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Expertise, Mediation, and Technological Surrogacy: A Mixed Method Critical Analysis of a Point of Care Evidence Resource

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A thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Library & Information Science

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Abstract

While evidence-based medicine (EBM) is a widely accepted feature of contemporary medicine, the applicability of evidence to clinical practice is often questioned. The proprietary system UpToDate has emerged as one of the most heavily used point-of-care evidence resources. While some existing research evaluates UpToDate's utility and features, no critical analysis of its content exists. This thesis is a multiple, mixed methods case study examining how evidence, authors, and the patient-physician relationship are situated in UpToDate. A descriptive analysis of the type and features of the cited evidence, as well as an overarching textual analysis of the clinician and patient information entries was completed for seven cases (conditions), chosen to represent different levels of certainty (with respect to diagnosis and/or treatment), medicalization, and contestation (with respect to the 'legitimacy' of a condition). Cross-case analyses were also conducted. Data analysis was informed by the field of Science and Technology Studies, which recognizes the study and development of science and technology as social and interactive processes. Findings indicate that, in the absence of explicit and transparent guidelines, authors who contribute to UpToDate adhere loosely to the general principles of EBM. The content of entries suggests that UpToDate acts not only as an evidence provider but as a 'mentor' and 'curbside consultant' to users, functioning as a technological surrogate for in-person interactions. UpToDate is an attempt to bridge a real gap between evidence and practice, however, this study brings to light signs of a 'hidden curriculum' embedded in this clinical tool. While on the surface UpToDate is designed to support 'scientific' practice by incorporating clinical judgment, expertise, and advice about tailoring care for patients with research evidence, it may also perpetuate physician-centred, rather than patient-centred, care, and focus on the "art" rather than "science" of medicine, seemingly contradicting EBM's core purposes.

Keywords:

Evidence-Based Medicine; UpToDate®; Medical Education; Patient-Centred Care; Science and Technology Studies; Critical Analysis; Multiple Case Study

Acknowledgements

First, I must thank my son, Otis, for seeing me through to the end. When writing my dissertation, I would tell him that I had been working on this homework since before he was born. He never questioned what homework could possibly take more than eight years, and always pushed me to persevere. He was the most consistent part of my life through this degree. Day in and day out, Otis kept it all in perspective: He made sure that I always knew that there was so much more than this, and never let me believe that it was all just too much.

Thank you to my parents who instilled in me that any level of education was within my reach. My dad stepped in at the right moment with the right words for the final push. My mom took the brunt of my lows, my fears, and my frustrations throughout the degree. Without my mom, those very things would have taken ahold of me: She was there to listen, to absorb, and to encourage. Also thank you to two inspiring women: my sister Nancy and my aunt Linda, who never doubted that a PhD was possible. My family's love, belief, and pride in me was invaluable throughout this process.

Dissertation acknowledgements often include a shout out to the librarians who have helped them generate the research. But since I am myself a librarian my gratitude runs deeper than searches, interlibrary loans, or study carrels. I have deep gratitude for the friendship and support that my colleagues have provided me through this process. I have had the privilege of working with a whole gaggle of very special librarians and each one deserves so much more than merely a mention: Thank you, Kristin Hoffmann, Cathy Maskell, Courtney Waugh, Heidi Jacobs, Tamsin Bacon, Scott Cowan, Karen Pillon, Virginia Wilson and many, many other very special bibliophiles. I also thank the medical students that I had the pleasure of teaching and learning from over the last eight years. They inspired so many of the questions within this dissertation, and always kept things real.

Sincere gratitude to my dear friends in Saskatoon who lifted me up through my sabbatical year and made sure that it was not only productive but also filled with love and laughter. A special mention to my dear friend Krista Zerr who is an inspiration second to none. She never let me forget that I was doing something big, something special—coming from her that meant so much.

And thank you to Michelle, who was an inspiration to start and a vital support to the very finish. She stepped in to listen to ideas and proofread my writing far beyond what would be expected. Michelle watched this dissertation grow, witnessed my progression, and repeatedly told me that I was getting better. Her heart and her mind contributed to that ‘better,’ and I would never have thought that this was possible without her.

I must also extend my thanks to the University of Western Ontario and the Faculty of Information and Media Studies for providing an amazing program and accommodating part time studies. As well, thank you to my fabulous team of examiners, Drs. Lorie Donelle, Pamela McKenzie, Jacquie Burkell and Trish Greenhalgh. To sit around the table of six amazing women scholars discussing this work was an amazing experience. Thank you all.

While my friends and family cheered and supported from the sidelines, it was my two co-supervisors, Nadine Wathen and Roma Harris, who were there in the thick of things. Nadine and Roma not only stuck with me through the rough times of my degree, but also through the rocky personal ones. They had to hang tough until I could regroup and re-engage multiple times. I had the honour of being the last student supervised by Roma. She stuck with me long past her retirement and I will forever be thankful for the guidance of these two scholars. These two women were amazing role models in scholarship and life. I could not have asked for better supervisors.

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Chapter 1: Introduction and Literature Review

Introduction

The breadth and depth of medical evidence has expanded greatly in the last half-century. To address the information overload reported by physicians and healthcare practitioners (Bennett, Casebeer, Kristofco & Collins, 2005; Cook, Sorensen, Wilkinson & Berger, 2013), information resources and tools that distill and summarize clinical evidence have been developed. These tools are rapidly becoming the go-to information sources for clinicians who are integrating evidence into their clinical decision-making. UpToDate is reported to be the most popular summary resource currently used by doctors (Cooper & Elnicki, 2011; Duran-Nelson, Gladding, Beattie & Nixon, 2013; Ensan, Faghankhani, Javanbakht, Ahmadi & Baradaran, 2011; Hoogendam, Stalenhoef, Robbe & Overbeke, 2008; Leff & Harper, 2006; Peterson, Rowat, Kreiter & Mandel, 2004; Schilling, Steiner, Lundahl & Anderson, 2005). By using tools such as UpToDate, physicians who may previously have struggled to find applicable and usable answers by consulting original research publications (Chambliss & Conley, 1996; Gorman, Ash & Wykoff, 1994; Hoogendam et al., 2008; Thiele, Pairo, Scalzo & Nemergut, 2010) are now able to find more concise and seemingly certain answers to their clinical questions (Campbell & Ash, 2006; Ensan et al., 2011; Hoogendam et al., 2008).

The content of UpToDate is developed by experts in the field of clinical medicine with the goal of articulating their recommendations to fellow clinicians. While clinical science is often presented as objective and precise, the actual practice of medicine relies heavily on judgment and reasoning (Turpin & Higgs, 2009). Likewise, the creation of content for UpToDate and the related decisions regarding the inclusion and exclusion of certain

information resources into summary resources derive from thoroughly social and interactive processes. Using a Science and Technologies Studies (STS) lens, in which technologies and social practices are understood to be deeply connected, this study is an attempt to discover what information is lost and what information is privileged during the distillation of traditional health information sources, such as clinical studies and systematic reviews, into point of care resources, specifically, UpToDate. While the evolution and distillation processes which occur when the results and conclusions of original studies are summarized into systematic reviews have been well explored, the process through which clinical research is distilled into highly synthesized summary levels of evidence for clinical practice is not well understood. The study reported here is an attempt to begin to address this gap (Figure 1 represents the area of research interest). Further, while summary resources, like UpToDate, have been evaluated repeatedly in terms of their timeliness, breadth, depth of coverage and the level(s) of evidence included; a critical analysis of the distillation and summarization processes has yet to be undertaken. This study is one of the first systematic critical analyses of the most popular resource used in clinical practice and represents an attempt to understand the value and meaning of UpToDate within medical practice. As such, this study will be of interest to medical librarians, clinicians, health educators and product developers, as well as STS scholars.

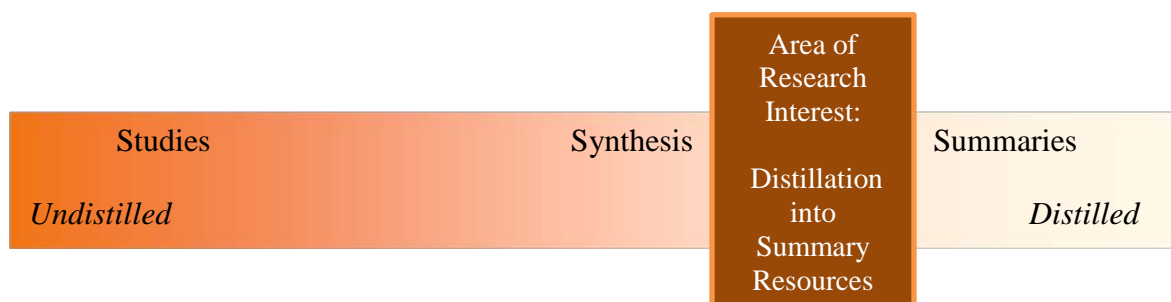


Figure 1: The Continuum of Evidence Summarization: Area of Research Interest

Literature Review

Evidence-Based Medicine

Prior to the evidence-based medicine movement, clinicians relied heavily on “the art of medicine” for medical decision-making. This comprised a knowledge base combining a clinician’s experience and the collective experiences of the profession learned primarily through apprenticeship and modeling (Daly, 2005). The art of medicine was the dominant approach to medical care until the 1970s, when its validity began to be questioned. The art of medicine was considered, in part, to blame for the field of medicine being fraught with inconsistencies, overspending, and unproven and patriarchal health care practices. The movement towards evidence-based medicine was, in part, an effort to downplay the ‘artistic’ practice of medicine to a model of consistent clinical care based in science.

The ways in which evidence-based medicine is enacted in practice have evolved from its roots more than four decades ago. Archie Cochrane’s 1972 text, *Effectiveness and Efficiency: Random Reflections on Health Services*, laid the foundation for evidence-based medicine. In this text, Cochrane’s goals were connected to his commitment to social justice and his belief that limited health resources should be used to provide equitable access to those treatments shown to be most effective through high quality research studies (specifically, the randomized controlled trial, or RCT). Cochrane’s early text provided the seeds of what has now evolved into the Cochrane Collaboration and, more broadly, evidence-based medicine. Building on his early writings, in 1979 Cochrane called for the medical profession to create an organized collection of summarized RCTs (Cochrane, 1979). A decade later, Cochrane made the first reference to a systematic review of RCTs in obstetric care, referring to the review as “a real milestone in the history of randomized trials and in the evaluation of care” (Cochrane, 1989, p. 3). He urged health practitioners to continue this

practice in support of what was later termed evidence-based medicine. Five years following Cochrane's death in 1993, the Cochrane Collaboration, a not-for-profit volunteer organization committed to the systematic organization of medical research, was established and over time many of his ideas came to fruition.

