing research team centered on spiritual health issues and the realization of our Institution’s responsibility as an important partner in a national consortium of chaplaincy research. Years of patience and maturation led to an otherwise rapid establishment of a team. My own education through the development of the team has led to the steps supported in this chapter. These steps are most directed to chaplains and other spiritual health consultants who are interested in becoming researchers previously focused in clinical work with little or no education/experience in research.

Acquiring Research Etiquette

Chaplains as researchers are rare, in part, because the establishment of research protocol in departments of chaplaincy is not yet considered to be a core component of the discipline’s practice. While other health disciplines are revenue-based and, naturally, academically and clinically prepared to produce results associated with research, this has not occurred in chaplaincy.

There are impediments to chaplains acquiring the skills necessary to join interdisciplinary teams and to conduct investigations. This is clearly a challenge resulting from a deficit of research coursework in the basic Master of Divinity (or equivalent master’s level theological academic degree) and subsequently in the required Clinical Pastoral Education toward board certification as a chaplain (large ACPE, Inc. centers are now conducting research literacy programs but this is just scratching the surface of the need). Nevertheless, it is possible for a professional chaplain to apprehend his or her own gifts for research and to seek out the resources necessary to join existing interdisciplinary team efforts and to lead a team as well.

In this chapter we offer a step-wise progression that leads to research team inclusion. The key to successfully being included on a research team is getting to know the researcher partners in your institution and then placing yourself in a viable position to participate. A chaplain will be encouraged to immerse her/himself into the culture and language of health science research and to then join a team as a learner and a member. Even in a learner role it will be important that a chaplain's spiritual health expertise become integrated as a complementary skill to the team project.

The first step that leads to research team inclusion of a chaplain is that the chaplaincy research candidate comes knowing that s/he is qualified as a healthcare professional—vetted and evaluated on demonstrated outcomes in a professionally rigorous certification process and a developed expertise as a clinician. It is this kind of competence that generates trust across disciplines. Thus, a chaplain with this foundation would therefore not assume that he or she comes empty handed to the research table. Even with this foundation, however, it is not uncommon to feel unprepared to begin the steps necessary to becoming a researcher. A chaplain may need to calculate his or her value to the total health experience by collecting and reflecting on statistics and stories of the work and then practice in the art and science of describing that work to other disciplines and to the institution that one serves. Over time, the maturation that comes from the clinical experience can provide internal and external confidence in that person's ability to investigate spiritual health. Establishing a documentation relationship to the electronic medical record and then data mining for the content and qualities of the work goes a long way toward developing this clinical competency. Therefore, competence and confidence as a clinician can signify a readiness to study relationships associated with spiritual health and the other components of health.

The next steps leading to a chaplain sitting at the research team table include embracing the science of research, being available for study inclusion, and possessing the fortitude necessary to overcome barriers in becoming an investigator. For instance, there will be some in the scientific community that will be suspect of the ability of a chaplain to bracket religious beliefs that are perceived to be leaving too much to mystery or magic. Persons not familiar with the common standards of professional chaplaincy¹ may assume that the practice of chaplaincy is centered on promoting the religious convictions of that particular chaplain as opposed to responding respectfully to who a person "is" regardless of cultural or religious background. Colleagues from other health disciplines who are evidence-based adhere to cause and effect relations and they may assume that a chaplain is averse to outcome measures that lead to results of effectiveness. These assumptions may contribute to the perception that chaplains are not available either as "value free enough" to be scientific or available to be regarded as institutionally protected researchers with time and space allocation.

Chaplaincy, apart from hospice, which is reimbursed for spiritual care, is considered a non-revenue service and until such a time that the service becomes evidence-based, through the outcomes of research, it will remain so. Protected time and experience can only come through substantial funding and if chaplaincy service is already perceived to be an expense

then the current best pathway to a research effort is to join an existing apparatus that values spiritual health and chaplaincy as critical features of a research project. These types of studies may very well be external to the chaplain's own institution but with the potential and promise of adding to internal value. Through the joining and funding of established research efforts, a chaplain researcher can gain a toe hold and draw her institution toward a goal of becoming a whole person health study site leading to enhanced clinical outcomes. Therefore, barriers to sitting at the research table need not be seen as impenetrable, but more as potential springboards toward reward. Additional steps will include substantial training in research protocol, basic language education, a suitable clinical context, an understanding of clinical questions/problems, and a successful team experience--these will all come as challenges confluent with "at the table" learning.

Chaplaincy and the Table of Science

The call for chaplains to become researchers within healthcare is concurrently an invitation for the discipline to become engaged in evidence-based practice. This follows the paradigm within the health sciences that drives the expression of health results from standardized outcomes derived through research. Like other clinical health roles, chaplaincy can no longer be afforded a critical position within a healthcare team without the verification of benefits associated with best practice. For this to be accomplished, a chaplain must grow a "second skin." While the first skin worn by health science colleagues allows for the sharing of preparation and resources for chaplains who lack experience and expertise, it will be necessary for the chaplain to engage in steps of becoming that require "on the project" growth. Chaplain researchers' growth of a "second skin" will require and enable them to engage the scientific method and risk that it may uncover gaps in a variety of interventions associated with spiritual health and most certainly the effectiveness of the education and training of chaplains. Chaplains should generally have the relational skills to adapt to this new environment and be able to roll with the consequences of outcomes. However, the new scrutiny may be difficult, in some respects, for the chaplain discipline that has largely been untouched by outcomes research since its establishment as a certified profession.

For the past three decades physicians, psychologists, nurses and social workers have worked alongside the first generation of chaplain researchers by including instruments to ascertain positive and negative influences of religion and spirituality on health outcomes. To this point in time, the spiritual health of a patient or a population has primarily been viewed and understood from measurements and analyses of metadata that are assessments of data points on a continuum related to a condition. A chaplain desiring to be included on such interdisciplinary studies must have first been willing to seek out colleagues from other disciplines. Interested chaplains will seek out persons investigating properties of experience that touch upon the social, psychological, spiritual and/or religious relational qualities and dynamics inherent in the environment of care. Establishing contact and exchanging interests serves to alert the research community to the potential of a "soloist" spiritual health clinician/researcher who could be included on a research team in pursuit of rigorous studies. When chaplains were included on such teams, it was largely due to their individual initiative and preparation along with a clinical practice

network relationship. Sometimes there was intentionality around the inclusion while other times it was due to happenstance (or providence!). Not much has changed. A chaplain must investigate the investigators and know their studies.

Research is also a “thick skin” endeavor. There is a risk in studying the effects of your work because you may discover that what you hoped would be a good result, occurring through intervention, may well in fact be proven otherwise. A discipline must put itself through examination in order for it to discover the values associated with its practice.

Defining the role of a chaplain and the impact associated with spiritual health must be at the core of any research team effort that is engaged in a comprehensive patient and family centered environment of care. Discovery, evidence and subsequent improvements in training are the marks of growing the discipline in the field of other health science disciplines. These marks also help religious, faith and spiritual traditions link and integrate their ministries to the overall health of persons and communities.

Chaplains have had a hard time sitting at the table of science especially with regard to an examination of clinical services. Increasingly, however, chaplains are being held accountable for measured productivity through the numbers of encounters and for the reported quality of that experience. Given this quantitative form of accountability, there are a considerable number of chaplains that question the motives and purpose of research by chaplains and about chaplains. There is both *resistance* and *anxiety* regarding research.

The “resistance” may stem from a reticence for anyone to know what actually did or did not occur in an encounter. Our training methods have centered on a verbatim conversation report that is recalled by the chaplain—this is without any actual recording in real time. What gets lost in the recall or how one chooses to present the conversation to supervision or peers is a subjective experience that may be helpful to the chaplain but imprecise as to the perceptions of the care-seeker(s) – i.e. the “quality” of the experience.

The “anxiety” of closer examination may result from an anticipation of judgment placed on the work according to the outcome of that encounter. A chaplain may feel good about what occurred, but this does not mean that the “intervention” made any significant difference to or for the care-seeker. It can be daunting for a chaplain to put his or her work under this type of scrutiny—particularly when much of outcome evidence has been considered to be intangible.

In some instances, it has been safer to take on the chaplain identity of an “outsider” who is protected from assessment due to a special role in working with spiritual and religious conversation. This type of relationship has served to maintain a separation of a chaplain’s work from the institution’s overall goals of care for a patient.

The lack of understanding of what occurs in the chaplain encounter has caused colleagues from other disciplines to interpret and characterize the work according to speculation and stereotype. With a definition out of reach, the integration of spiritual health can be

marginalized as a component of care which has undocumented and perhaps questionable value.

In the Center of the Table: Chaplains as subjects and investigators

As related to an evidence-based discipline, there are three chaplain modes associated with chaplaincy research: chaplains as co-investigators; chaplains as principal investigators; and chaplains as subjects. Key to becoming an investigator on a research team is a willingness to become a subject.

Important to the survival of the spiritual health role of a chaplain, there requires a substantial body of evidence leading to how chaplains contribute to the health of patients, families, staff, and others in a healthcare community. In order to do this, an investigation must occur of the chaplain's themselves and their work. Chaplain as subject can be quite an uncomfortable position. With the chaplain as subject, there may be discomfort (or exhilaration) on the part of chaplains as they allow themselves and their work to be examined critically. In this new frame, what the chaplain identifies as the sacredness of his or her work is subject to investigation and inquiry in unaccustomed ways. Chaplaincy outcomes will be observed and assessed by researchers using the scientific method of inquiry, including the application of standardized protocols: 1) ask a question, 2) perform background research, 3) construct a hypothesis, 4) test the hypothesis through experimentation, 5) analyze the data and draw a conclusion, and finally 6) communicate results.

Increasingly, chaplains will be invited by established chaplain and non-chaplain researchers to join in research about or involving the chaplaincy and spiritual health. The status conferred when a chaplain is invited to be an active participant in the intellectual creation of the work by a more established researcher is typically that of co-investigator. When funding is available, the chaplain is given some dedicated percentage of funding to protect time to work on the research (e.g. "percent effort"). This status confers a responsibility to contribute to the team in a manner dedicated by the research protocol. Even when funding is not available, the role of co-investigator is an important one because through this role chaplains are mentored into research leadership by being a part of a team where intellectual exchange and responsibility occurs.