Following soon after the development of the Cochrane Collaboration, in 1995, Frank Davidoff and his colleagues launched the journal *Evidence-based Medicine* and provided the following description:

Evidence-based medicine is rooted in five linked ideas: firstly, clinical decisions should be based on the best available scientific evidence; secondly, the clinical problem, rather than habits or protocols, should determine the evidence to be sought; thirdly, identifying the best evidence means using epidemiological and biostatistical ways of thinking; fourthly, conclusions derived from identifying and critically appraising evidence are useful only if put into action in managing patients or making health care decisions; and, finally, performance should be constantly evaluated. (Davidoff, Haynes, Sackett & Smith, 1995, pp. 1085-1086)

Davidoff et al. provided the first and most comprehensive definition of evidence-based medicine (Cohen, Stavri & Hersch, 2004). One year later, Canadian physician David Sackett and his colleagues (1996) formalized and defined the term Evidence-based Medicine (EBM) as “the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients” (p. 71). It is this definition that is commonly used and operationalized. EBM is intended to bring a scientific foundation to clinical work and to assist physicians to apply results from the vast amount of medical research to clinical practice. As a result of the EBM movement, publishers, clinicians and authors have developed new types of information tools and resources, including systematic reviews and the very popular electronic point of care information tools, including UpToDate¹.

¹ Other summary resources available include DynaMed and FIRSTConsult

STS Perspective: EBM as a Technology of Medicine

Science and Technology Studies (STS) is a diverse and innovative field of scholarship in which numerous fields of study, including sociology, history, philosophy, anthropology, technology, medicine and information science, intersect. STS provides a unique and much needed perspective on information technologies. Outside STS, technologies are often conceived of as relatively straightforward and practical applications of science; however, scholars of STS challenge this assumption and examine science and technology as social activities. STS scholars assert that while scientists and engineers use the material world in their work, their work is not merely translated into knowledge and objects by a mechanical process, but rather through thoroughly social and interactive processes (Sismondo, 2010). A necessity of scientific development is the sharing of research results within and between scientific communities. Research can be challenged, defended, supported, or built upon—but all scientific sharing and exchange is social and interactive. Similarly, the process of distilling the body of clinical research into a usable and summarized format is not a mechanical or neutral process but rather a process driven by social interactions and personal judgment. Clinical experts make choices during the summarization process about what information to include and what information to discard. These choices are made not only at the resource level (what clinical studies to include or reject) but also at the content level (what information that was reported in the clinical research to privilege enough to include in these short summaries). The type of information that is included or excluded is significant because summary resources are developed as a means to convince or at least explain to physicians the best approach to clinical care.

STS provides an important and helpful lens to study the development, design and use of information technologies. Information and STS scholars, Bowker and Star (2000),

explored the ways in which information is formally and informally categorized and classified. Their observations about the informal and invisible categorizations of information that exist in communities of practice are helpful to understand the development and creation of summarized resources. Systems that are used to organize knowledge and information shape what we know and how we understand our environment. Bowker and Star suggest that communities of practice (or groups of individuals who conduct activities together and share items, processes and routines associated with these activities) often share ‘naturalized’ systems of categories of information. Naturalization occurs when individuals and communities forget about how a system or object is created and lose sight of the situated nature of such a system. Members of communities often forget that the meanings of such systems or objects embedded in their activities are local in nature. The more entrenched individuals become in a community, the more likely they are to forget that their own categories may seem odd or out of place to those outside the community. Bowker and Star use the example of the anachronistic “cut and paste” metaphor used for using a mouse, selecting text, and digitally moving the text from one space to another. A basic medical example is physicians’ routine use of the word negative to mean ‘normal.’ For example, “your blood test came back negative for mono”. Conversely, ‘positive’ is used to imply an abnormal result, which signifies bad news. Bowker and Star suggest that infrastructural technologies “become a form of collective forgetting, or naturalization, of the contingent, messy work that they replace” (p. 299). As these systems become increasingly embedded into communities, they also become more invisible and more potent. The exploration of such classifications is important because they may have significant political and ethical dimensions and consequences. In this study, evidence selected by the community of physicians who create and develop the summarized information for UpToDate was

examined. The types of research and evidence selected as references for UpToDate content, as well as what content is selected for inclusion in the UpToDate entries, were investigated. In addition to gaining an understanding of the information included in the evidence summaries, some of the features of the evidence not included in the entry were identified. As Bowker and Star point out, there is value in understanding what and who are left out or remain invisible within a community's information categories.

When problems of knowledge and practice arise in healthcare, technological solutions are often advocated (May, Rapley, Moreira, Finch & Heaven, 2006). Technologies such as the electronic health record, patient blood pressure monitoring devices, diabetic insulin and blood glucose meters are technological solutions for problems encountered in health care and these technologies have been investigated by STS scholars. Similarly, the tools that deliver health evidence to professionals, as well as the evidence itself, are technologies that also warrant attention using an STS lens.

May (2007) has examined information innovations in clinical care. He suggests that while autonomy and control over knowledge is a hallmark of professionalism, the current information landscape in medical practice poses two challenges to physicians' autonomy and control over their knowledge. First, because medical knowledge is continually expanding, the body of medical knowledge is impossible to master and within this massive corpus of knowledge are variations and contradictions that bring about uncertainties and inconsistencies in practice (Haynes, 2001). Second, physicians are faced with health policies and practices, such as patient centered care², that increasingly rest on the assumption that patients are active consumers of health information and capable of developing their own

² The IOM (Institute of Medicine) defines patient-centered care as: "Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions".

expertise, assessing and choosing treatment options, and managing personal illness trajectories (May, 2007). It is in the context of these two attributes of the health information landscape that evidence-based medicine and its related tools are proliferating, including summary sources such as UpToDate.

Circuit of Culture. Scholars of Science and Technology Studies have an interest in how technologies acquire cultural meaning, shape our environments, and enact the cultures in which they are created. One model which is helpful in understanding the cultural meaning and value of an object is Hall's Circuit of Culture. The Circuit of Culture framework is made up of five coexisting processes: Representation; Production; Consumption; Identity; and Regulation, which are all connected and interconnected (du Gay, Hall, Janes, Mackay & Negus, 1997). The resulting Circuit provides a means to understand the cultural text or artefact through examination of "how it is represented, what social identities are associated with it, how it is produced and created, and what mechanisms regulate its distribution and use" (du Gay et al., p. 3). Originally used to understand the cultural meaning of the Walkman, the Circuit of Culture provides a framework to garner a greater understanding of the shared meaning of textual objects and technologies, like UpToDate, within contemporary medical and information environments (Hall, 1997).

Resistance to and Acceptance of EBM

Evidence-based medicine garners both significant support, and critique. The professional and scholarly body of literature addressing evidence-based medicine is replete with voices from both positions. Both sides are passionate, as evidenced by the zealous language used: those who celebrate EBM often describe it using terms of religion and salvation, while those who are critical sometimes rely on radical political and authoritative language to support their claims.

Resistance to EBM. Published literature highlighting the shortcomings and limitations of EBM emerged quickly after Davidoff and colleagues first defined it in 1995 (Feinstein & Horowitz, 1997; Horowitz, 1996; Maynard, 1997; Naylor, 1995). The number of scholars who express criticism and concern over the adoption of EBM has continued to grow in the last two decades (Freshwater & Rolfe, 2004; Goldenberg 2006, 2010; Green, 2000; Holmes, Murray, Perron & Rail, 2006; Staller, 2006).

In a 2004 review, Cohen et al. identified five themes found in EBM critiques : 1) EBM is based on empiricism, misunderstands or misrepresents the philosophy of science, and is a poor philosophic basis for medicine; 2) the definition of evidence in EBM is too narrow and excludes important information; 3) the usability and application of evidence to individual patients is limited; 4) EBM threatens the autonomy of the patient and physicians' relationship; and 5) there is no evidence that EBM is effective, and therefore, EBM itself is not evidence-based (*re-ordered from Cohen et al.*). These themes, described by Cohen et al. a decade ago, continue to be explored in current publications. Of particular interest in current research are the first four themes:

EBM is based on empiricism, a poor philosophic basis for medicine. One of the foundational concepts of EBM is that studies that 'count' as evidence should adhere to the guidelines of positivistic quantitative research and provide an evidence base that minimizes bias and attempts to generate an objective observer. However, EBM conflates the aim to reduce bias and ensure objectivity with the notion that these qualities are actually achieved in empirical research (Cohen, Stavri & Hersh, 2004). As a result of having the focus on observation rather than understanding as the basis of medical knowledge, EBM is criticized for disconnecting medicine from its scientific roots. Medical practitioners also condemn EBM for drawing their focus away from understanding physiological processes and the

mechanisms of disease towards evaluating the statistical purity of studies (Charlton & Miles, 1998). The objectivity, evaluation, and bias inherent in observation gives rise to the criticism that the epistemological approach of empiricism on which EBM is based is inappropriate for medicine and draws attention away from more scientific and holistic understandings.

The definition of evidence in EBM is too narrow and excludes important information. The notion of ‘best’ evidence is a key concept in all definitions of evidence-based medicine. EBM ranks and grades evidence with the goal of excluding *poor* evidence and including only the *best* evidence. EBM has identified and defined the best study design for the array of clinical questions including diagnosis (cross sectional study), prognosis (cohort study), aetiology (cohort study); however, the preeminent example of this classification of research quality is the randomized controlled trial (RCT) as the *best* evidence for the evaluation of interventions. The evidence defined as *best* is given precedence – in a literal hierarchy - over all other types of evidence such as ethnographic studies, qualitative research, or clinical experience/case study/anecdote.

The criticism of the RCT is longstanding. In 1991, Alvan Feinstein accused clinical epidemiologists of being obsessed with RCTs, assuming that the methodology possesses a superior form of truth, rather than recognizing it merely as an effective method for assessing whether treatment A is better than treatment B (Daly, 2005, p.104). The restriction on the types of results considered to be ‘evidence’ within specific types of research designs, namely the RCT, has given rise to multiple critiques. First, the RCT can only answer a limited number of types of questions. Research topics, such as quality of life and personal wellness in relation to treatment protocols, require more subjective evaluation (qualitative methods or natural observation) and cannot be effectively investigated by the methods that EBM deems ‘best’ (or even acceptable). Second, when epidemiological and statistical methods are applied

to clinical trial results, the individual patient results are averaged out, which can lead to the exclusion or disregard of important clinical details found within the data (Cohen et al., 2004). Lastly, the narrow definition of evidence deemphasizes other types of clinically relevant knowledge, including the patient and/or professionals' qualitative understanding, knowledge and experiences with respect to medical interventions and related psychosocial factors.

Critics of EBM suggest that the notion of *best* evidence, a fundamental element of all definitions of evidence-based medicine, has the potential to eliminate, or at least discount, other potentially important forms of knowledge. In other words, the selection of specific evidence for EBM does not capture the 'whole story' of what occurs in clinical practice.

The usability and application of evidence to individual patients is limited. The ability to effectively apply the results of the *best* evidence to specific patients has been called into question. EBM requires clinicians to begin by utilizing "knowledge derived from large trials, or from systematic reviews and meta-analysis—and translating this knowledge about collectivities into an individual plan for a specific patient" (May et al., 2006, p. 1026). However, the application of the results of clinical trials to clinical practice is not straightforward because, unavoidably, the patients who comprise the subject base of a study do not precisely reflect the population seen by physicians in their clinics (Daly, 2005). RCTs enroll a restricted population: often those expected to be responsive to the treatment or intervention being evaluated (Feinstein & Horowitz, 1997; Greenhalgh, Howick & Maskrey, 2014). Tonelli (1998) asserts: "to the extent that *relevant differences* between individuals cannot be made explicit and quantified, an epistemologic gap between research and practice must remain" (p. 1238). The heterogeneity of the population as well as the complexity of the human body are substantial hurdles in the application of evidence to the individual patient.