Table 1.
Glossary of Roles in Research Leadership

Principal Director/ Principal Investigator	The individual(s) designated by the applicant organization to have the appropriate level of authority and responsibility to direct the project or program to be supported by the award. The applicant organization may designate multiple individuals as program directors/principal investigators (PD/PIs) who share the authority and responsibility for leading and directing the project, intellectually and logistically. When multiple PD/PIs are named, each is responsible and accountable to the applicant organization, or as appropriate, to a collaborating organization for the proper conduct of the project or program including the submission of all required reports. The presence of more than one PD/PI on an application or award diminishes neither the responsibility nor the accountability of any individual PD/PI.
Co-Investigator	An individual involved with the PD/PI in the scientific development or execution of a project. The co-investigator (collaborator) may be employed by, or be affiliated with, the applicant/grantee organization or another organization participating in the project under a consortium agreement. A co-investigator typically devotes a specified percentage of time to the project and is considered senior/key personnel. The designation of a co-investigator, if applicable, does not affect the PD/PI's roles and responsibilities as specified in the NIH Grants Policy Statement (NIH GPS), nor is it a role implying multiple PD/PI.

From Participant to Leading Research

The first step in realizing a place at the team table is to locate a mentor and/or a support community of established researchers. Depending on local resources these persons may or may not be close at hand. Investigators will have produced studies that have included a wide spectrum of psychological, sociological and spiritual and/or religious variables using quantitative, qualitative or mixed method approaches. A chaplain will want to read the outcome literature of these studies and to see if there are intersections of interest that can be investigated local to the chaplain's work. If mutual interest is identified, a relationship can be developed according to the expertise and schedules of the parties. The expertise made available by a mentoring community may require grant funding, fee for service, exchange of gifts, etc. Once a contractual arrangement is agreed upon, an assessment can determine the readiness of the chaplain research candidate to join an existing study or to be engaged in the formation of a team on a proposed study idea. "On the project" development can proceed knowing that there may be gaps in basic research education that require confluent education apart from the team (see step 2 in **Table 2**).

Learning protocol will mean that the candidate will work alongside and hands on with the mentor and the other investigators as the study progresses from addressing the research funding asking criteria, through the phased proposal development, and application submission. Included in this step is the incorporation of the literature supporting the proposal and establishing a database of relevant sources. Becoming familiar with previous work in the area and relating it to next steps and future directions following the published outcomes, is key.

A chaplain will hopefully come to understand that research study teams might be interested in including spiritual health as a variable, but unless there is a clinical engagement with this variable then chances are it will not be studied. Studies in healthcare can and usually do originate through a practice problem. If there is significant clinical presence of a chaplain then it is possible that engagement on the clinical team can lead to invitation on the research team (academic medical centers certainly have a leg up on this possibility). An invitation however will require a working knowledge of research procedures that enable a person to feel comfortable (albeit initially quiet!) at the table. A first step in joining an existing team will be to learn research protocol (see step 1 in Table 2). It is crucial that a budding chaplain researcher link with a Mentor/Support community and to methodically walk through and actually practice the basic processes for conducting a study. This tutoring phase will allow the chaplain researcher time to learn the language associated with research in general and with that team in particular.

Table 2.
Steps into Research Leadership

Step	Resource	Process/Action	Results
Learned Protocol	Working with a Research Mentor/Support Community	Literature Review, Bibliographic database, Internal Review Board training, Study Design, data collection, Interviewing, Coding, Analysis, Publication	Investigator experience leading to new studies with funding support
Chaplain Research Prep	Workshops, seminars, academic coursework/degree, support of chaplain agencies/departments outside of your own institution	Chaplain Research Collaborative engagement, departmental support and protected time, secure analytic support services	Designation as a Chaplain Researcher in role and responsibility
Spiritual Health Context and Construct	An ongoing conversation and relationship to/with a professional chaplaincy practice	Focus groups, advisory board, team discovery sessions toward hypotheses and model building	Hypotheses and models that lead to studies investigating spiritual health impact
Identifying the Clinical Question	Stakeholder interviews, critical clinical issues	Revising approaches while staying true to original intent	Evidence to support null or alternative hypotheses
Team Workflow	Project Manager, Coordinators and Principal Investigators	Accommodation of values and method, flexibility with differences, regular engagement and accountability, shared leadership	On time product, development of permanent research team

Chaplain Research Preparation

It may seem that this step should come prior to the invitation to be on a team, but without some kind of initial firsthand experience on a project it will be very difficult for a chaplain researcher candidate to advocate for further training within her/his institution. A professional chaplain will first prove his or her mettle through acquiring several years of professional practice, certification, and additional education in research methods (see chapter 10 of this handbook for educational resources). It will be imperative that a chaplain researcher become connected and associated with spiritual health and chaplaincy research initiatives such as the Spears Research Institute of Healthcare Chaplaincy Network², the research webinar community of the Association for Professional Chaplains³ and the Association for Clinical Pastoral Education Research Network⁴.

Institutional Review Boards⁵ will be the local monitoring agencies responsible for ethical study designs and funded grants. The candidate will need to become familiar with submitting required materials to the IRB and how to adequately address concerns that arise and to then submit amendments to the original plan. The whole of the design will match the expectations of the funding apparatus and will include the aims of the study, the background experience, the research plan, the outcome dissemination plan, and the qualifications of the study team. If by good fortune a proposal is funded then the process of running the study/grant is a carefully parsed out operation of roles and responsibilities according to expertise.

There will be opportunities for the researcher candidate to gain experience leading to expertise. The collection of data through the devices of surveys, interviews and other modalities places the investigator into the heart of the project in such a way that allows for deeper appreciation of the problem and a way to discover gaps that may lead to revisions. Once data is collected, there is an opportunity to learn the means by which that data is assembled and analyzed. Quantitative data can be analyzed through software and assembled through statistically significant tests, Qualitative data can first be transcribed, fed through coding software and then assembled and analyzed to themes that are “weighed” significant according to redundancy.

Publications can begin at any point during the conducting of the study but generally the data collection is completed and analysis underway before deliberating on journal targets and topics covered. Publications will also include abstracts and poster presentations at appropriate health science conferences and academic forums. Concurrent and subsequent to this “on the project” experience of the chaplain researcher, there will be a realization of preparation gaps that will need to be filled for future success. The goal of the team will be to submit to journals that have high impact value to the field or fields that are related. The next step in the process is to gain further competence through work outside of the team.

Setting a Table: Chaplains Becoming Principal Investigators

As chaplains become comfortable at the table of projects led by colleagues from the other health sciences, they begin to formulate clinical questions to which they will want to investigate and then revolving leadership of interdisciplinary studies can begin. It follows

that a chaplain researcher may be so proficient as to be on several teams or choose to work on one strong team and exchange the roles. Becoming a principal investigator may necessarily mean that the chaplain researcher consider the work as a full-time vocation. The economics of continuing to split time in education, service or administration roles make it very difficult to focus on the important problems and the ongoing training necessary to be engaged in credible research. The hard work of re-tooling is an investment that the chaplain researcher makes for herself, the spiritual health research field, and the institutions that she serves. Achieving principal investigator funding signifies that the chaplain researcher's primary contribution to the field of professional chaplaincy is scientific investigation. While it may have never been the intent for the chaplain to become a researcher, maturation in the clinical field and the opportunities to participate on research teams enables her to discover gifts that culminate into a vital vocation.

Yes You Can

Chaplains are listeners of stories and observers of affect. A response to the care-seeker comes through an empathically balanced presence of the chaplain. Chaplains are trained to pay attention to the words and behaviors. This kind of interaction is not foreign to research. Chaplains can consider themselves to be in constant relationship to research through the kind of "data" gathering that occurs in a care-responding moment. If chaplains embrace this "need to know" as a primary function of a chaplain's work then it is not a far leap to understand the import of becoming proficient in describing the efficacy of this work to others.

As noted above, much will be made about lack of preparation, fears about scrutiny of the work and the economics of support. All of these are likely challenges, but we are encouraged to view them as challenges that are ever present for any research team in its development. Roles and expertise are appreciated and learned as a design unfolds. Chaplains and other related spiritual health consultants have been, and are increasingly becoming critical members of interdisciplinary healthcare teams. Chaplains are incorporating assessments into their practice and they are documenting in the official medical record. The work is being studied and benchmarks are being established as to cost and value of chaplaincy. Chaplains need to now ensure that preparation and support is in place in order to fully function in this environment. Research teams are eager and are increasingly required to include spiritual health in an interdisciplinary study. Both parties can find each other. Some of us will be more prone to join these efforts, but all of us participate by embracing the projects and the outcomes.

Arriving at the research table is possible through taking deliberate steps. Some of those steps will need to be retraced from time to time, but that is true for all researchers. It is promised that as more chaplains join research efforts—the profession will change. We won't necessarily be able to predict how this practice and the work of spiritual health will look. We will be assured, however, that outcomes will allow us to constantly revise our models and modes of education and training in order to be increasingly effective in our care. It is a big step for any profession to integrate its artistic qualities with that of science, but the health and sacred worth of humanity and the planet demand that we take it.

¹ Common Standards in Professional Chaplaincy and Education

<http://www.professionalchaplains.org/content.asp?pl=198&sl=254&contentid=254>

² A Research Institute

<http://www.healthcarechaplaincy.org/sri.html>

³ Examples of Chaplaincy Research Webinars

<http://www.professionalchaplains.org/content.asp?pl=72&contentid=72>

⁴ A Chaplaincy Educator's Research Network

<http://acperesearch.net>

⁵ An Institutional Review Board Description

http://en.wikipedia.org/wiki/Institutional_review_board

Chapter 12

Meeting the Logistical Challenges of Doing Research with Terminally and Chronically Ill Patients

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A. Introduction

Prior chapters have focused on the “why” and “how” of conducting research. This chapter will address the logistics of conducting research in health care settings or patients’ homes, and suggestions for approaching potential research participants who are experiencing significant life changes and limitations due to illness and injury and are nearing the end of life.

Chaplains are well poised to join clinical research teams. They have experience and are comfortable in their roles as members of clinical health delivery teams providing palliative and end-of-life care. They likely already participate in team meetings and case conferences, and embrace the interdisciplinary approach in caring for people with advanced illness. In a multidisciplinary team model, each member brings a unique skill set to the group. Each has a specific role(s) to play in the care of the patient and loved ones, and communicates with team members to ensure critical information is exchanged, duplication of effort is avoided, members are supported and acknowledged, and issues are addressed. A clinical research team is similarly multidisciplinary, but with some areas of expertise that may be less familiar to chaplains. A health research study team may be a compilation of some or all of the following personnel: clinicians (RNs, LPNs, SWs, PTs, MDs), administrative/operations personnel, data managers, statisticians/data analysts, recruitment/enrollment personnel, and support staff. Building on the familiarity of a team model may be a useful paradigm to view research and its value in providing information to enhance practice.

B. Identifying, respecting, and resolving the tensions between a good death and chaplaincy research

The fundamental role of a chaplain in a palliative care or hospice team is to support patients and loved ones. Support may take many forms, including, but not necessarily spiritual support. Issues of finding meaning, forgiveness, leaving a legacy, and the afterlife are common themes. By design, the chaplain’s role must be flexible, individualized to meet each person’s needs, and not wedded to completing a predetermined list of tasks. That said, chaplains as professionals are employees, have a schedule of people they need to attend to each day, and are accountable for their time and work. Adding a set of research study tasks into a restricted time period could potentially exacerbate this tension of meeting the patient/caregiver’s needs and the employer’s requirements.

In preparing for this chapter, the authors interviewed a number of palliative care and hospice chaplains to gain perspective on how they viewed and felt about conducting

clinical research with people who have an advanced life-limiting illness. While not widely generalizable, the opinions offered highlight the tension between supporting a “good death” and conducting research. On one end of the spectrum, chaplains expressed *“research has no place in my chaplaincy practice and would interfere with the job I’m doing,”* *“what I do as a chaplain is really an art and not conducive to research,”* and *“it would be disrespectful to the patients who are dealing with such challenging decisions.”* At the other end of the spectrum were comments such as *“I am open to it [research] but would not know where to start. I have never had any training or course work in doing research...”* *“Without research, I may not be doing my chaplaincy work the best that I can,”* and *“Without research I cannot demonstrate the value of the work I do and my role [as a chaplain] could be considered optional.”* These disparate perspectives will need to be considered and addressed when launching any research initiatives.

Perceived Tensions

Interestingly, the conversations held with chaplains illuminated similar concerns about patient / caregiver burden as have been previously identified by other palliative and end-of-life care researchers. The most common barriers noted were:

- Patients are “too sick.”
- Patients have limited time left and it should not be spent answering questionnaires.
- The family wants as much time as possible with the patient– adding research into the mix is intrusive.
- The establishment of trust and rapport with the patient is paramount – I can’t do that when I am trying to collect research information.

Palliative care researchers have found that these assumptions are largely unfounded and, in fact, they have found people with advanced illness often have a strong need to contribute something to the larger good.

What does/could chaplaincy research look like?

The research questions posed by chaplains may be complementary to other clinicians’ research or be unique to chaplaincy practice. For example, questions regarding palliative care patients’ and loved ones’ quality of life are equally compelling for the treating physician and chaplain, although the two disciplines may approach this from different vantage points. For chaplains new to research, identifying topics of mutual/common interest with other healthcare disciplines may be an advantageous starting point. Research also has varying levels of complexity. When first designing a research study, one may wish to identify the “who, what, where, when, and how” early in the process. Below are some examples of design elements to consider:

- Who will provide the data? The patient with a life limiting illness? A caregiver/loved one? A health care provider? A combination of sources?
- Who will collect the data? The research clinician? The chaplain? The study research coordinator?

- What information is being gathered? Patient reported information? Information gathered through observation? Physical exam data? Demographics? Religious / spiritual beliefs?
- What information is necessary to answer the research question(s) and what is “nice to have” information?
- Where will this information be collected? Patient’s home? Inpatient hospice? Hospital room? At a number of sites throughout the local area, state or nation?
- Where will the data be recorded? On paper forms? In an electronic data capture system? A combination of methods?
- When will the data need to be collected? Once? More than once? What is the study data collection timetable?
- How will the data be collected? Directly interview palliative care patient or loved one? Review medical record retrospectively? Review medical record prospectively? Observation?
- How will the process of information gathering affect the study participant? Loved ones? Health care team? How long will it take to collect the information at each data collection time point?

Asking these questions not only fleshes out how the research protocol will be implemented, but the exercise will likely showcase areas of participant burden and various logistical issues associated with the proposed study.

Finally, research can be and is conducted in a myriad of ways, as the preceding bullets imply. For chaplains who are concerned about adding research activities to patient encounters, research designs not requiring direct patient interaction may be considered (1-4). Some examples include retrospective chart reviews, evaluating how chaplaincy interactions are documented, or research focused on formal and informal caregivers. Furthermore, getting connected with other research groups such as the Palliative Care Research Cooperative (PCRC) group may be a way to get introduced to research without the pressure of being responsible to spearhead the research.

Are the concepts of a “good death” and chaplaincy research mutually exclusive?

During the interviews, several chaplains expressed reservations about adding research responsibilities to their daily workload, as they already feel that their time with the patient and family is limited. This concern, coupled with the underlying need to build and maintain rapport and trust with the patient and loved ones, caused some to conclude research and chaplaincy practice may not be compatible. Through this lens, one can understand why some chaplains consider research involving direct contact with hospice and palliative care patients as burdensome and stressful. Furthermore, it was inferred that conducting research would hinder the chaplain’s ability to support the person in achieving a “good death.”

But what exactly is a good death and who determines what a good death looks like? When research efforts are viewed as competing for time rather than a necessary component of the encounter, non-research needs may take priority. To succeed, both

responsibilities will need to be viewed as important and worthy of time investment. The chaplain must feel that the research question is important and worthwhile, both for the knowledge to be gained and for the participant's benefit. It is not up to the chaplain, or any other healthcare researcher, to decide on behalf of the potential study participant if they should/could participate in research and the impact of research participation on a "good death." Inviting eligible participants to enroll and allowing them to make informed decisions exemplifies respecting the person and acknowledging their experience and ability to contribute, regardless of health status.

C. Accommodating the Study Participants' Burden

For chaplains new to research, retrospective studies may provide an introduction to how research is conducted without intruding on patient care issues. In such cases, the chaplain, rather than a patient, loved one, or other healthcare team member will experience the research burden.

The concept of what constitutes burden is subjective. Chaplains may benefit from examining their personal beliefs about research and the burden it may impose on themselves or others. They may want to ask themselves questions such as:

- Do I view research as proving opportunity and benefit?
- Do I believe the research question is important and worthy of study?"
- Do I see study involvement as a choice for the potential participant and an opportunity to advance knowledge and help others dealing with an advanced illness?"
- Do I see research as providing a way for potential participants to finding meaning in their struggle and provide a legacy?

Consideration of questions such as these can help chaplains to view research through a positive lens and in a broader context, thereby moving beyond thinking of it as intrusive and burdensome.

Research participation does require extra time and effort. Thus the study participant, family members, and the chaplain may initially view it as burdensome. As part of the recruiting and consenting process, it is key that the chaplain researcher be honest and forthright about the time demands and requirements of the study. Researchers can help engage potential participants and their families to participate by ensuring that the key messages are offered: a) the benefits of participating in a study, b) that being in a study is voluntary, c) highlighting the ways the study may not be an extra burden or how the study accommodates perceived burden, and d) participants right to withdraw at any time.

The ways that research opportunities are presented to potential study participants needs to be carefully considered in advance. Issues such as who should be present, where it should take place, and what time of day is most conducive, needs to thought through and planned. The invitation to participate needs to be offered in a manner that is respectful of the many issues that patients and families are dealing with at a very difficult and challenging phase of life. A skilled recruiter knows the study, consent form and study

details so well that extending an invitation to participate in a study and the administration of questionnaires can be conducted in a conversational manner.

This level of familiarity with all study aspects takes effort and preparation. The most successful data collectors spend time practicing and “role playing” with others (e.g., research team members, friends, family). Chaplains already have a good sense of family/patient dynamics and issues at end of life. Mine this knowledge to design practice scenarios/vignettes, which could be acted out prior to study implementation. Practicing with loved ones or other research team members allows one to refine the delivery of information, calm nerves, and ensure knowledge of the study.

Research studies typically offer participants the choice about completing all or only part of the research questions. Chaplains need to be sensitive to how the participant is feeling at any point in time when research questions or interventions are being obtained. Asking, “Is this a good time to answer some research questions?” shows sensitivity to their situation and provides participants with a sense of control over their time. Always let participants know the amount of time that will be needed for each questionnaire or intervention. Negotiate with them on how much they may be willing to provide at any point in time. Consider conducting questionnaires by phone, or breaking them up into more than one session.

Pick up on verbal or body language cues. Saying “*you are looking or sounding really tired, are you okay with answering these questions for me?*” offers the study participant a choice, and can often result in achieving the desired goal of obtaining the research data. The participant may request to be seen at a future time, and the chaplain researcher’s flexibility in rescheduling demonstrates respect, strengthens trust, and conveys that the participant is in charge, because it is a voluntary activity. This is very important to consider when the research requires multiple visits over a period of time. Keeping the rapport with the study participant increases the likelihood that they will continue to volunteer for the entire study and not withdraw prematurely.

While obtaining all the desired data and doing all the desired interventions is the ultimate goal, participants’ conditions may be such that this is not achievable. The chaplain will need to decide if it is worth pushing the patient to achieve a desired outcome and run the risk of having the participant discontinue participation because of the study demands. The tension between study participant retention and complete data collection at any given time point is a fine line.

D. Coordinating with team members' differing schedules and locations

How the research protocol is administered is largely dependent on the study sponsor (e.g., National Institutes of Health, Centers for Medicare & Medicaid Services, Robert Wood Johnson Foundation, etc.) as well as how the Principal Investigator¹ designed the study. There are varying levels of complexity. The research may be conducted at one or many sites, or even many sites within a site! The chaplain may be the Principal Investigator or may carry out a variety of study roles depending on the specifics of the research, protocol, their expertise, interest and factors such as staffing capacity. For the project to flow smoothly and be operationalized effectively, regular contact with team members and holding team meetings are important. Research team meetings provide the forum where study business can be communicated and addressed and may be offered in formats including face-to-face, telephone, telephone with visual (e.g., Skype), or using the web (e.g., Webex). Depending on the nature of the research, research team members may need to coordinate their schedules and locations with other team members, study participants, potential study participants, and/or caregivers to effectively and efficiently meet the study needs.

E. Accessing varied locations of potential participants

Palliative and end of life (PCEOL) care is provided in a variety of settings, including hospitals, outpatient clinics, facilities such as skilled nursing facilities (SNFs) and assisted living facilities (ALFs) and in patient homes. These settings will need to be described in Institutional Review Board (IRB) applications. IRB requirements and processes are addressed in Chapter 13. Depending on the study design, team members may need access to and/or need to visit each of these settings. Systems will need to be established to support case finding, recruitment, providing interventions and data collection. Building these systems takes time and effort, and may fall on the chaplain to develop or help develop. Processes for things such as 1) strategies for identifying potential study participants, including locations (specific floors, facilities, and clinics), 2) determining what assistance is needed from others in the organization, estimating and communicating realistic time and resource estimates, and 3) understanding what tasks can and should be delegated and which you need to maintain control. Building systems requires that the chaplain feel empowered and confident when asking for help and representing the research study to professional leaders who can assist or curtail access to the research population.