Further, when applying research that evaluates treatment options, it is the *average*

that is considered for each individual patient; however, “average” may not suffice in many situations (Greenhalgh, Howick & Maskrey, 2014). Clinicians themselves do not consider the application of a recommendation based on an average derived from the results in a select population sample acceptable to answer the questions presented by the unique and complex predicaments of their patient population (Greenhalgh, 2002). Greenhalgh and Weiringa (2011) argue that “knowledge obstinately refuses to be driven unproblematically into practice” (p. 501) because clinical practice is much more than a series of clinical questions answerable by clinical trials. In spite of these concerns, *The Users’ Guide to Medical Literature: Essentials of Evidence-Based Clinical Practice* encourages clinicians to consider the question: “is there some compelling reasons why the results do *not* apply to the patient?” (emphasis added, Guyatt, Rennie, Meade & Cook, 2008, p. 103) and continues its guidance to physicians by suggesting that clinicians “usually will not find a compelling reason, and most often you can generalize the results to your patient with confidence” (Guyatt et al., 2008, p. 103). While questions of whether or not there is a compelling reason to *not* apply the evidence, this approach turns a blind eye to what STS scholars Zuiderent-Jerak and Jensen refer to as the “radical indeterminacy of the actor” (2007, p. 232). In their discussion of ‘intervention’ in STS studies, they remind us that interventions, like medical treatments, are themselves risky, complex and partly uncontrollable process(es), given that patients themselves are largely unpredictable.

EBM threatens the autonomy of the doctor and the patient. Critics also suggest that the autonomy of both the doctor and the patient is jeopardized by EBM in multiple ways (Cohen et al., 2004; Holmes et al., 2006; May, 2007), and therefore the relationship between the two can be compromised. Since its inception, EBM proponents have fought the notion that it is merely ‘cookbook medicine’, and that it restricts patients’ and doctors’ choices in

care (Tonelli, 1998). Those who conceived of EBM are adamant that it is not about restrictions, however as Cohen et al. point out “the originators of EBM have no control over how EBM is used or deployed” (p. 41). EBM’s focus on statistics has been condemned for inflicting “the weight of numbers down on [clinical decisions],” perhaps restricting or influencing the choices that are made (Cohen et al., 2004, p. 40). The *weight of numbers* is not only a consequence of physicians’ review of evidence in the literature, but also as a result of organization-imposed standards. EBM critics suggest that evidence-based medicine has provided the groundwork for enforcing guidelines intended to control clinical practice and, in some instances, to contain costs.

The development and creation of Clinical Practice Guidelines (CPGs) has been an area of interest to STS scholars, in particular their role in monitoring, regulating, and standardizing medical practice. May (2007) argues that, increasingly, medicine and the clinical interaction are becoming an “intensively governed terrain” (p. 29). Guidelines, protocols, standards and algorithms can be seen as a series of directives that prescribe what should be done in each clinical instance (Sepers & ter Meulen, 2005). Some suggest that, by prescribing the interventions that physicians are to use, there is an intrusion of the interests of corporate entities, both public and private, into the clinical encounter. Increasingly, the clinical encounter is undergoing surveillance, regulation and governance, with the goal of standardizing medical care. This type of management and control also makes way for performance-based medicine to be implemented whereby physicians can be rewarded for observing guidelines set by the organization(s) for whom they work or by whom they are paid (and, presumably, penalized when they do not) (Lewis and Orland, 2004). STS scholars frame the regulation and standardization that are a result of information systems and technologies as “technogovernance” (May, 2006, p. 1022).

In the last decade, critiques of EBM have become increasingly political, with a focus on the systemic effects of standardization. Canadian nursing scholar David Holmes and his colleagues describe the power that EBM imposes on doctors and patients in the clinical encounter as “a good example of *microfascism* at play in the contemporary scientific arena” (Holmes et al., 2006, p. 180). In a later article, they argue that EBM adopts

corporate models of efficiency and accountability, right down to a corporate lexicon; EBM relies reductively on quantitative evidence in which RCTs are fetishised; EBM denigrates other forms of knowledge, including clinician experience and patient testimony; finally, EBM evacuates the social and ethical responsibilities that ought to distinguish health care professions, such as nursing (Murray et al., 2008, p. 27).

Although Holmes frames the limitations of evidence-based medicine in an extreme fashion, even EBM’s more moderate critics cite similar concerns.

Acceptance of EBM. EBM’s proponents argue that it addresses overspending, inconsistencies, and unproven and patriarchal health care practices. By enacting EBM’s tenets, physicians no longer need to rely on intuition and experience to provide clinical care. The resources (studies, reviews, summary resources) and tools (critical appraisal techniques) that have evolved from the EBM movement represent attempts to give physicians new ways of providing the best clinical care supported by the best possible evidence. Daly (2005) explains:

Instead of having to face the dishearteningly subjective task of basing their decisions on intuitions we could not explain (Sackett et al. 1999, p. ix), clinicians had available to them a science that generated objective knowledge of effective interventions based, where possible, on the results of unbiased experiments (p. 1).

By directly applying the knowledge gained from the best available evidence, such as the “unbiased experiments” that Daly (2005) mentions, EBM is heralded for promoting consistency in treatments, contributing to the establishment of national standards of patient care, ensuring optimal patient outcomes, and measuring performance in medical practice (Lewis & Orland, 2004). EBM supporters argue that positive outcomes for patients include

the: “[prevention of] numerous avoidable deaths and injuries while improving the quality of life for millions of individuals” (Roberts & Yeager, 2004, p. iv). Such was the enthusiasm for EBM that Feinstein and Horwitz (1997) wrote that EBM had acquired the “sanctity often accorded to motherhood, home, and the flag” (p. 529). Indeed, *The New York Times* hailed the “revolution” of EBM as one of the most influential ideas of the year (Hitt, 2001) and, in 2006, Borry and Schotsmans described EBM as a moral imperative.

EBM and Medical Education

The conversation regarding the applicability and appropriateness of evidence-based medicine is clearly polarized; nevertheless, EBM has survived much of the criticism that has been levelled at it and is now well integrated into undergraduate and graduate medical curricula worldwide, as well as part of continuing medical education programs for practicing physicians (Guyatt, Cook & Haynes, 2004; Green, 2000). In 1992, the Evidence-based Medicine Working Group defined evidence-based practice in terms of four basic competencies: (1) the recognition of a patient problem and construction of a structured clinical question; (2) the ability to efficiently and effectively search the medical literature to retrieve the best available evidence to answer the clinical question; (3) the ability to critically appraise the evidence; and (4) the ability to integrate the evidence with all aspects of individual patient decision making to determine the best clinical care for the patient. In order to train effective evidence-based practitioners, EBM proponents advocate focused educational interventions targeting each of these specific skills (Ghali et al., 2000). Currently, research efforts in EBM education focus on building evidence to demonstrate the effectiveness of teaching EBM in undergraduate and graduate medical curricula (Dorsch, Aiyer, Meyer, 2004; Green, 2000; Hatalla & Guyatt, 2002; Vidyarthi, Kamei, Chan, Goh & Ngee, 2015; West, Jaeger & McDonald, 2011). EBM teachings appear to have a positive

impact on students' knowledge and perceived value of evidence-based medicine. However, systematic reviews suggest that EBM education does not result in a change in behaviours and outcomes in clinical practice (Coomarasamy & Khan, 2004; Norman & Shannon, 1998; Young, Rohwer, Volmink, Clarke, 2014).

Clinical relevance and biological focus. The direct connection of EBM to clinical practice is appealing for many, especially medical students who are eager to embark on their medical careers and identify themselves as physicians. Evidence-based practice places student learning out of the classroom and into the clinic. As Rosenberg and Donald (1995) explain, “[a]n immediate attraction of evidence-based medicine is that it integrates medical education with clinical practice” (p. 1125). Through the lens of evidence-based medicine, the socialization of new professionals into the practice of medicine focuses on the biological and technological aspects of health and illness. EBM’s technological focus on clinical care allows medicine to downplay other issues. For instance, Daly (2005) suggests that incorporating EBM into the medical school allows the messy and complicated issues of community health and the related social and political issues to be relegated “to the sidelines” (p. 126).

Uncertainty in medical knowledge. The relationship between evidence-based medicine and uncertainty in medical knowledge-- whether it addresses or alleviates uncertainty-- is another antecedent to the preoccupation with EBM in medical education. The transformation of medicine into a practice based on concrete, scientific, evidence can be attractive to stressed physicians and medical students (Armstrong, 2002; Daly, 2005). Not only has the basic element of EBM, the clinical trial, been “institutionalized as the ultimate arbiter for resolution of uncertainty about therapeutics” (Djulbegovic, 2001, p. 390), but the packaging and summarization of evidence in clinical tools, such as UpToDate, has contributed to a sense of attainable certainty in clinical practice. Timmerman and Angell’s

(2001) research on medical residents suggests that synthesized and summarized information not only distills information into an easily accessible format but also guides “the budding physician through the clinical encounter... [offering] a definitive answer to the problem of clinical uncertainty” (pp. 343-344). According to Timmerman and Angell, even if these tools do not provide the answer, they provide comfort to practitioners.

Six decades ago, medical sociologist Renee Fox (1957) argued that the practice of medicine is inherently uncertain due to gaps and disparities in the knowledge base. While the volume of medical information and research has exploded in the intervening years, uncertainties in medical knowledge continue (Fox, 2012; Haynes, 2001; May, 2006). Multiple ambiguities—unknowns, biases, errors, and differences in personal views—weaken connections between a patient’s actual condition from the selection of a diagnostic test or treatment. Medical information scientist Szolovits (1995) captures multiple points of uncertainty in medicine through various levels of the process of clinical care:

Patients cannot describe exactly what has happened to them or how they feel, doctors and nurses cannot tell exactly what they observe, laboratories report results only with some degree of error, physiologists do not understand precisely how the human body works, medical researchers cannot precisely characterize how diseases alter normal functioning of the body, pharmacologists do not fully understand the mechanisms accounting for the effectiveness of drugs, and no one can precisely determine one’s prognosis (p. 111).

Although uncertainty is woven throughout the medical encounter, doctors and patients regularly make decisions about diagnosis, treatment and prognosis. Prior to the EBM movement, to handle this uncertainty clinicians relied on a knowledge base made up of their own experience, along with the collective experiences of the profession learned through the apprenticeship and modeling of clinicians, teachers and mentors (Daly, 2005). The movement towards EBM in the 1980s was, in part, an effort to move away from this ‘art’ towards clinical care that is based in ‘hard science’. However, while the goal of clinical

research and the evidence derived from it is to reduce uncertainty, uncertainty is inherent to EBM. Uncertainty exists in EBM by way of unknowns, biases, errors, non-responders, and even communication challenges. These attributes weaken the connections between an actual patient's reality and the EBM knowledge base. Szolovotis (1995) suggests that the uncertainty in medicine is so "tacit and so obvious that it is beneath mention" (p. 113). The application of research and evidence to clinical practice is a way to temper or mitigate uncertainty in the clinical encounter and provides clinicians with a "secure foundation for their clinical task" (Daly, 2005, p.1).