Because family members often are involved in helping provide care and supporting the patient in making decisions, chaplains as researchers will need to consider the needs of the participant/potential participant in the context of family wishes as well as individual choice. Likewise, if caregivers are the study participants rather than patients, consideration will need to be given to their schedules. Setting up meetings to address the research needs for the participant as well as family members may require working outside

¹ Any member of the healthcare team might be the Principal Investigator (PI), including the chaplain. Alternatively, there may be sponsors outside of the palliative and end-of-life community leading research that includes palliative care patients, but is not necessarily "palliative care research."

of the 8:00-5:00 Monday through Friday work week paradigm. Research may need to include both evening and weekend times. As a member of a care team for palliative care and hospice patients, chaplains are likely familiar with the flexible schedule approach. Research may also involve participants or potential participants who are cognitively impaired and therefore the data are collected from the participant's legally authorized representative (LAR) such as Medical Durable Power of Attorney (MDPOA)². Additional time may need to be invested in confirming LAR status. This is another example of how the research may add time to the chaplain's day, and should be planned for in advance.

F. Other logistical challenges

In order to be successful as a researcher, chaplains will need dedicated training in areas such as how to recruit, how to offer and obtain consent, how to gather study data and offer interventions, and accurate record keeping/ building tracking systems. The Palliative Care Research Cooperative (PCRC) Group has several training videos and a research coordinator handbook available on the website ⁽⁵⁾.

Additionally, institutions will require that regulatory programs and certifications pertinent to conducting human subject research be completed. Finally, some healthcare settings (e.g., community-based skilled nursing facility) not familiar with chaplaincy research may have additional requirements (e.g., acquiring a badge).

Training and refining skills through practice in these areas will take time outside of the scheduled chaplain visits. Research team meetings also will need to be scheduled. Leadership support and knowledge of these additional requirements is needed to ensure chaplain researchers are successful.

G. Summary

Research by chaplains in their fields of practice and expertise is relatively new. Opportunities abound to enhance practice, inform other disciplines about their roles, explore alternate strategies for service delivery, and learn from patients through research. By engaging in research, chaplains can expand their field of expertise beyond what may now be familiar and comfortable. They can ask questions and test hypotheses that have remained unasked and unanswered to date. Findings from chaplaincy-focused research studies have the potential to further legitimize the role of and unique contributions made by chaplains, particularly to healthcare leaders. Through research, both the art and science of chaplaincy care can be honored.

² Including cognitively impaired persons will require additional steps in the IRB application. See Chapter 13.

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Chapter 13

The Inner Workings of the Institutional Review Board: What Should Chaplains Expect

Dane R. Sommer, D.Min., M.Div., BCC

The future of health care in most hospitals will increasingly require a careful balance of three initiatives: clinical care, education and research. Nearly every chaplain understands the first two of these initiatives as we regularly care for patients and others and engage in life-long educational activities. The third activity is coming into focus for many of us. With great zeal many individuals and departments are becoming acquainted with the urgent need for careful research in chaplaincy that will not only influence what we do but help us develop theories and methods that lead to excellence. Research development will also help us connect with other disciplines in health care that depend on developing research that demonstrates their value and thereby assures their continuation.

Our ability to engage in research must be built on an understanding of the standards that are in place for all researchers. Chaplain research cannot be less rigorous than the research done by other health care professions. It should be designed and completed with the high standards that guide credible research, in other words it should be able to endure the rigors of scientific review. And it should be safe and ethically sound. While chaplaincy has had a long history of openness and personal introspection that builds the foundation of our ability to relate to others in a deep and meaningful manner, the need for scrutiny and criticism by others may make it difficult for chaplains to engage in the development of research projects. Our reticence may be caused by the perception of a division between religious and scientific disciplines, or it could be the possible result of our grappling with sacred moments in our own lives and in the lives of vulnerable people.

The process of preparing and presenting a research protocol for review by an Institutional Review Board is challenging for all researchers—not just chaplains! This chapter outlines the role of the Institutional Review Board. It also outlines some of the major issues that chaplains face in presenting material to an IRB. In addition this chapter offers a practical review of the importance of the IRB. My observations are based on over twenty years as a member of the pediatric IRB and more than three years as co-chair. The latter role has put me into the perspective of being involved with the day-to-day operations of our IRB. This includes working with the staff of our Office of Research Integrity, our compliance officer, senior administrative staff and, of course, our researchers. This includes developing agendas for our monthly meetings, reviewing changes to research protocols and often sorting through conflicts that arise when research does not go as planned. Some of the issues are incredibly complex – such as developing a repository for our center for genomic research – and some are simple and straightforward – such as reviewing patient care surveys. Nonetheless, this work has offered me a fascinating position from which to observe how research is conceived and brought to fruition. It also helps me to understand the role of the IRB in conducting research in chaplaincy.

Jurisdiction and Scope

The first – and maybe most important concept – is jurisdiction. The jurisdiction of every IRB is defined by federal statute. Summarized by the Office for Human Research Protections (OHRP), these laws outline the scope of authority that is held by the IRB and its activities. It is important to note that this differentiates ethics committees from IRB's. The activities of an ethics committee are usually consultative and non-binding, whereas the activities of the IRB are authoritative and definitive. The IRB has its own power to make *and enforce* decisions related to human subjects research. At the same time, the activities of the IRB are subject to review by the OHRP and the Federal Food and Drug Administration (FDA). (Our IRB was audited by the FDA in December 2013 during a three day review that included complete access to all protocols, written procedures and meeting minutes.) These federal agencies have the authority to levy punitive sanctions against researchers and institutions, up to and including closure of all research activities within an institution. Such closures can be catastrophic to patient care that is heavily dependent on elements of research, such as cancer treatment. As a result, one of the primary concerns of every IRB is to ensure that researchers are compliant with all federal statutes so that federal sanctions are not imposed upon an institution.

While most IRBs can appear to be focused on adherence to rules and regulations, and some may appear intentionally to create impediments to research, it is important to understand that most individuals who are involved with IRBs are great advocates of research. The makeup of every IRB is dictated by federal statute. It is a blending of scientist and non-scientist (that is MD/DO's, Ph.D.'s, RN's, APN's as scientists and chaplains, social workers and attorneys as non-scientists). There are employees of the institution as well as community members. The composition of the IRB should reflect the diversity of the community within which it exists relative to race, ethnicity, religious tradition and language. This diversity helps the IRB evaluate all aspects of research: scientific merit, ethical balance, clarity of communication and, most importantly, protection of the rights of subjects.

At the same time, the IRB functions to improve the quality of research that is being conducted. Another way to state this is to say that IRBs help researchers become better researchers (whether they want the help or not!). They help improve the quality of written protocols and improve the communication that takes place between the researcher and the subject. As a non-scientist, my primary function as a board member and as chair has always been to monitor the ethical issues that must be considered in research. On a practical level, this usually focuses on the need for clarity of communication. One almost trivial example that was important in nearly every protocol the IRB reviewed was the quantification of the amount of blood that would be drawn during research. For years, researchers used metric measurements. In the consent forms they would write, "5 ml of blood will be drawn." In reality, there are very few patients or family members who understand the actual volume of 5ml of blood. It took several years of "badgering" our researchers to change their language to "about one teaspoon," language that is now nearly universally adapted in our consent form.

This example might seem a bit superfluous, and there are times when researchers may feel that IRB members are “pesky flies” irritatingly buzzing around their heads. (One researcher threatens to bring a fly swatter every time he presents a new protocol to our IRB!) But there are times when the IRB must address more complicated issues that evaluate the scientific merits of a protocol. For example, there are always concerns about whether or not the proposed research can actually be completed. Does the institution have the infrastructure, including facilities, equipment and qualified staff to do everything that needs to be done? Do we have the right laboratory equipment for long term storage of specimens? Do we have enough research coordinators to process the recruitment of subjects, consent and data collection to make the research feasible to do? Do our researchers have the financial resources needed to do what is proposed?

We recently began requiring a financial feasibility review of all protocols by our department of grants administration prior to submission of any protocol to ensure that our researchers were accounting for all expenses involved in research. Do the researchers have the qualifications they need to do the research that is being proposed? Have they had previous success, or have they had problems? Do they have any conflicts of interest? Many researchers serve on advisory boards for clinical and pharmaceutical companies and are engaged as consultants in the development of drugs and devices. Researchers may receive compensation for these activities. This creates a potential conflict of interest if the researcher engages in the recruitment of subjects that might ultimately result in direct financial benefit. This then raises the question of how conflicts of interest are presented in written materials and how they are honestly communicated to subjects during the consent process. This can be a very difficult issue because it frequently involves senior researchers who attract important financial resources to an institution. The IRB is responsible for the review of all aspects of each protocol.

Informed Consent and Privacy

Another concern reviewed by the IRB is that all subjects have been informed of what is entailed in research and have given consent. It is a confluence of imperatives that form the basis of most federal statutes regarding research. The need for informed consent may be the primary reason for the existence of IRBs. There are various ways to express the need for informed consent: that it is an a priori requirement of the researcher/subject relationship, without which there can be no research; that it is an inherent right of the subject; that it is mandated by law (again, the federal statutes!). The requirement of informed consent seems significantly clear in both theory and practice. And yet, the history of medicine is fraught with numerous examples of great and horrendous cases where harm has been caused by research that was conducted without the consent of the subjects involved. Most of us know the names of individuals and institutions where harm was done in the name of good research: Tuskegee, Willowbrook, Jessie Gelsinger...the list can go on and on. While these cases might seem part of a different and unenlightened past, they are operative reminders of the need for the objective review and approval of ALL human subjects research.

Informed consent is obviously an essential part of all medical treatment. We get informed consent from patients and surrogates for nearly all aspects of care, ranging from admission to a hospital to emergent and elective treatments, some serious some almost benign. There are somewhat universal elements to informed consent:

- What is being done?
- What are the alternatives?
- What happens if nothing is done?
- What are the risks and benefits?
- Does the patient (or surrogate) understand what is being explained?
- Has the patient (or surrogate) made a voluntary decision?

There are times when these primary requirements are abridged, especially during emergencies. Informed consent maximizes the patient's autonomy, giving the patient the opportunity to make a decision that reflects the patient's own values and needs. When informed consent is by-passed or shortened, decisions are made based upon the values and motives of others. This can result in treatments that are not congruent with what the patient wants. When treatments take place against a patient's wishes physical, emotional, spiritual and financial harm occurs.

The need for informed consent creates a high ethical and normative standard in health care, but research sets the standard even higher. This is tied to the absolute that all research is voluntary. All research subjects must give informed consent. No person can be part of research unknowingly or against their wishes. Individuals are harmed when they are unknowingly involved in research without their awareness. This absolute is expressed in pediatrics by the need for assent in minors: the minor subject may not fully understand all the details of a research protocol but nonetheless retains the right to say "yes" or "no" to what will be done. In pediatrics, researchers are challenged to find creative ways to explain complex concepts and processes to subjects who do not have the emotional and cognitive abilities of an adult. The barriers to comprehension and understanding must be overcome, and sometimes these barriers are more difficult to articulate than the steps of a research protocol, per se. Researchers may have to overcome barriers of moral development, language, education, learning methods and cultural differences to ensure that ALL subjects have the chance to make an informed decision to be part of any research.

The need for protection of subjects extends the responsibilities of an IRB beyond informed consent to issues related to privacy. Concerns about privacy include measures taken to be sure that information is only shared appropriately with others who have a defined reason to have access to such information. Higher levels of protection are required in research because the information may impact issues such as access to health care, employment and insurability. The reality that more and more data is being stored electronically actually increases the ease with which large amounts of data – including private health information – can be moved from one place to another with just a few key strokes of a personal computer. More personal information is being scattered on different types of electronic devices ranging from desktop and laptop computers to tablets, cell phones and other hand

held devices, all of which can be compromised allowing unauthorized individuals to access information that must be protected. All breaches in confidentiality can result in harm to research subjects.

Advances in Research

Privacy and security have also become increasingly complex because of advances in genetic and genomic testing. Every subject in research should know within reasonable means exactly how their blood or tissue samples will be used. The well documented account of the misuse of cells from Henrietta Lacks demonstrates how abuse can occur when researchers engage in activities without the knowledge and consent of the subject. In the early 1950's, cells were taken from Lacks without her awareness or permission. These cells were developed into an immortal cell line (HeLa Cells) that has been used continuously for medical research. Two specific endeavors require special scrutiny simply because they involve research that is often undefined.

First, genomic research explores the seemingly limitless internal universe of the human genome, or genetic structure. Some genomic research is very well defined as researchers know exactly which sequence of genes they want to study and have some idea of how those genes affect our health. Oftentimes, researchers will pinpoint a small section of genes for studies that record the frequency of genetically related diseases or anomalies. This can result in new methods of diagnosis and treatment that can make a huge impact on patients and families. But journeying into the depths of the genome has just begun. To gain more information about the human genome and its impact on health, researchers must cast a wide net – they must study the genes of many individuals, some who are healthy as well as some who are ill. Sometimes researchers know exactly what they want to do with the cells they collect, but quite often they design protocols to hold cells for future research possibilities.

The great benefit of undefined future studies is that they give researchers opportunities to hold in reserve samples that can be studied as new advances and concepts in genetic research develop. The risk to subjects, however, is that they may not realize that their tissues will be reviewed in the future, perhaps for protocols that they would not accept and by researchers who are outside of the current treatment or research teams. IRBs are responsible to look carefully at these undefined studies to determine if there is a possible end point at which these samples can be safely destroyed. Are there safeguards in place to define who will have access to the samples? Are there clear statements about what will – or most likely will not – happen if the individual samples are used to discover an advancement that has potential financial gains? What procedures are in place to ensure the rights of subjects who are minors when they start a protocol? Is there a procedure in place to “re-consent” the subject when that individual becomes an adult? If so, how is the private health information secured and separated from the samples while they are being stored? And finally, there is the practical question, will samples be stored in equipment or medium that will preserve their integrity? Ultimately, the responsibility for all these safeguards to privacy and security is held by the researcher and the IRB.

The second issue that is new to IRBs arises with the creation of repositories. Similar in design to the collection of tissue and blood samples for genetic studies, repositories cast a wide net to include individuals who may or may not be actively enrolled in a research protocol. The aim of most repositories is to collect a large number and variety of samples that would not be feasible using traditional research methods.

Also, the aim and design of the protocol is focused on the collection, storage and access of samples rather than upon that comparison of treatment options with another. To cast this wide net, the repository may seek samples from individuals who may have sought care with minimal risk, like a routine, annual blood draw at the time of a physical. A small amount of the blood draw is needed for the test, and rather than “wasting” the rest of the tube, it is sent to the repository. The patient is completely unaware that the blood will be used for research purposes. Is this ethical? If the keystone of all research is informed consent, IRBs must struggle with whether or not researchers should be allowed to create research protocols that have so many undefined elements, while realizing that many future research endeavors will only be successful by analyzing data from a wider sample set. This is an example of how the IRB must struggle with a new concept and work with researchers to figure out how to proceed. It will require caution and care.

Conclusion

So, what does all of this mean to the discipline of spiritual care--to chaplains? The broad scope of this article was meant to offer a basic introduction to the issues that are discussed and adjudicated by an IRB on a regular basis. As chaplains consider developing research protocols they should begin by considering how the issues of informed consent, privacy, security, and the overall protection of all human research subjects will be addressed within a written protocol and in *collaboration* with an IRB. Chaplains can seek the support of other researchers as well as members of the IRB who can provide guidance on current and future IRB research approval requirements.

Chapter 14

Strategies for Introducing the Role of the Chaplain Researcher to Administrators and Team Member

Making the Case for Research

The Rev. George F. Handzo, MDiv, BCC

So you are a chaplain who wants to do research. You've read the preceding chapters of this book. You've maybe listened to some George Fitchett webinars. You get it about why this is important and you want to get into the game. However, you have become aware that your administrators and maybe even your chaplaincy colleagues in the institution don't share your enthusiasm. In fact, they may be openly opposed and even dismissive of the idea. Be assured, that, for better or worse, this is the norm. Of course, especially if you are the chaplaincy director, it is possible to get involved in some research as a sidebar to your job. Your administrator may tolerate it because it doesn't seem to impinge on the rest of your work and your colleagues will tolerate it as long as they don't have to be involved. However, wouldn't it be so much better to have everyone on board and supportive? So how can you get there?

The first, and most important, strategy in introducing the role of the chaplain researcher to administrators and team members is building the case for why a chaplain getting involved in research is a good idea. A common mistake that many of us make introducing any new role or program is we assume that because the program seems to be a good idea to us and we are excited about it and that it makes obvious sense to us, everyone else will be excited as well. Or we think that doing something because "everyone is doing it" or "this is what good chaplaincy services do" will be enough. It is only rarely enough. At base, the case for any new program or role has to persuade the people or group who are being asked to support it that there is something in it for them. That is, for administrators, what is the institution going to get for supporting a chaplain being involved in research that helps meet some of its perceived needs? For chaplain colleagues, the same question applies especially if you are asking your colleagues to participate in the research and/or cover some of your work while you are researching. How is the research you are proposing going to make their life easier or increase their acceptance as members of the health care team?

A useful way to start building this case is to understand some of the basic trends in health care. For many years, health care providers in the United States were paid for each procedure or service they delivered. Thus, the more surgeries you did, the more you would be paid. The extension for chaplains is that high number of visits or visiting every patient was valued as a measure of productivity.

This paradigm is rapidly shifting to one in which the key is value provided. Using the surgery example, while the number of surgeries still has some importance, value is determined by outcomes such as how many surgeries are successful, how quickly patients get out of the hospital, how few infections there are, and how satisfied the patients are with the hospital. The paradigm is also often described as the "triple aims"- clinical outcomes,

cost reduction, and patient satisfaction. While true evidence for this value is sparse throughout health care because it has seldom seemed important before, it is almost nonexistent in chaplaincy with the exception of a small amount of research in patient satisfaction. Thus, chaplains who were previously able to generate evidence for their worth in a volume based economy because they can produce a large volume of visits for a relatively low cost, have very little evidence to support their worth in a value-based system. Since reimbursement is now often based on demonstrated value, services and processes which do not demonstrate value are subject to cuts in funding or even total defunding.

The argument can be then made that the future of health care chaplaincy, and in turn, the inclusion of care for the spirit in health care, are dependent in some large part on the development of evidence for the value-added of chaplaincy. This evidence will only come from research.

There are also other services hospitals provide, palliative care maybe chief among them, whose own demonstration of value is likely tied at least in part to attending to the spiritual and religious dimensions of care. Thus, the argument for the inclusion of chaplains in research is not just to demonstrate the value of chaplaincy as a stand-alone service, but to help demonstrate the value of other services, like palliative care which help meet spiritual needs and include chaplains as part of the service. Palliative care will certainly grow as a service with or without the inclusion of chaplains. However, having chaplains involved does give an opportunity to further demonstrate the value added of spiritual care.

Another major trend in health care is the emphasis on patient experience which has been defined by the Beryl Institute as “the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care.”ⁱ Patient experience indicators such as over rating of the hospital and the likelihood of recommending the hospital to others are increasingly being included as part of what determines a hospital's reimbursement. The field of patient experience is fairly new and there is not a lot of evidence to date on what improves or detracts from patient experience. What is clear is that any service or process which can be shown to improve patient experience will be highly valued in most medical institutions because it impacts at least two of the triple aims- patient satisfaction and revenue. It would seem that chaplaincy could be a significant contributor to patient experience, but again, there is no research evidence to support this contention.

The Joint Commission which accredits most hospitals in the US has driven the inclusion of Continuous Quality Improvement (CQI) as maybe the defining process of the institutions they accredit. This emphasis has given new importance to outcomes like patient safety and, in turn, communication and cultural sensitivity as major determinants of that safety. It is no longer good enough for a process to be effective (i.e. yield positive result), it must also be efficient (i.e. yield positive results using the least amount of resources and producing the least waste). Increasingly, all health care employees and all services, including chaplaincy, need to be involved in CQI and CQI is a form of research. It involves gathering data, hypothesizing solutions, testing those solutions, and evaluating the outcomes. A couple of

chaplaincy CQI projects I have participated in include improving the reliability of off hour calls to the chaplain being responded to in a timely manner and improving the documentation of a patient's religious preference in the medical record. In one hospital, the investigation of the time between when a chaplaincy referral was generated on a nursing unit and when it arrived in the chaplain's office revealed a subset of those referrals which took a very long time to arrive. An investigation of what those referrals had in common turned up a problem within the hospital's message transmission system which was easily remedied.

Finally, for chaplains who are located in medical centers associated with medical schools and/or universities, it may be the culture that every department does research. Thus, chaplaincy might gain legitimacy by being involved in research. The challenge to this arrangement can be that the research is expected to be at a fairly high level of sophistication and publishable in an academic journal although if the chaplain can manage to attain this level, the added value will be substantial.

The Specific Case for Chaplaincy

The trends toward value over volume, emphasis on patient experience, and continuous quality improvement have all been around for years. What has changed and is changing with increasing speed is that reimbursement policies in health care are increasingly supporting these trends and making them almost mandatory for any health care institution which hopes to stay economically viable. As part of this imperative, health care institutions are applying these strategies across all units of their operations- even those with relatively small budgets like chaplaincy. Thus, the days when chaplaincy could stay "under the radar" with regard to these issues is rapidly drawing to a close.

Further, waiting until an administrator decides to ask chaplaincy to demonstrate value to begin to gather data is a dangerous strategy because the time required to collect this kind of evidence is often much longer than many administrators are willing to wait.