The desire for a 'secure foundation' and its potential to alleviate uncertainty may, in some measure, account for the uptake and proliferation of EBM as a pillar of medical education and practice (Good, 1998). The role of summarized evidence in clinical practice appears to be clear: Physicians seek and use this type of information to confirm their speculation or raise their level of certainty about their decisions (Gorman & Helfand, 1995).

Information Needs and Information Behaviour of Physicians

Reviews by Elayyan (1988), Verhoeven, Boerma, and Meyboom-de Jong (1995), and Haug (1997) capture the research findings concerning the information needs and preferences of physicians up to the 21st century. Numerous themes run through these three reviews. Print textbooks and journals in printed format were important resources to meet physicians' information needs, with academic and scholarly journals being the most important sources for the latest developments in medical care (Elayyan, 1988; Haug, 1997; Verhoeven et al, 1995), and, in comparison with practicing physicians, medical students, residents and inexperienced physicians were more likely to make use of medical textbooks and medical libraries (Elayyan, 1988; Verhoeven et al., 1995). Physicians gained access to the medical literature primarily by browsing journals, apparently because they had little knowledge about

and experience with print indexes and abstracts (Elayyan, 1988).

At the time of these reviews, online databases were in their infancy. Interestingly, at a time when physicians were largely limited to the medical research available through print resources, they were already reporting information overload (Elayyan, 1988). Consultations with colleagues were found to be equally, if not more important information sources than the printed medical literature (Elayyan, 1988; Haug, 1997; Verhoeven et al, 1995). Accessibility and time were found to be critical factors in the choice of information physicians used in clinical practice (Verhoeven et al., 1995).

In an effort to build a model of information-seeking for professionals, Leckie, Pettigrew, and Sylvain (1996) examined and synthesized what was known about information seeking practices of three distinct professional groups: engineers, health care workers, and lawyers. They found that several information-seeking and information-related practices crossed professional divisions and that these practices are more similar across diverse professions than had been previously thought. Leckie and her colleagues identified five themes and patterns that traversed the different professions: (1) Despite training in a particular area of expertise, professionals assume multiple, complex, and diverse work roles; (2) these roles have a constellation of tasks associated with them; (3) these tasks are likely to prompt information seeking; (4) intervening factors, including the awareness of information and sources of information, may facilitate or inhibit information access and use; and (5) it often takes more than one attempt to find appropriate information. These themes informed Leckie's General Model of the Information Seeking of Professionals. Six components comprise the model, including work roles; associated tasks; characteristics of information needs; factors affecting information seeking, such as awareness of sources; sources of information; and outcomes. In summary, the roles and related tasks that are a part of the

professionals' daily work trigger information needs and initiate an information seeking process. The information-seeking outcome is affected by multiple variables and throughout the model feedback loops capture the iterative and non-linear nature of the process.

Of particular relevance to this research is the way in which the five themes are manifest in information-seeking behaviours of health care professionals. Studies of the information behaviours of physicians, nurses, and dentists were included in Leckie et al.'s synthesis. Patient care is the most often cited trigger for information needs; however, health care professionals' information needs are also prompted by related tasks associated with distinct work roles including practice management, administration, teaching, research, current awareness, and continuing education. Health care professionals seek information from multiple sources—formal and informal sources, interpersonal sources, and “print” sources (much of the research reviewed was conducted before the Internet revolution). The preference for and choice of certain resources is very much influenced by ease of access, past experience, availability of time and the perceived quality.

Since Leckie et al.'s model was published in 1996, research and reviews examining the information needs and behaviours of physicians have continued to support the model. Patient care remains the primary role, which leads to an information need and to information seeking (Bryant, 2004; Clarke et al., 2013; Gonzalez-Gonzalez et al., 2007), and interpersonal sources of information and knowledge continue to play an important role in answering the clinical questions of physicians (Andrews, Pearce, Ireson & Love, 2005; Clarke et al., 2013; Gonzalez-Gonzalez et al., 2007). While these patterns continue to be supported, one cannot turn a blind eye to the impact of digital technology on the information landscape of physicians. Less than two decades ago, printed books and journals were critical information sources for physicians (Dawes & Sampson, 2003; Elayyan, 1988; Haug, 1997).

However, since the advent and proliferation of digital and Internet-based resources, print resources have dropped dramatically in popularity (Bryant, 2004; Clarke et al., 2013).

Physicians not only have access to research studies and articles in digital format, but also new types of evidence resources, that is, new and summarized evidence resources.

Evolving Medical Evidence for Clinical Practice

In order to address the reported shortcomings of more traditional forms of evidence, such as the research article, in answering physicians' clinical questions (Bennett, et al. 2005; Gorman & Helfand, 1995; Rosenberg & Donald, 1995), producers and publishers of evidence resources have attempted to build new tools to capture evidence in a way that meets the needs of physicians. These new resources are described by EBM scholars, such as Haynes (2001), as increasingly 'evolved'. An exploration of what is currently understood about this *evolution* of medical evidence to meet physicians' needs is significant to the research undertaken in this thesis.

The likelihood that physicians will search for information is greatly influenced by their beliefs about whether an answer exists for their clinical problem. According to Gorman and Helfand (1995), *often* doctors do not believe that they will successfully answer their clinical questions through the published literature (Gorman & Helfand, 1995). Doctors' conviction that they will be unsuccessful is attributed to their belief that studies are "invalid and irrelevant" (Rosenberg & Donald, 1995, p. 1122). Twenty years ago, Gorman, Ash, and Wykoff (1994) studied the effectiveness of the medical journal literature to answer primary care physicians' questions. The design of the study employed librarians to locate articles that provided "answers" to clinical questions arising from physicians' clinical practice. Clinicians were then asked to provide feedback regarding the relevance and usefulness of the information retrieved. Clinicians felt that the information provided a "clear answer" to their

questions in less than half of the instances (44%). At the time of Rosenberg and Donald's study, the primary information resource was published journal articles. Since then, synthesized and summarized information sources have proliferated. Moja and Banzi (2011) posit that "publishers' mission is changing: publishing trials and reviews in general or specialist formats is perceived as too static and remote from practice" and suggest that "[p]ublishers should find a balance between information consumed at the point of care—necessarily distilled, unnecessarily simplistic—and fidelity to a cumulative and extended approach to information" (p. 10). The physician-identified barriers of too much information, too few searching skills, and too few answers in the medical research and primary literature have led scholars and publishers to develop resources in which information is pre-packaged in a synthesized and summarized format. The use of these resources has been strongly supported by EBM advocates (see, for example, Guyatt et al., 2008).

The various levels of health information synthesis and summarization have been described by numerous authors, many of whom conceptualize these classes of information as a hierarchical evidence pyramid (for example: Grandage, Slawson, Shaughnessy, 2002; Pandis, 2011; Haynes, 2001). Of these hierarchical schematics, the 6S Model—originally created as a 4S model in 2005 (Haynes, 2001) and then later evolving into the 5S and 6S models (Haynes, 2006; DiCenso, Bayley, Haynes, 2009)—is currently the most widely used (Brown-Epstein, 2012) (see Figure 2). Initially, the four levels of organization of evidence in the 4S model were studies (original research articles), syntheses (systematic reviews), synopses (succinct summaries of articles), and systems. Here, 'systems' were defined as computerized decision support systems that were integrated into electronic health records, as well as advanced electronic decision support tools, such as UpToDate and Clinical Evidence. One year later, products such as UpToDate, Clinical Evidence and DynaMed were classified

in the fifth “S”–*Summaries*. The sixth and final “S” created a distinction between synopses of studies and synopses of syntheses (DiCenso, Bayley & Haynes, 2009).

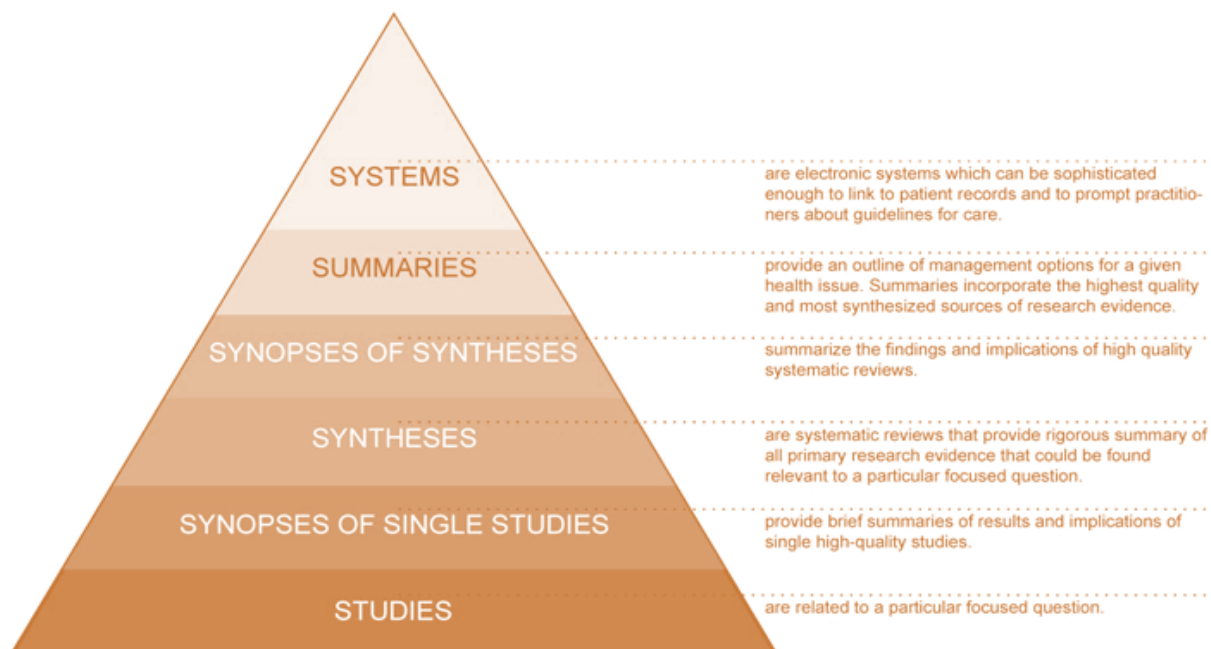


Figure 2: Levels of Organization of Evidence as suggested by Haynes and colleagues
 From: National Collaborating Centre for Methods and Tools:
<http://www.nccmt.ca/eiph/search-eng.html>

Haynes (2001) suggests that “[p]roviders and consumers of evidence-based health care can help themselves to the best current evidence by recognising the most *evolved* information services in the topic areas of concern to them” (emphasis added). Practitioners are directed to “begin the search for evidence to guide clinical decisions at the highest possible level of the 5S pyramid of evidence” (Haynes, 2007, p. 7). If you do not find the answer in one level then drop to the next level, but when one of the resources addresses the query, “you don’t need to look any further” (Haynes, 2007, p. 7). According to Haynes (2001), it is only when “every other S fails (ie, no system, [summaries,] synopses, or syntheses)” that it is appropriate to look for original studies (p. 37). Embedded in such guidance is the assumption that all the evidence physicians need for clinical decision-making

can be found in a single summary resource; or, indeed, that this evidence even exists.