There is also the question of whether we shouldn't be doing this anyway because we want to bring patients, caregivers and staff the best spiritual care possible. George Fitchett continues to remind us that being a research-informed profession does not mean that intuition, training, and clinical judgment cease to influence our clinical practiceⁱⁱ. Research is only one more way of gathering data about what we do and how effective our interventions are. The late Art Lucas reminded chaplains that we have always had outcomes. Whenever we say "I hope Mrs. Smith has....." or "I wish X for Mr. Jones" we are talking about outcomes.ⁱⁱⁱ

The value of chaplaincy has always been clear in concept to chaplains and many administrators. Chaplains and many others believe that spiritual/religious care can be a central component of patient experience and patient satisfaction. Chaplains have always been commonly acknowledged as effective communicators and the Joint Commission has labeled chaplains as central to cultural sensitivity in the institution.^{iv} Increasingly communication and cultural sensitivity are seen as essential contributors to patient safety meaning that they are now "must have" competencies that affect cost rather than "nice to

have” competencies which only influence patient satisfaction. However, having an idea, a process or a program be widely understood to be good or true is no longer enough. Research evidence is needed.

In sum, research is good for patients and caregivers because it improves chaplaincy effectiveness and efficiency. It is good for institutions because it can show how to improve patient experience and patient satisfaction, and potentially contribute to clinical effectiveness and patient safety by improving communication and cultural sensitivity.

Picking a Study

It might seem like the next step after making the case for research in general is to establish the role of chaplain/researcher and get buy in to function in that role. However, it is important here to return to the initial premise of needing to establish the benefit of research for our administrative and chaplaincy colleagues. Sometimes this can be done in a general sense as outlined above. However, it is often simpler and much more persuasive to demonstrate the benefit by proposing concrete research projects and topics.

One first step can be to investigate whether there are research or CQI projects or groups in the institution which could benefit from the addition of a chaplain to the team. If there are research or CQI presentations routinely done by other departments, especially palliative care and the psychosocial disciplines, attend. Get to know the participants. Become familiar with what they have in progress, but, more importantly, what they are planning. Think about where you might add some value to what they are considering. Then talk to them about whether they would be interested in a chaplain as a member of their team. Maybe the most likely way to get initially involved in research is to have someone on a research team ask your administrator for you to come on board.

Another strategy is to talk to your administrator and/or your chaplain colleagues about issues that they might like researched or CQI issues that might benefit from a project. What process isn't working? Where in the hospital is patient satisfaction very low? Some years ago, we started a Pastoral Care Department in a hospital that had never had professional chaplains before. The chaplain started on nursing units one by one over several months. We watched the patient satisfaction scores on those units rise very soon after the chaplain was introduced to the unit which confirmed to hospital administration that they had made the right decision. There was not even a need for an official project here. All that was needed was to watch an already available metric in relationship to chaplaincy deployment. Many hospitals now are concerned about patients with much longer than normal stays. Since length of stay is routinely available to chaplains on every patient, it would be easy to visit them preferentially and report to administration, not only that the chaplains are attending to this important population, but what the chaplains find in terms of issues that are bothering these patients and they see as barriers to discharge.

What are your colleagues saying when they start a sentence “it would be really great if we knew.....”? Some of these issues are quite simple to investigate and would be easy to do without funding and without taking any time away from your regular responsibilities.

Some take a little more effort than that but answer important questions. With some support from a researcher, the cooperation of her palliative care team and no budget, Chaplain Holly Gaudette successfully demonstrated the correlation between anxiety and spiritual coping in a small sample of palliative care patients (i.e. the more positive spiritual coping the patient had—the lower their anxiety).^v This is a very important and never before documented result that helps to confirm the need for chaplains on palliative care teams. Completing this small study also goes a long way to legitimizing research as part of Chaplain Gaudette's role.

Another strategy is to look for data that is already available from sources like electronic medical records (EMR). Often there are questions that can be investigated just by using some already available data. For instance, if your department collects data on referrals and who made them, has anyone ever looked at what units refer and which do not? This information can lead to an investigation of why the referral pattern is as it is and whether there is a need for staff training on certain units. If referrals are documented in the EMR, it might be possible to persuade the information technology department to run an analysis of referrals by diagnosis. Again, this research can lead to some useful findings that can be used to help make the chaplaincy more effective and efficient and the analysis can be done at little or no cost.

Special Issues in Introducing the Role to Other Chaplains

In introducing the role of chaplain researcher to our chaplain colleagues, it is essential to first elicit and deal straightforwardly with their misgivings and concerns. Given the arguments for research above and even the seeming urgency of doing it, it is all too easy to dismiss concerns about participation in research or, worse, give the message that those concerns are not allowed to be discussed. This stance will only lead to ongoing resistance, lack of cooperation with any research that requires their participation, or even a sabotaging of research projects themselves. It is essential to legitimize the concerns of others. Even if we who are proposing research believe that these concerns are trumped by the benefits of research, the concerns of others should be given legitimacy.

That said, often the misgivings of our chaplain colleagues can be traced to a misunderstanding of the research process and a misunderstanding of scientific inquiry itself. Some explanation of what research can be and doesn't have to be, along with some reframing of the products and processes of the research undertaking can be helpful. I would begin with defining terms. We talk a lot about developing the "evidence" for the efficacy of spiritual care. Many chaplains understand "evidence" to only be that data which is produced by quantitative research. In fact, common definitions of evidence include case reports, expert opinion, consensus panels, guidelines, examples of best practice and other practice-based evidence. George Fitchett has advocated for chaplains to publish cases as part of developing the evidence for and dialogue around what it is that chaplains do and how to do it better.ⁱⁱ The American Psychological Association has implied an equally broader definition of "evidence" when it defines "evidence-based practice" as the intersection of best evidence (which I take to mean evidence as defined above), client values and expectations, and practitioner's individual expertise.^{vi} The Association of

Professional Chaplains (APC) seems to have used this definition when it states in Standards 12 of its Standards of Practice that “The chaplain practices evidence-based care.....” and defines “evidence based” as “the integration of the best research and available clinical evidence with one’s clinical expertise and knowledge of patient/family values in order to facilitate clinical decision-making.”^{vii} Unfortunately, there is confusion in the literature because of the use of the “evidence-informed” and “research informed” to define chaplaincy practice without clear distinctions between this and evidence-based. “Evidence-informed” often sounds better to chaplains but implies a different definition of “evidence” (i.e. one which defines evidence as restricted to that developed by research). Given the usage at the moment, it seems best to say chaplaincy is a “research- informed” profession borrowing from Fitchett & Groehmeme using “evidence-based” practice using the APA definition of evidence-based.^{viii} However, the most important take home for chaplains is that no definition of “evidence” should be taken to imply that the chaplain’s intuition, “gut”, or clinical judgment are no longer important or no longer count.

Another issue that needs to be assumed to be present among chaplains with regard to research is the issue of violating the sacredness of the chaplain-patient encounter. Chaplains often like to think of the process of this interaction as a mystery which will be somehow desecrated by subjecting it to scientific inquiry. On this issue, we do well to concede that research is a reductionist process as is charting. Neither can hope to capture the fullness of the encounter. That said, we can hope and expect that both research and charting will capture important and meaningful elements of the encounter in a way that can lead to improvement of the care provided. Another way to think about this is to appreciate that understanding and measuring outcomes in chaplaincy does not need to involve any analysis or even intrusion on the intimacy of the transformative encounter between the chaplain and the patient. Another analogy that helps me is that understanding with a lot of specificity what happens to the human body at the time of death does not need to detract from the existential mystery and sacredness of being in that moment. This issue also tends to surface as a resistance to standardization of practice which is so necessary for both research and quality improvement.

First, this resistance denies the reality that each of us has standardized ways we tend to practice that we have developed over our training and experience. It also ignores or doesn’t understand that “standardization” is not the same as “manualization” in which every part of a client encounter is closely scripted. Standardization can mean simply that we follow the APC standards of practice which call for every chaplain to do an assessment and document it. Finally, we have to at least be aware of if not actually confront the reality that this resistance is at least sometimes rooted at least in part in a resistance to being accountable for what we do. This resistance needs to be named as unprofessional conduct and inconsistent with our oft-voiced desire to be integrated into the health care team. I would also agree with Fitchett and Grosseohme that there is a theological/moral imperative to improve our practice in order to be a better steward of the resources we have and deliver the highest quality care we are capable of.ⁱⁱ This imperative is well documented across Western religions inⁱⁱ their chapter in Stephen Roberts’ edited volume. Another side of this argument is that research helps us to know with greater certainty

about programs we have been doing that take up our resources but no longer (or maybe never did) contribute to the spiritual well-being of those we care for.

The issue of confidentiality is an important and often contentious one within chaplaincy especially with regard to chaplain charting and documentation, but it can also be an issue in research most prominently in qualitative research such as case studies but sometimes even in research collecting data on the issues identified in spiritual assessments. Some chaplains will say that they cannot chart or otherwise report on their conversation with the patient because it is “protected” by clergy/person confidentiality and therefore they cannot document anything they learn from the patient. As with some of the issues above, we need to start off by acknowledging that some patients do expect a higher level of confidentiality from chaplains than from other health care practitioners. That said, this is not a black and white issue and many chaplains do use it as an excuse to evade transparency and accountability for their practice.

Some background is important here. “Clergy confidentiality” historically refers to the information that someone seeking forgiveness shares with a clergyperson within the context of ritual confession. It has also often been understood as part of a pastoral relationship in which someone is seeking religious counsel from their community’s leader in the areas of marriage counseling or child-rearing. While every state has different understandings of what “clergy-communicant” confidentiality is and how it is to be determined and protected, it is typically applicable to religious community relationships when a clergy/religious leader is employed by the congregation/synagogue/temple and serving in the role as pastor, rabbi, priest, etc. However, another corollary to this principal is that the information belongs to the patient. Thus if the patient gives consent for the clergyperson to share information received otherwise in confidence, the clergyperson is free to do that.

It is essential to understand the difference between being a clergy person or a leader in a religious community and being a professional chaplain working as a member of an interdisciplinary team in a non-religious community setting. The fact is that very little communication between a multi-faith chaplain and a patient falls into either of these categories.^{ix,x}

Professional chaplains are employed by their health care organizations and as such are staff members of interdisciplinary teams. It is practice for all health care disciplines, including chaplains, that no information about a patient is communicated to those who are not members of the patient’s treatment team without the patient’s consent; this is what HIPAA (the Health Insurance Portability and Accountability Act) is all about. In addition, only information relevant to the patient’s care is to be communicated to the treatment team. However, it is expected that all members of the team will communicate to others on the team information which is relevant to planning and carrying out the patient’s care so that the care can be delivered safely and effectively. The APC Standards of Practice for both acute and long-term care state that the chaplain enters information into the patient’s

record that is “relevant to the patient’s medical, psycho-social, and spiritual/religious goals of care”.