In the 6S model, the concepts of quality and synthesis appear to be conflated in a problematic way. Haynes' (2006) use of the term 'evolved' implies more advanced knowledge, yet synthesis and summarization refers to a distillation process in which some information has been removed. The National Collaborating Centre for Methods and Tool's (NCCMT) tutorial explicitly states, "starting a search at the top (or the highest possible layer of the 6S pyramid model) yields the highest *quality* and most synthesized research evidence first" (NCCMT, 2011, emphasis added). Even though the summarization and distillation process is not well understood at the top of the evidence pyramid, the most summarized and distilled information is clearly presented in this teaching tool to be of the highest quality and the most "evolved" information available to clinicians.

Currently, the resources that occupy the top "S" of the pyramid, systems, are not well developed nor are they readily available. Systems are sources of evidence that are integrated into electronic health records, delivering to doctors and health care professionals relevant evidence as called upon via the electronic health record. Although it is anticipated that these resources will greatly improve the integration of evidence into the clinical encounter in the future (Bates et al., 2003), summaries are the highest level of organization of evidence currently in widespread use. Haynes (2006) argues that "a current *summary* trumps an individual synopsis, synthesis, or study or a collection of these" (p. 6), suggesting that summary sources provide all the information/evidence necessary for clinical understanding and decision-making.

Research demonstrates that clinicians have readily adopted the recommended guidance of integrating only the highest level of evidence into clinical practice. A study of residents at the University of Minnesota Medical School revealed that the most popular

resource accessed for information at point of care is the summary resource UpToDate, with 85% of residents using it daily (Duran-Nelson, Gladding, Beattie & Nixon, 2013). In contrast, only 13.3% of residents accessed PubMed/MEDLINE (the main access point for research studies) daily. Moreover, Wikipedia and the Google search engine were used with greater frequency than PubMed/MEDLINE. While both speed and trust in information quality were important factors in choosing a resource, speed appeared to be the users' more important consideration (Duran-Nelson et al., 2013); these results that align with Leckie's 1996 model of professionals' information seeking.

A more in-depth analysis of the 6S's three main levels of organization - Studies, Synthesis and Summaries - as well as the recommended structure for clinical questions that provide the basis for these resources, is needed to understand the evolution of evidence for clinical practice.

Clinical questions. The Centre for Evidence-based Medicine at the University of Oxford declares that "one of the fundamental skills required for practising EBM is the asking of well-built clinical questions" (Centre for Evidence Based Medicine, 2017). Evidence-based medicine recommends a standard framework for clinical questions, the PICO framework, which includes four elements: Patient or Problems, Intervention, Comparison and Outcome. This framework was first proposed in a journal editorial by Richardson, Wilson, Nishikawa, and Hayward (1995) for therapy-type clinical questions, but later expanded to questions of aetiology. Proponents of EBM suggest that the PICO framework helps clinicians with the queries by clearly articulating the essential components of their question and assisting the clinician to identify concepts. While PICO is widely advocated and taught to medical students and clinicians, research indicates that the format may not reflect real-world clinical questions. For example, Huang et al. found that actual primary care

questions rarely contain all four elements (Huang, Lin & Demner-Fushman, 2006).

Nevertheless, the PICO format is often used as a structure for research study and systematic review design, and provides a helpful structure for examining UpToDate.

Studies. Clinically-focused primary biomedical research can be organized in two main categories: clinical studies and preclinical research. Preclinical studies provide a strong knowledge base in order to ensure safety and efficacy prior to human clinical studies, for example via animal studies, model-testing, etc. Clinical studies comprise the observational medical research on human subjects that generate safety and efficacy data for health interventions (therapies, diagnostics, devices, prognostics). Practice is informed by these clinical studies and clinicians are directed to them to answer the questions that arise in their practice. While the most commonly discussed clinical questions relate to therapies and other treatment-oriented interventions, other types of clinical questions include those relating to diagnosis, prognosis, and aetiology (particularly risk factors). For clinical questions that address therapy, the RCT is considered to be the best study design to reduce bias and increase validity. Randomization, in this sense, is the allocation of patients into treatment groups so as to increase the likelihood of creating groups that are comparable on pre-identified baseline factors, both known or unknown, which may affect the study outcomes.

As noted earlier, clinicians question the application of research studies at the point of care and claim that the usefulness of primary research is quite limited in practice (McKibbin, Lokker, Keepanasseril, Wilczynski, Haynes, 2013). Specific limitations of clinical studies cited in the literature include the speed at which single clinical trials are contradicted or challenged; the inefficiency of clinician search skills (Bennett, Casebeer, Kristofco & Collins, 2005) and subsequent time it takes for clinicians to find credible and applicable research studies (Chambliss & Conley, 1996; González-González, et al., 2007; Gorman et al.,

1994; Rudolph et al., 2002); and clinicians' overall attitude that there is too much information available and they are unlikely to find an answer regardless of their search efforts (Bennett et al., 2005). In general, clinicians have not embraced clinical studies as an efficient and effective source of evidence for their point of care needs.

Synthesis. Systematic reviews comprise the synthesis level of the 5/6S schema. The Institute of Medicine (IOM) defined systematic review in 2011 as "a scientific investigation that focuses on a specific question and uses explicit, prespecified scientific methods to identify, select, assess, and summarize the findings of similar but separate studies." Systematic reviews are structured and rigorous reviews of literature pertaining to a focused clinical question aimed to identify, select, appraise and synthesize all available high quality evidence relevant to that question. Systematic reviews were a key element in Cochrane's vision of evidence-based medicine and are considered to be a foundation for the development of evidence-based clinical practice guidelines (Cook & Greengold, 1997). The Cochrane Collaboration, and its more than 5,000 reviews is considered a leader of evidence-based medicine³.

The development of systematic reviews, specifically the decision to include or exclude studies in systematic reviews, has generated a great deal of attention and debate in the literature. Developers of systematic reviews recognize that the conclusions of a systematic review can only be trusted and implemented if the studies included are of the

³ In 2000, the Campbell Collaboration was formed to focus on the effect of social interactions, encouraging the creation of systematic reviews on non-biomedical (and often more complex) topics. The Campbell Collaboration contains just over 100 reviews in its collection compared to the Cochrane Collaboration's more than 5,000 reviews. Synthesis of qualitative research differs from synthesis of quantitative research, as the end product is a meta-synthesis, where findings from across the research are integrated to generate new interpretations, formulate understandings, and produce new generalizations.

highest quality, but how quality is defined and assessed is contentious (Juni, Altman & Egger, 2001). One approach is to exclude trials that fail to meet a pre-defined standard of quality, although this practice has the potential to exclude studies that might contribute valid information. For clinical questions related to therapies, most systematic reviews exclude all studies that are not RCTs or related comparative designs employing randomization.

The use and application of systematic reviews is not without critics. For instance, Greenhalgh (2012) writes: “The problem is that the Cochrane machinery is built on the assumption that by summarizing the findings around tightly focused questions we will build a meaningful knowledge base” (p. 371). Systematic reviews best address ‘tightly focused questions’ such as the efficacy of treatment A on condition X, however many health challenges are complex and multifaceted. In addition to the narrowness and inapplicability of the questions that are addressed through systematic reviews, the vast number of systematic reviews (over 5000 in the Cochrane Library alone) has also been called into question. The large and diverse body of systematic reviews may be overwhelming in much the same way that the huge array of primary studies once overwhelmed (Hyde, Stanworth, Brunskill & Murphy, 2005). As such, systematic reviews have been dismissed as a point of care resource, and instead are suggested to “feed” point of care resources, including Summaries (Banzi et al., 2010).

Summaries. Summary resources are intended to provide health care professionals an outline of the evidence suitable for the point of care. Summary resources are suggested to be appropriate when physicians need the “clinical bottom line” (Windish, 2013, p. 96). Summaries are intended to incorporate the highest quality and most synthesized sources of research evidence. Two categories of resources are included in the summary level of the 5/6 S schemes: evidence-based summary resources (like UpToDate and DynaMed) and clinical

practice guidelines (CPGs). One of the defining qualities of summary resources is their goal to “[convey] a clear and concise message about what to do within the context of a provider-patient dyad” (Moja & Banzi, 2011, p. 6). The summary resource explicitly lays out a recommendation for clinical care.

CPGs provide clinicians with clear recommendation about how to provide care for patients with specific conditions. Evidence-based CPGs are “statements that include recommendations intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options” (Institute of Medicine, 2011). Such guidelines “seek to bring recommendations that generally prescribe where, when and how care professionals should act, aimed at reaching more uniformity and transparency in health care delivery” (van Loon, Zuiderent-Jerak & Bal, 2013, p. 2). Empirical research on the use of guidelines in everyday clinical practice raises questions about their applicability and usability (Kendall, Sunderland, Muenchberger, & Armstrong, 2009; Rashidian, Eccles & Russel, 2008). Identified shortcomings of guidelines include a narrow focus on one specific and static condition, restricted options for treatment, and a lack of recognition of the diversity of roles that health care practitioners hold (Van Loon, Zuiderent-Jerak & Bal, 2014; Kendall, Sunderland, Muechenberger & Armdytoh, 2009).

The most popular of the summary resource tools, related in many ways to CPGs, is UpToDate. UpToDate is described as “an evidence-based, physician-authored clinical decision support resource which clinicians trust to make the right point-of-care decisions” (UpToDate, “About Us,” 2017). It is this resource that forms the base for the current research study.

Summarised resources are now the ‘go-to’ resource for clinical questions (Alper,

White & Ge, 2005; Edson et al., 2010). In a multi-institution study (Edson et al., 2010) UpToDate was identified as the most effective resource for knowledge acquisition by 94.6% of residents and cited as the first choice for answering clinical questions by 88.9% of residents. In addition to noting the dramatic preference of clinicians for tools such as UpToDate, their effect on clinical practice is noteworthy. Alper, White, and Ge (2005) found that by making use of the summary resource DynaMed, primary care clinicians answered more questions and changed clinical decisions more often without increasing overall search time.

UpToDate: Overview and Previous Research

UpToDate is an online resource that provides physicians with evidence to support their clinical decision-making. UpToDate is also the name of the parent company of the resource, a brand of the Health Division of Wolters Kluwer Publishing. In 1992, UpToDate was launched by nephrologist Dr. Burton Rose, with the aim of “creating the information that doctors needed” (UpToDate, “The UpToDate Story,” 2012). After a potential publisher claimed that no money was to be made by the Internet, Dr. Rose and his colleague Dr. Joseph Rush developed UpToDate in Rose’s basement with the initial content being a print nephrology textbook authored by Rose. UpToDate now provides articles related to more than 24 specialties, authored by over 6,500 physicians, editors and peer reviewers (UpToDate, “About Us,” 2017). More than 10,500 topics are included in UpToDate, covering a wide variety of medical conditions, therapies, and issues. All entries include *Summary and Recommendations*, and *References* as consistent subtopics. Beyond these core subtopics, there is a varied level of specificity relating to individual topics that, ultimately, does not facilitate a consistent structure across all entries/articles. Possible subtopics included in UpToDate entries are: *Physiology and Anatomy*; *Treatment*; *Evaluation*; *Management*; and

Prognosis. An additional feature of UpToDate available for some topics is the classification of the level of recommendation based on the Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) system. GRADE is a system of rating the quality of evidence and strength of recommendations in synthesis and summary resources (Guyatt, et al., 2011). GRADE uses an explicit and transparent process and criteria to evaluate the evidence including study design, risk of bias, inconsistency, indirectness, and magnitude of effect. The inclusion of this classification of recommendation is not included in all UpToDate articles (Farrell, 2008).

The translation of current evidence into clear recommendations for clinicians is a unique feature of UpToDate, which relies upon physician expertise to determine what evidence should be applied to individual patients and provide clear recommendations to their colleagues (UpToDate, “Creating Content,” 2017). The necessity for the expertise offered by UpToDate’s physician-authors is captured in UpToDate’s philosophy that “(e)vidence alone is never sufficient to make a clinical decision — expertise is required to move from evidence to recommendations”. UpToDate describes the work of the physician-authors as “a *systematic process* for identifying, reviewing and synthesizing the medical literature as it applies to a clinical question” (UpToDate, “Creating Content”, emphasis added). The details of the ‘systematic process’ referred to by UpToDate are not readily available. However, a short description on the UpToDate website reads:

UpToDate follows a hierarchy of evidence consistent with most evidence-based resources. At the top of the hierarchy are meta-analyses of randomized trials of high methodological quality, followed by randomized trials with methodological limitations, observational studies and unsystematic clinical observations. Inferences are stronger when the evidence is summarized in systematic reviews of the literature that present all relevant data.

Each topic has an author who is an expert in the area discussed, and at least two separate physician reviewers. This group works together to perform a comprehensive review of the literature and carefully select studies for presentation based on the quality of the study, the hierarchy of evidence discussed above, and clinical

relevance. When current, high-quality systematic reviews are available, UpToDate topics and recommendations rely heavily on these reviews. When such reviews are unavailable, UpToDate summarizes the key studies bearing on the clinical issues at hand. (UpToDate, “Editorial Policy,” 2017)

The UpToDate site states that the authors select the evidence for the topic based on the widely accepted hierarchy of evidence, with no additional details. This brief description can be contrasted against the processes followed and made public by the Cochrane Collaboration. The details of the meticulous Cochrane process are described in a 670-page handbook, *Cochrane Handbook for Systematic Reviews*, and is made publicly available through the Cochrane website (Cochrane Collaboration, *Cochrane Handbook*, 2015). While the systematic process claimed by UpToDate is not clear, UpToDate positions itself as a leader in using the best available evidence: “While other clinical information resources may use — or claim to use — the best available evidence, UpToDate excels in determining how that evidence is applied to the individual patient.”

UpToDate provides a list of 466 journals that are hand-searched by a community of physician-authors that is responsible for selecting the evidence to be included, and using this evidence to inform the creation of each UpToDate entry. In the study described in this thesis, these journals are referred to as UpToDate’s *core journals*. In addition to the hand-searched journals, UpToDate provides a list of resources from which evidence is derived including electronic searching of key databases, practice guidelines, published reports of clinical trials by governmental agencies, conference and meeting proceedings, and “the clinical experience and observations of our authors, editors, and peer reviewers” (UpToDate. “Editorial Policy”, 2017). These resources are the base of evidence from which the content of UpToDate is derived.

Over 1,300,000 physicians in more than 187 countries use UpToDate to find medical

information for clinical decision-making; access is online, and more recently on mobile devices, primarily through personal and institutional subscriptions (UpToDate, “About Us”, 2017). As well as being one of the most popular medical resources, UpToDate is also one of the most well-researched point-of-care summary resources. More than 25 empirical studies have been undertaken by information scientists, clinicians, and librarians to examine the structure and use of UpToDate. These studies reveal that UpToDate is consistently one of, if not *the* most consulted evidence-based resource for clinical practice (Chisolm & Finnel, 2012; Cook, Enders, Linderbaum, Zwart & Lloyd, 2014; Marshall et al., 2013, Nasir, Nicholson, Vandermeer, Kumar & Robinson, 2014; Shariff et al., 2011) and is rated very positively by physicians for ease of use, layout, and quality of content (Campbell & Ash, 2006; Duran-Nelson, Gladding, Beattie & Nixon, 2013; Ensan et al., 2011; Marshall et al., 2013; Phua & Lim, 2008). Doctors consult UpToDate to obtain information about treatments, to find drug information, to identify appropriate diagnostic tests, to reduce delay in treatment, and to seek reassurance about clinical decisions (Addison, Witcombe & Glover, 2012; Chisholm & Finnell, 2012).

More than one-third of the identified studies of UpToDate focus on how medical students, clerks and residents adopt, use and learn from UpToDate (Duran-Nelson, Gladding, Beattie & Nixon, 2013; Egle, Smeenge, Kassem & Mittal, 2015; Hoogendam, Stalenhoef, Robbe, Overbeke, 2008; Kim, Willett, Murphy, O’Rourke, Sharma & Shea, 2008; Leff & Harper, 2006; O’Carroll, Westby, Dooley & Gordon, 2015; Phua & Lim, 2008). Medical students have been found to be more likely to adopt UpToDate than practicing clinicians (Peterson, Rowat, Krieter, and Mandel, 2004; Marshall et al., 2013) and students identified UpToDate as the most effective and most popular resource for knowledge acquisition (Edson et al., 2010; Lai et al., 2006; Leff & Harper, 2006). Students tend to use UpToDate primarily

for patient care and preparation for physician rounds, and much less for exam preparation (Cooper & Elnicki; Edson et al.; Peterson et al.). However in two studies it is reported that UpToDate was an effective learning tool for exam preparation (McDonald et al, 2007; Reed et al., 2012).

Many studies have compared the efficacy and efficiency of UpToDate with other evidence resources. Table 1 outlines evidence resources across the 6S pyramid and the studies that compare these resources to UpToDate.

Organization of Evidence (6S)	Resources	Study reporting comparison to UpToDate.
Systems	Currently in development	
Summaries	UpToDate, DynaMed, ACP PIER (now ACP Smart Medicine), Essential Evidence Plus, BMJ Point-of-Care, Cline-Guide, Nursing Reference Centre, Micromedex, PEPID Best Practice, BMJ Clinical Evidence, Bandolier, MedScape Reference, Diseasedex, InfoRetriever, FirstConsult, ClinicalKey Clinical Practice Guidelines (accessed via National Guidelines Clearinghouse),	Ahmadi et al. (2011); Campbell & Ash (2006); Chan & Stieda (2011); Egle et al. (2015); Farrell (2008); Fenton & Badgett (2007); Hayes (2012); Hoogendam et al. (2008); Jeffrey et al. (2012); Ketchum et al. (2011); Kronenfield et al. (2013); Nasir et al., (2014); O’Carroll et al., 2015; Prorok et al. (2012); Shurtz & Foster (2011); Turvey et

		al., 2013
Synopsis of	Cochrane Summaries, Evidence	
Synthesis	Based Abstract Journals (e.g.,: ACP Journal Club, Evidence- Based Medicine, Cancer Care Reviews)	
Synthesis	Cochrane Collaboration / Library	
Synopsis of	Evidence Based Abstract Journals	
Studies	(e.g.,: ACP Journal Club, Evidence-Based Medicine, Cancer Treatment Reviews)	
Studies	Journal articles indexed in PubMed, OVID Medline, PsychInfo, AMED	Ensan et al. (2011); Hoogendam et al. (2008); Schulling et al. (2005); Thiele et al. (2010)
Other	Google, Google Scholar, Wikipedia	Duran-Nelson et al. (2013); Hasty, et al. (2014); Thiele et al. (2010)

Table 1: Resources across the 6S Levels of Organization of Evidence and related studies

Because UpToDate is not the only summary resource designed for clinicians, several studies have set out to compare it with other competing products (Ahmadi et al., 2011; Campbell & Ash, 2006; Chan & Stieda, 2011; Farrell, 2008; Thiele, Pairo, Scalzo & Nemergut, 2010; Hoogendam et al., 2008; Ketchum, Saleh & Jeong, 2011; Shurtz & Foster, 2011; Turvey, Hussain, Banfield & Bhandari, 2013). Multiple studies in which student and

physician ability to answer clinical questions using UpToDate (a summary resource) is compared with use of PubMed (a database providing access to studies and synthesis, and to a lesser extent clinical practice guidelines, synopsis of studies, and synopsis of synthesis) (Ensan et al., 2011; Hoogendam et al., 2008; Schilling et al., 2005; Thiele et al., 2010) suggest that, by using UpToDate, study participants were able to locate more relevant answers to clinical questions, and to find answers to clinical questions in a shorter time. In addition to PubMed, UpToDate has also been evaluated against a variety of combinations of products including: ACP's PIER, DISEASEDEX, FIRSTConsult, InfoRetriever, BMJ Clinical Evidence, Bandolier, Google, OVID, Essential Evidence Plus, BMJ Point-of-Care, Clin-eguide, AskMayoExpert, ClinicalKey, Nursing Reference, and the National Guidelines Clearinghouse (Ahmadi et al., 2011; Campbell & Ash, 2006; Chan & Stieda, 2011; Farrell, 2008; Fenton & Badgett, 2007; Kronenfeld, Bay & Coombs, 2013; Theile et al., 2010; Turvey et al., 2013). In studies evaluating a resource's usefulness for answering physicians' clinical questions, UpToDate consistently rated at the top (Ahmadi et al., 2011; Campbell & Ash, 2006; Thiele et al., 2010). Physicians were also able to answer clinical questions more quickly using UpToDate in comparison with other products (Ahmadi et al., 2011; Thiele et al., 2010). Only Google was reported to be as quick as UpToDate, however physicians did not report a high level of trust and confidence in Google. In only one study, in which UpToDate and related products were evaluated by non-physicians (nurses, administrators, librarians) as well as physicians, was no difference between product preferences reported (Chan & Stieda, 2010).

The breadth and depth of UpToDate's content for two specialties, primary care and orthopaedic surgery, has been compared against similar products. While UpToDate had greater breadth of content related to primary care than National Guidelines Clearinghouse

(Fenton & Badgett, 2007), UpToDate had the most limited orthopaedic content compared with ACP Pier, DynaMed, FirstConsult, and Clinical Evidence (Turvey et al., 2013). While UpToDate claims to address twenty-one specialties, the depth of coverage across specialties appears to be inconsistent.