For example: A chaplain has a conversation with a tearful patient, Mrs. H, on the palliative care service. As the patient is talking about her life and family, she is reviewing the ways in which she feels as though she “failed” her family. Specifically, she tells the chaplain that she had been unfaithful to her husband several years ago and was wrestling with feelings of guilt and shame. She had never been able to talk with him about it before his death a few years earlier, and had also never talked to her children. She expressed her fear that not doing so had also compromised her religious faith, and was wrestling with how she would be able to face her death. The relevant issue in this conversation is not the fact of the adultery, but the patient’s emotional and spiritual distress which is clearly interfering with the patient’s ability to process her diagnosis, make decisions about her future, and ultimately face death. In this situation, the chaplain would never chart about the details of the patient’s unfaithfulness. Rather, an appropriate chart note to alert the other team members of the issue would read “facing death.” Further, since the patient owns the information, she can give the chaplain consent to share it with the team.

In Outcome Oriented Chaplaincy Care, which includes assessment and documentation, one of the essential elements of the interaction is that the elements of the chaplaincy care plan and expected outcomes are always negotiated with the patient, meaning that the outcomes are the ones that the patient expects and wants, not the ones the chaplain expects or wants. As part of this principle, it is presumed that the chaplain will come to agreement with the patient on the information that needs to be communicated to other members of the health care team in order to achieve the expected outcomes. Since informed consent is a mandatory part of all research and it requires full disclosure of what the researcher is going to do with the information gleaned from the patient, obtaining consent from the patient should obviate any confidentiality issues.

Nuts and Bolts Issues- Or the Devil is in the Details

Like so many other endeavors, successfully engaging in research as a chaplain takes a vision and goals that appeal to the people who have to support it including administrators and other chaplains. Our experience at HealthCare Chaplaincy Network with our Staking a Claim project which supported six major research projects and was funded by the John Templeton Foundation is that many distractions, frustrations, and resistances are caused by failure to account for some of the nuts and bolts issues which seem like they should be easy to negotiate but can, in fact, be time consuming, can create ill will which will cause resistance to future research, and even can occasionally be irresolvable.

A common issue is failure to negotiate a mutual agreement with both administrators and chaplain colleagues about how much time the participation in research will take- both for the researcher and for colleagues who may be involved as subjects or data reporters. First, this time is almost always greater than anticipated. Coming to a reasonable estimate is one of the many places where the consultation of an experienced researcher is invaluable. What clinical or educational responsibilities will the researcher not be able to fulfill and others

have to assume? Another aspect of these issues involves working with research teams. One of the issues that can occur when one is working with people who are full-time researchers is that they have little or no idea what the chaplain's clinical and educational commitments are and can forget that the chaplain has any non-research commitments at all. This issue can play out in research meetings that run long or are scheduled at the last minute.

Related to time issues are money issues. If the chaplain-researcher will be part of a funded project in another department, does the project budget provide adequate money to cover the chaplain's time and is a mechanism in place to make sure that money is credited to the chaplaincy department? If extra chaplaincy resources are going to have to be engaged to cover for the chaplain deployed for research, is that cost adequately budgeted in the project funding? If there are costs to chaplaincy for any project funded, is the return in usable data and evidence for the efficacy of chaplaincy agreed by the chaplaincy department to be worth that cost? Research is never going to make money, but it also shouldn't cost chaplaincy more money than the other returns justify. It is good practice to make sure someone in chaplaincy actually sees the project budget to make sure that chaplaincy financial interests are adequately covered.

Chaplains often assume that there is no way to fund a project they want to do so they do it on a shoestring which often produces a substandard project. While funding is often not available, it is worthwhile to investigate local foundations and hospital auxiliaries. In one hospital I have worked with, the Director of the Chaplaincy Service found that the ladies auxiliary had a special restricted fund to finance projects that were judged to improve the patient experience in the hospital. Through this program funds were provided to renovate the chapel. While this was not a research project, the point is to not assume that funding is unavailable especially in this time when improving the patient experience is so critical. One important caution—never approach one of these groups without checking with the institution's development department. Some administrator's are very possessive about these funds and have their own plans for them.

In working with research teams or on cross-departmental quality improvement projects, it is essential to be clear what is expected of you as a chaplain and that these expectations match your skills, knowledge, and availability. Often because of our inexperience as chaplains with how research and CQI teams work and the team's lack of familiarity with a chaplain's skill set, there can be a lack of clarity and unrealistic expectations of what the chaplain's actual contribution to the team will be. Often the solution to this is to understand that the chaplain brings a familiarity with how spiritual care is delivered in the institution along with a real-world understanding of what spiritual and religious issues are present for certain types of patients and their care givers.

Finally, on chaplain run projects, have you fully understood and leveraged other resources the institution can offer to assist on the project? Often chaplains try to do parts of the project themselves that a friendly local information technology person or the local biostatistician can easily and quickly do. The other side of this issue is building in parts to

the project which seem to us as chaplains like they should be easy, but turn out to be difficult or even undoable. This difficulty often emerges in response to technological or data capture issues.

In short, attending to all of these issues well up front will not only help make the current project successful but will help insure that your administrators and chaplaincy colleagues will be willing to accept the chaplain-researcher role and undertake more research in the future.

Finally, if you are just starting your life as a researcher, having a research mentor is invaluable. It matters little what their discipline is. If they have done research, they have likely encountered many or all of the potholes named above and have strategies to counter them. They can save you huge amounts of time and can significantly increase the likelihood that you will succeed in introducing the role of chaplain-researcher into your institution.

ⁱ The Beryl Institute (www.theberylinstitute.org).

ⁱⁱ Fitchett, G., & Grosseohme, D. (2012) Health Care Chaplaincy as a Research-Informed Professional. In S. Roberts. (Ed), *Professional Spiritual & Pastoral Care: A Practical Clergy and Chaplain's Handbook*. (pp.387-406) Woodstock, VT, Skylight Paths Publishing.

ⁱⁱⁱ Lucas, A., & VandeCreek, L. (2001) *The Discipline for Pastoral Care Giving: Foundations for Outcome Oriented Chaplaincy*. Philadelphia, PA: Hayworth Press.

^{iv} Joint Commission Resources (2006) *Providing Culturally and Linguistic Competent Health Care*. Oakbrook Terrace, IL: Author.

^v Gaudette, H., Jankowski, K. (2013) Spiritual Coping and Anxiety in Palliative Care Patients: A Pilot Study. *J. of Health Care Chaplaincy*. 19, 131-139.

^{vi} APA Presidential Task Force on Evidence-Based Practice. (2006). Evidence-Based Practice in Psychology. *American Psychologist*. 61(4), 271-285.

^{vii} Association of Professional Chaplains. (2009) Standards of Practice for Professional Chaplains in Acute Care. Retrieved from http://www.professionalchaplains.org/files/professional_standards/standards_of_practice/standards_practice_professional_chaplains_acute_care.pdf.

^{viii} Fitchett, G., & Grosseohme, D. (2012) Healthcare Chaplaincy as a Research-Informed Profession. In Roberts, SB ed, *Professional Spiritual and Pastoral Care: A Practical Clergy and Chaplains' Handbook*. (pp.387-406) Woodstock, VT: SkyLight Paths.

^{ix} Handzo, G., Flannelly, K., Murphy, K., Bauman, J., Oettinger, M., Goodel, E., ... Jacobs, M..(2008). What Do Chaplains Really Do? I. Visitation in the New York Chaplaincy Study. *J. of Health Care Chaplaincy*. 14(1), 20-38.

^x Handzo, G., Flannelly, K., Kudler, T., Fogg, S, Harding S, Hasan, Y., Ross, A., Taylor, B.. (2008). What Do Chaplains Really Do? II. Interventions in the New York Chaplaincy Study. *J. of Health Care Chaplaincy*, 14 (1), 39-56.

Chapter 15

Future Directions for Chaplaincy Research

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Introduction

Human spirituality has been a subject set apart from medical research. Starting its heyday of productivity, medical research initially focused on the physical aspects of how the human being works. Then it included psychosocial research, bringing rigor to these ‘soft’ sciences. But research in the workings of the human spirit – either its normal functioning or under conditions of illness – have been less explored. This leaves the present day field open and awaiting research on some fundamental questions. What follows is a set of ten fundamental questions that researchers may engage in the coming era. Answers to these and other questions could redefine the subject and revolutionize chaplaincy and its place in the medical care team. These ten questions are not intended to define the most important questions or to rapidly yield definitive answers; rather they are selections that illustrate where in a range of possibilities the field might explore.

What is the topic?

The scope of the field is still wide open. As the field develops, participants will become accustomed to differentiating whether their interest is in:

- divinity or transcendental matters;
- spiritual matters or how the human being relates to them;
- spiritual illness in general or only spiritual responses to physical and mental illness;
- care practices - how to support a person’s spiritual needs in the health care setting, whether that care comes from a lay or trained person, a health care team member or a professional chaplain
- health care chaplaincy in general or in a specific setting such as palliative care when the focus on imminent mortality and bereavement may be acute.

Each juxtaposed option is distinct and each of the choices is important. The nature of the chaplaincy discipline provides some guidance on which direction to lean.

The distinction between a scope defined by divinity versus transcendent matters points chaplaincy research to the latter, broader topic. Divinity suggests a focus on a type of spirituality that has a concept of what is divine. Since some types of spirituality, such as Buddhism, do not have such a concept of the divineⁱ, the broader focus is more inclusive. This is appropriate for chaplaincy which serves all people.ⁱⁱ

Considering fundamental spiritual matters rather than the specific ways in which human beings relate to them also points to the latter focus for chaplaincy research. Spiritual matters are the foci of faith traditions, but understanding how humans relate to spiritual matters is analogous to physiology/pathophysiology in the physical realm.ⁱⁱⁱ It may be that, as research moves forward, discoveries about how the human spirit reacts in times of

illness will also yield insight into how the human spirit works in times of well being, including perhaps different genetically or epigenetically determined types analogous to personality types. However, for the immediate future, it seems prudent to stay with the focus on what happens in the illness context. This offers a defined scope of focus that is distinct from religion, which already has its own various approaches and methods of study. Touching on the subject of whether there can be such a thing as illness in the human spirit remains controversial and may be a matter for later research after the field has developed. Since there is little controversy about the activation by illness of spiritual responses in some people,^{iv} this may be the most useful focus for spiritual care research initially. Health care chaplaincy is the only discipline in medicine where the sole purpose is to care for the human spirit during illness. However, many people without specific training in chaplaincy – clergy and lay people from community religious organizations, family, friends, etc. – also provide care for the spirit. Studies will need to be clear what kind of support by whom is being examined; some have already noted comparisons between the impacts of care from different categories of people.^v

Finally, spiritual care research could focus on any type of illness or on specific types. There may be differences in spiritual response depending on the setting. For instance, it is readily imaginable that the spiritual issues in pediatric oncology are distinct from those in an obstetrics ward, those faced by Alzheimer's disease, and those faced by heart disease, and so on. Furthermore, some disciplines have a greater expectation that spiritual care is a necessary part of whole person care. It is partly for this reason that palliative care, a discipline founded on the expectation that spiritual care is an integral part of what a person needs,^{vi} has drawn some researchers in chaplaincy care.