The influence of UpToDate on clinical decisions and clinical practices has also been explored (see, for example, Addison et al., 2013; Bonis, Pickens, Rind & Foster, 2008; Isaac, Zheng & Jha, 2012; Phua & Lim, 2008; Phua, See, Khalisah, Low & Kim, 2012; Schilling et al., 2005). Physicians have repeatedly reported that consulting UpToDate affects their clinical decision-making: Phua and Lim found that 57.9% of physicians using UpToDate reported that the use of UpToDate led to a change in the way that they managed patients. UpToDate it touted as the “ONLY decision support resource associated with improved outcomes” (UpToDate, “About Us,” 2017), and, indeed, two studies by Bonis et al. (2008) and Isaac et al. (2012) provide particularly startling results about the effects of using UpToDate on outcomes. It should be noted that UpToDate funded both of these studies and two of the authors of Bonis et al.’s study were employees of UpToDate. The authors compared the practices and outcomes of hospitals with and without access to UpToDate and report that hospitals using UpToDate consistently demonstrated reduced length of stay, lower risk-adjusted mortality rates, and higher quality performance⁴. From this comparison, the authors extrapolate that UpToDate can save lives, going so far as to announce that UpToDate prevented 11,500 deaths in 424 US hospitals in a three-year period (Isaac, Zheng & Jha, 2012).

⁴ To assess the quality of hospital performance the researchers used the US Hospital Quality Alliance process measures for four conditions (acute myocardial infarction, congestive heart failures, pneumonia, surgical infection prevention). The quality of performance is judged according to how well an entity provides care to its patients based on the evidence that particular processes are followed. In other words, ‘quality’ here reflects process adherence.

While UpToDate has been the subject of numerous studies, its structure, development, and content have not been extensively or systematically studied. Three small studies examined its structure and content. Jeffrey et al. (2012) compared the currency of DynaMed, UpToDate, ACP Pier, and Best Practice and found that, across 200 topics, the time elapsed since the last update varied substantially for the four platforms. The average time since the last update for each topic ranged from 170 days for DynaMed to 488 days for PIER and the topics in UpToDate averaged 427 days since the last update. When assessing the need for topics to be potentially updated, UpToDate lagged significantly behind DynaMed, with 104 topics in UpToDate needing potential updates in comparison with 47 topics in DynaMed. Health sciences librarian Andrea Ketchum and her colleagues compared the number, levels, and currency of evidence used in five resources, including UpToDate (Ketchum et al., 2011). Again, UpToDate was found to be not as current as DynaMed. DynaMed also had significantly more references per topic and relative to the other 4 resources, UpToDate had the lowest percentage of evidence from two of the top levels of evidence, systematic reviews and randomized controlled trials. Amber, Dhiman, and Goodman (2014) examined UpToDate's treatment of six topics that have controversial or uncertain treatment. They examined the topics for evidence of potential conflict of interest (including financial) and report that authors and editors of UpToDate were allowed to maintain financial relationships with drug companies whose products are evaluated within these articles. Each of these three studies provides indications of the structure and content of UpToDate, as well as suggesting some of its potential shortcomings.

Medicalization

As noted earlier, more than 10,500 topics are covered in UpToDate, and more topics are continuously being added. Interestingly, not all the topics covered by UpToDate would

be found in medical textbooks from 100 or 50 years ago. Included in the vast number of UpToDate entries are ailments and illnesses that have been ‘medicalized’ over time. Medicalization is the process by which medical definitions and practices are applied to behaviours, psychological phenomena, and somatic experiences not previously within the conceptual or therapeutic scope of medicine. In the simplest terms, medicalization arises when previously non-medical problems are defined and treated as medical problems, usually in terms of illnesses or disorders. Medicalization has been a topic of interest to researchers in sociology, anthropology, medicine, history, and science and technology studies for more than four decades (Davis, 2010). In 1972, Zola’s definition of medicalization as “the involvement of medicine in the management of society” focused on medicalization as a means of medical control and regulation (p. 488). Originally, researchers interested in this field focused on the medicalization of deviant behaviours (for example, children’s misbehaviours and child abuse) and natural life processes (for example, childbirth and menopause). However, the concept of medicalization has evolved and expanded. Medicalization is not only about medical control but also results from individuals’ eagerness to seek diagnosis, affecting not only the utilization of medical interventions but also the expansion of medical categories themselves (Conrad, 2005, 2007).

Changing patterns of medicalization have been attributed to the “rise of corporate managed care and the corresponding decline of physicians’ professional power” (Barker, 2008), p. 21). Researchers and critics note that the practice of medicalization can: increase unnecessary medical labelling, promote poor treatment decisions, and increase the marketing of unnecessary pharmaceutical treatments (Moynihan, Heath, & Henry, 2002; Conrad & Leiter, 2004). Moynihan et al. (2002) examine medicalization in relation to “widening the boundaries of treatable illness in order to expand markets for those who sell and deliver

treatments” (p. 886), characterizing it as a form of ‘disease mongering’. They describe five (non-discrete) categories of medicalization: ordinary processes or ailments of life classified as medical problems; mild symptoms portrayed as portents of a serious disease; personal or social problems seen as medical ones; risks conceptualised as diseases; and disease prevalence estimates framed to maximise the size of a medical problem. Medicalized conditions often are unique in the ways in which the patient is positioned, the certainty of the “evidence” available, and the roles in which experts and expertise enact; this makes them a useful site of investigation for the present study.

Chapter 2: Research Questions and Methods

As evidenced in the published literature, UpToDate dominates as the resource tool of choice for physicians who are looking for answers to their clinical questions. A physician's choice to use the information found in summary sources of information, such as UpToDate, is supported by the principles of evidence-based practice (Guyatt et al., 2008) and aligns with Haynes's suggestion that "[providers and consumers of evidence-based health care can help themselves to the best current evidence by recognizing the most evolved information services in the topic area of concern to them]" (2001, p. 37). The drive towards the use of summary resources is directly tied to the notion that these resources provide information that is more evolved and as such, of a higher quality. However, the discursive practice of referring to these resources as 'evolved' may be problematic as evolution infers a transformation from a simpler form to a more complex form. This is actually contrary to the process that evidence goes through during the summarization process. As the basis of evidence moves from the bottom of the 6S pyramid (studies) to the top (summaries and systems) information does not become more complex; in fact, it becomes less complex, and seemingly more certain. A key question posed in the present study is how a more simple (and certain) product 'evolves' from the complex (uncertain) inputs and how evolution corresponds with a process that actually distills and strips away detail.

While summarized resources have been examined in several studies in terms of their editorial quality, uptake and application, breadth of coverage of medical conditions, and timeliness, the 'evolution' of primary evidence into summary resources has not yet been systematically investigated. Important questions to be explored about the 'evolutionary' process include what evidence is selected for inclusion and how such evidence is positioned vis-a-vis clinical practice.

Summary resources, such as UpToDate, present the body of clinical research on a topic in a usable and understandable format suitable for clinical practice. Greenhalgh (2012) describes the evolution of clinical research to systematic reviews as the “technical process of stripping away all but the bare bones of a focused experimental question” and further contends that this stripping away “removes what practitioners and policymakers most need to engage with: the messy context in which people get ill, seek health care (or not), receive and take treatment (or not), and change their behaviour (or not)” (p. 371). Greenhalgh describes a distillation—rather than evolution—process, i.e., a process that purifies and condenses in order to collect a refined product. This process, by definition, requires the loss or removal of some of the initial substance. This research delves into the distillation process that moves (some) clinical research into the summary resource, UpToDate. The main research question addressed in this study is: What information is sacrificed and what information is privileged during the summarization process? Additional research sub-questions include how the complexities inherent in clinical practice are presented in summarized information sources and how the patient and patient-centered care is or is not presented in UpToDate.

In the summarization process, potentially thousands of pages of information that make up the corpus of evidence on a topic must be distilled into a few paragraphs. Unlike chemical distillation, however, the selection, filtering, and condensing of information is not mechanical, consistent or pure, rather these are conscious human and social acts. The UpToDate website describes this summarization work undertaken by its authors:

Drawing on their extensive experience, our physician authors and editors begin with a structured clinical question, placing the latest evidence about the topic in context with the larger body of available evidence. Next, they synthesize that evidence into recommendations clinicians can use to diagnose and treat their patients, even when the evidence is thin or no consensus exists. (UpToDate, “Physician Authors and Editors,” 2017)

A multiple case study analysis explored these processes. By examining seven cases⁵ and following up with a cross-case analysis, what information is privileged and excluded in UpToDate at various points in the distillation process was identified. The investigation included what types of evidence as well as what content from the evidence base was included.

Content Analysis and Multiple Case Study Design

Content analysis is a useful method for identifying both the conscious and unconscious messages within a text (i.e., what is stated explicitly and what is implied by the manner in which content is expressed) (Krippendorff, 2013). It is a flexible methodology that lends itself to both qualitative and quantitative analysis (Cavanagh, 1997). Its roots are found in the 1950s as a quantitative method used in the study of mass communications. Since then, researchers across many fields have adapted content analysis as a quantitative and qualitative approach to address a wide range of research questions and research strategies. It is used extensively in library science, information studies, and medical fields (Hsieh & Shannon, 2005; Krippendorff, 2010; Neuendorf, 2002; Weber, 1990; White & Marsh, 2006).

Descriptive information was collected to understand the evidence base utilized by UpToDate and a qualitative content analytic approach was used to gain a more holistic understanding of the context and process of summarizing evidence for clinical practice.

Qualitative content analysis "is the intellectual process of categorizing qualitative textual data into clusters of similar entities, or conceptual categories, to identify consistent patterns and relationships between variables or themes" (Julien, 2008, p. 121). Analytic

⁵ The multiple case study analysis is made up of seven cases. Because the grief and bereavement case is made up of two entries: one addressing normal grief and bereavement and one addressing complicated grief and bereavement, eight UpToDate topic entries are analysed to make up the seven cases.

constructs, or rules of inference, are used to find prominent patterns within the data and yield inferences from textual data. While there is quite an extensive body of literature evaluating and describing selected resources supporting evidence based medicine, an analysis of the context, process, and underlying meaning of how lower order “S”s (e.g., studies and syntheses) become higher order summaries has not been evaluated. The flexibility afforded by the content analysis methodology was important to this research because there was some uncertainty about what would emerge from the data. An inductive approach was used in that, rather than looking for preconceived categories in the analysis, the categories were allowed to emerge from the data. Content analysis allows researchers to identify what is stated explicitly and what is implied by the manner in which content is expressed and, while it may not provide definitive answers to critical concerns, content analysis can provide ‘signposts’ for further inquiry (Beach et al., 2009, p. 136).

In this study, the units of text that were subjected to analysis were the main clinician entries of UpToDate for eight conditions (making up the seven cases), the associated patient information where available, and the abstracts of the referenced evidence (evidence cited within the UpToDate entry). The data from these texts were analysed individually by topic and then analysed across the topics to understand the points of divergence and convergence across the topics (Figure 3). Descriptive information from these three data sources was also extracted, collected, and analysed.