The questions that follow are in general most relevant for the narrower foci identified in the above five distinctions.

What happens in the human spirit when it is challenged by illness?

If chaplaincy research is to offer chaplains guidance in how to offer effective care, it is critical to understand what happens to the human spirit in its various forms and states. In addition, one can learn about the nature of the human spirit from what happens to it when it is challenged. This is true of most things we study. If we watch how they change under varied circumstances, we learn about their nature. Chaplains routinely observe how people in crisis have a more apparent spiritual life; there is a sense of their raw humanity without the usual defenses and facades. They are present, aware, and open. People in this setting are often more impressionable, more open to learning, and they remember things that might otherwise not have been recalled. Often they have a sense for what really matters in life. They may be more open to guidance or support in their spiritual lives than usual and they are often appreciative of the listening, care and connection that chaplains offer. Many are also open to creating new meanings, to realizing new attitudes, and new ways of experiencing self-efficacy.^{vii} While most chaplains would affirm this, research into what this openness tells us about the human spirit is sparse.

For instance, researchers may be able to discern if there are phases in a person's spiritual response to illness challenge analogous to the psychological phases of preparedness for behavioral change or phases of grief and resolution.^{viii,ix} If such phases can be identified, it may help chaplains to have a mental map of where a person might be at any given moment on a trajectory of response so that chaplains can offer more relevant care interventions.

What are the ranges of human spiritual capacities?

Research into what works in chaplaincy care can be conducted to some extent empirically without reference to the underlying model or assumptions people have about the nature of the human spirit and its needs. However, the nature of the care that is offered depends on a working model or set of assumptions by the chaplain and by the patients and family or community members involved. Therefore, in the end, research into chaplaincy that does not explore what these assumptions are will be limited to descriptive and epidemiological types of research. Testing hypotheses derived from a model may yield information about how human beings vary as they face spiritual challenges caused by illness. Researchers may be inclined to take up questions such as:

- Is the human spirit similar across all human groupings, but differently rendered in our diverse traditions? and/or
- Is the human spirit different among different people, perhaps in a similar fashion to current realizations that the human intellect has a variety of types (some are mathematically inclined, others have poetic ability, and yet others have emotional intelligence, etc.). As noted above, perhaps there are types of spiritual disposition among people that are genetically or epigenetically similar. If this can be ascertained, it could guide chaplains in their care.

How can we (humans) know?

Discussions about the nature and methods needed for chaplaincy research are contained in this volume. How humans know what we know is not a matter of confident consensus. One question about how we can know focuses on *who to ask*. For instance, one discussion among chaplaincy researchers is about whether the *presence* that chaplains bring to their encounters with patients and families is a part of the process or the desired outcome or both; the answer may depend on who is asked. It may be that for doctors and nurses the presence in the encounter is a matter of process that aids the outcome they seek such as reduced anxiety. However, for the patient, perhaps the presence is the experience he or she seeks and so it is the outcome for him or her.

Another question about how we can know focuses on *what to assess*. Biomarkers (stress hormones, blood pressure, etc.) may also be a way of knowing that is relevant in chaplaincy research. Biomarkers are increasingly used to monitor manifest physical correlates of spiritual experience.^x However, how and how well the two are linked is not clear. If a person's spiritual connectedness is in question, perhaps a better way to 'know' is to chronicle personally meaningful encounters, examine body language, or perhaps it is to ask people to describe their subjective experience. In all likelihood, the human spirit is not so simple that a few validated measures will suffice to research it rigorously. Again too, as

noted, perhaps there are ‘genotypes or phenotypes’ in spiritual matters that may eventually be helpfully assessed.

Which research methodologies are good fits for chaplaincy research is also a topic of discussion: are the methods used in other qualitative and quantitative medical research sufficient for chaplaincy research or are additional methods or adaptations of methods needed? Some of the best methods and measures for chaplaincy research are addressed elsewhere in this book, but it may well also be the case that, as the field develops, better methods and measures will emerge that are uniquely well suited to the topics in question.

Should religious traditions and/or inclusive frameworks be used for research?

One of the gifts of post-modernity is the worldview that many perspectives may be valid and co-exist contemporaneously in all their diversity. This multiplicity of viewpoints is something that the U.S. and some other countries seek to celebrate, including matters of religion. The frameworks of specific religious traditions as well as more general and inclusive frameworks may both be valuable for research. The field of chaplaincy research could benefit from both. No one model or framework for understanding spirituality, spiritual care, assessments, interventions, and outcomes is likely to explain human beings in all of their granular diversity throughout the world and time. Consider the huge difference between Eastern and Western medicine and thinking about health, for example. It may be that important research questions can only be addressed from within a specific religion or world view or a particular population, culture, or geographic setting. Other questions that relate to universal conditions of existence (such as mortality) may be best studied in inclusive ways with inclusive models and inclusive population definitions. The development and refinement of testable conceptual models^{xi} and clinical models (e.g. spiritual assessment^{xii} and intervention models), both theoretically and empirically derived, that represent both inclusive and diverse specific theological and philosophical perspectives is important. Hearing diverse perspectives from a range of settings—geography, culture, gender, race, ethnicity, sexual orientation, etc.—will generate some of the needed specificity and bring insight into what can be generalized.

What content areas belong in chaplaincy care?

In the Western world, spiritual care research demonstrates that patients find chaplain visits helpful;^{xiii} valued activities include prayer and listening;^{xiv} chaplains included on interdisciplinary teams are associated with improved spiritual well-being in palliative care patients;^{xv} and chaplain visits are related to less aggressive care and better quality of dying.^{xvi} However, some findings suggest that these impacts may not be sustained.^{xvii} Importantly, chaplaincy care is not well enough studied to know, but, like other fields that are not systematically designed for uniformity; chaplain practices are likely to be quite varied depending on the chaplain. Research is beginning to emerge that documents what diverse chaplains do when they provide care.^{xviii,xix} However, this is still new and even the words to describe types of action or inaction that chaplains choose are just emerging as a unifiable vocabulary.

Additional topics that researchers will likely want to address in the immediate future include identification of patients' and (separately) families' desired outcomes of chaplain care. These will likely vary with settings (e.g. acute care, long-term care, and outpatient settings) and different populations.

What screenings, assessments and interventions belong?

Spiritual screening and spiritual history-taking, distinguished from spiritual assessment, may be conducted by disciplines other than chaplaincy. For example, FICA and SPIRIT have been widely used by physicians as screening tools to gather data about patients, their history, needs and resources.^{xx} Spiritual screens and spiritual histories have been extensively studied and employed in disciplines, such as nursing.^{xxi} This is quite different from spiritual assessment and intervention, which is the purview of professional chaplaincy.^{xxii} Spiritual assessment is a process of diagnosing the patient's spiritual need(s). The exploratory nature of the care is such that addressing perceived needs with chaplaincy interventions and discovering the patient's response is part of the continuing assessment that occurs throughout the care process.

The field of chaplaincy requires research to develop an evidence-based practice of assessments and interventions that are effective with different patients. Researchers are divided on the question of whether effectiveness varies by spiritual need, faith tradition, culture, disease, etc. Different research methods may be required to pursue a full range of effective practices. Chaplains will need to become research-literate and involved in the practice of research to grow the field.

How to identify what works (what outcomes to study)?

Scales and measures exist in chaplaincy care research.^{xxiii} However, those that have been well validated are still fewer than in other fields. More are sorely needed, including the need to tailor measures to specific populations and settings.

The evaluation of chaplaincy through the use of research based Spiritual Assessment, Intervention and Outcome Models is one way to identify what works. As Peery noted, "Outcomes are simply the observable results of our care."^{xxiv} 'The Discipline' by Art Lucas was the first spiritual care model to establish defined outcomes, as well as assessments and interventions.^{xxv} A later outcome oriented chaplaincy model, which is distinguished by scientific research based upon it, is Spiritual AIM (Assessment and Intervention Model).^{xxvi} More such models with outcome measures are needed to reflect the full diversity of spiritual needs and possibilities for spiritual care.

How to study quality in health care chaplaincy?

Research into quality of services is an entire discipline within medical research. Such a sub-discipline within chaplaincy research will need to develop. One type of research looks at variation in practices and through information on what varies, considers what needs to improve and what can improve. Other types of research select services, comparing an intervention with a control, and then looks at desired outcomes to see what works best. Yet others use quality improvement methods which allow for the reality that services cannot

always be randomized into intervention and control groups. Using small changes and following a primary measure in 'run charts' over time, a good deal of information can be gathered and adjustments made to the service in question until the goal has been achieved. All these methods seem applicable to chaplaincy studies, but few have been used in this area.

Before reaching the capacity to conduct such standard, rigorous studies, chaplaincy research may do well to gather best practices and common adverse events through the associations of the discipline – for instance, the Association for Professional Chaplains, the Association for Clinical Pastoral Education, the National Association for Jewish Chaplains, and the National Association for Catholic Chaplains. A related line of inquiry may involve getting information from the certifying bodies for professional chaplains about why some people fail certification committees and addressing those issues in the training of chaplains.

How to assess chaplaincy need and capacity development

A remarkable feature about hospital chaplaincy is that people often have the perception that chaplains have 'all the time in the world' to sit and talk with people, as contrasted with busy physicians, nurses, and social workers. In reality, chaplains in a hospital setting tend to be very few in number and to see a very large number of patients in any given day. Possibly chaplains have a remarkably developed capacity for listening that makes people feel the chaplain has plenty of time. Or possibly there is great unmet need. Research into the needs that patients and families have and how to develop the workforce capacity to optimally meet that need is much needed.

Conclusion

This chapter has outlined ten areas of inquiry that seem to the authors to be ripe for research. We feel they are ripe for research in the sense that they would help define this emerging and much needed discipline of chaplaincy research and would help provide chaplains with empirical guidance for the provision of safe and effective care. Currently, chaplaincy is one of the disciplines in healthcare that provide much needed, appreciated, and impactful care without the benefit of much empirical guidance. While research into these ten areas of inquiry would likely benefit a good deal, other areas undoubtedly exist. Rigorous research into chaplaincy care is important and greatly needed by people facing illness every day.

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ⁱⁱⁱ I'd like to reference the Convocation presentation I did which I think was written up in one of the HCC outlets. LE

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