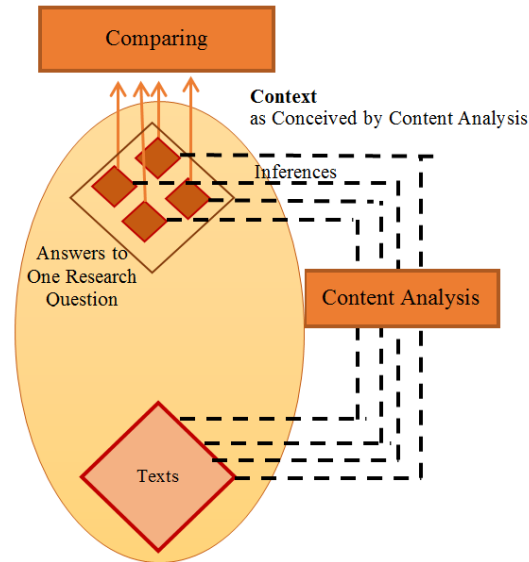


Figure 3: Comparing Similar Phenomena Inferred From Different Texts
(Adapted from Krippendorff, 2013, p. 94)

In order to ensure that this research captured a holistic and comprehensive understanding of how UpToDate functions within health information practices and culture, following the descriptive and qualitative analysis, the results were considered in relation to Stuart Hall's 'Circuit of Culture' framework (DuGay, Hall, Janes, Mackay & Negus, 1997). The Circuit of Culture framework presents five coexisting processes: Representation; Production; Consumption; Identity; and Regulation, which "taken together complete a sort of circuit...through which any analysis of a cultural text or artefact must pass if it is to be adequately studied" (DuGay, et al., p.3). Examining UpToDate using the framework of the Circuit of Culture provides insight into the position and meaning of UpToDate in medical and information environments, Figure 4 provides an overview of the model, including short definitions for the five elements.

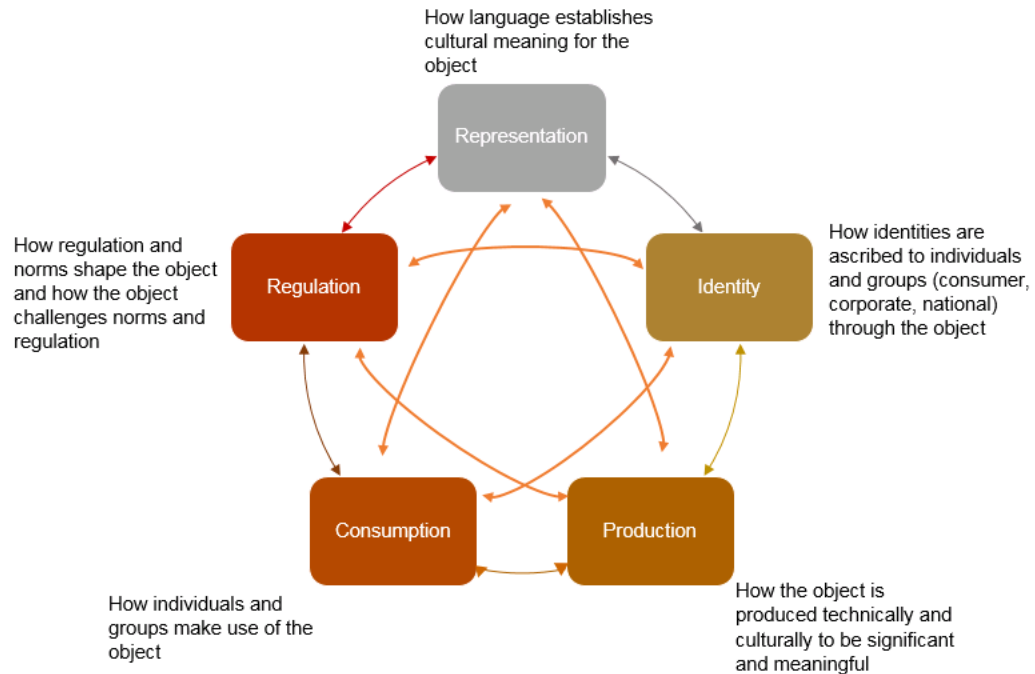


Figure 4: Circuit of Culture Framework (Adapted from Du Gay et al., 1997)

The framework poses several questions in this study: How and why is UpToDate created? (Production); How does the language of evidence based medicine and the language used in UpToDate create meaning? (Representation); How is UpToDate consumed and deployed by user groups (librarians and physicians)? (Consumption); What identities are created and reinforced by UpToDate? How is UpToDate used to create and reinforce the identity of its creators and users? (Identity); and What regulations, norms, and values influence how UpToDate is created and used? (Regulation).

Data Sources for Content Analysis

The number of topics that comprise the corpus of evidence for clinical practice is vast. More than 10,500 entries across 24 specialties are included in the UpToDate database. For this multiple case study analysis, eight UpToDate entries, representing seven case studies, were selected for evaluation. Each entry, along with the corresponding patient information (where available) was analysed as a separate case, with the exception of the

Grief case which comprises two UpToDate entries: the 2015 entry on treating complicated grief and the 2015 entry on non-complicated grief. As outlined in the Diagnostic and Statistical Manual of Mental Disorders by the American Psychiatric Association, the diagnostic criteria and subsequent treatment of grief underwent a substantial shift in 2013 (American Psychiatric Association, 2013; Zachar, First, Kendler, 2017). A comprehensive explanation of the changes and the decision to include two UpToDate entries for the Grief case are included in the results section for Grief and Bereavement. An UpToDate entry is defined in this study as a single UpToDate webpage addressing a discrete subject related to a single condition/illness for either professionals or patients. The main clinician entry is defined as the webpage content written for professionals accessible only by subscription to the resource.

A multiple case study structure allows researchers to examine how the phenomenon of interest presents in different environments (Stake, 2006). Whereas in a single case study researchers seek to identify the common themes within the case, in a multiple case study researchers are also interested in the atypical (i.e., unique concepts that do not transcend across the cases, and/or distinctive concepts that are not common across all cases) (Stake, 2006). Toward this end, entries selected for analysis represent varying levels of complexity and certainty. Per Stake (2005), each topic represents its own case study and the cross-case analysis forms the multiple case study.

A unique feature of this research is that, unlike interviews where the text is analysed as it is presented, and taken to be the entirety of the story or perspective, there is additional information that is critically important to understanding the meaning and material embedded in the text, i.e., the referenced evidence. The referenced evidence for this study includes the studies, systematic reviews or other sources of evidence cited within the UpToDate entries

examined. As such, in addition to the content of the entry, the referenced evidence is a unit of analysis for which descriptive data is collected.

Entries for Analysis

The selection of cases is a critical and often challenging step in designing case study research (Yin, 2009). In an attempt to reflect the realities of clinical practice, the topics chosen as the cases address varying levels of complexity and medicalization of conditions/illnesses, as well as of clarity, i.e., the level of certainty regarding interventions and outcomes. For example, the treatment for the topic, *Treatment of Children with Otitis Media*, would be expected to convey information about an illness with a clearly defined organic medical cause, in which drug and non-drug interventions are evaluated in an attempt to relieve the symptoms and cure the inflammation of the inner ear in children. In contrast, at the other end of the spectrum, *Complicated Grief and Bereavement in Adults* is a more complex and multifaceted topic. Unlike a physical ailment, grief and bereavement is an emotional, but also highly medicalized, response to the loss of a loved one, which does not have clear treatment. Seven cases were chosen for analysis. Each case contained one main entry, with the exception of Grief and Bereavement, which contained two interrelated entries (described below). The seven cases (eight entries) selected for this study were⁶:

1. ***Acute otitis media in children (AOM)***: Acute Otitis Media (AOM) is the medical term for inflammation of the inner ear. Otitis Media is a common childhood illness with a known organic cause and pathophysiology. While 80% of occurrences of AOM dissipate without treatment, AOM is the most common diagnosis for which children receive antibiotics (Grijalva, Nuorti & Griffin, 2009). While complications of acute otitis media are rare, complications include perforation of the eardrum,

⁶ Copies of the UpToDate entries analysed are available upon request

infection of the mastoid space behind the ear, and, in very rare cases, bacterial meningitis. For this case, the title of the entry analysed is *Acute Otitis Media in Children: Treatment*.

2. ***Androgenetic alopecia (AGA)***: Androgenetic Alopecia is the medical term for male pattern balding. While research demonstrates that hair loss can affect self-esteem in men (Cash, 2001), Moynihan highlights that ordinary processes or ailments, like balding, are often framed as medical problems. Androgenetic alopecia is commonly diagnosed and treated by physicians, and the treatment for baldness is a multi-billion dollar industry with many products in development (Ellis, Sinclair & Harrap, 2002). *Treatment of Androgenetic Alopecia in Men* is the entry analysed.
3. ***Irritable bowel syndrome in adults (IBS)***: Irritable bowel syndrome (IBS) is a chronic functional gastrointestinal disorder and has no known organic cause. As such, IBS is a symptom-based diagnosis characterized by chronic abdominal pain and altered bowel habits. While there are individuals with IBS who are incapacitated by their symptoms, for many, IBS is “a mild functional disorder- requiring little more than reassurance about its benign natural course” (Moynihan et al., 2002, p. 887). IBS has been identified as a condition that has been medicalized, i.e., the relatively mild symptoms of this common disorder may be portrayed as a sign of a serious disease (Moynihan et al., 2002). The title of the entry in UpToDate analysed in this case is *Treatment of Irritable Bowel Syndrome in Adults*.
4. ***Fibromyalgia in adults (FIB)***: This topic represents an illness or condition with a high level of uncertainty with respect to its cause and treatment. Because fibromyalgia involves unpredictable pain, has no known organic cause and the treatment options are not consistently effective, there is a high level of uncertainty

about it among both patients and professionals. Although, currently, there is a general acceptance of fibromyalgia as a legitimate medical condition, questions have been raised about its physiological authenticity, whether it is a single condition, and even whether it represents a “medicalization of misery” (Hadler, 2003, p. 1668). The entry analysed in for the FIB case is *Initial Treatment of Fibromyalgia in Adults*.

5. ***Chronic fatigue syndrome (CFS)***: Chronic Fatigue Syndrome (CFS) is an illness characterized by persistent fatigue for at least 6 months, and is often accompanied by several other symptoms including headaches, muscle pain, insomnia, and concentration issues. There is no clear cause identified and no effective diagnostic test developed for CFS. As such, CFS is diagnosed through symptom identification. The lack of cause and diagnostic test has led to questions and challenges about the legitimacy of CFS by some health care professionals who argue that a diagnosis of CFS may be self-validating, self-reinforcing and potentially a self-fulfilling prophecy (Huibers & Wessely, 1996). In February 2015, the United States Institute of Medicine (IOM) published a report renaming Chronic Fatigue Syndrome as Systemic Exertion Intolerance Disease (SEID), as well as proposing a redefinition of the diagnostic criteria for CFS. While the content of the entry primarily uses the term Chronic Fatigue Syndrome, the title does reflect the redefinition. The entry analysed for the CFS case is *Treatment of Chronic Fatigue Syndrome (Systemic Exertion Intolerance Disease)*.
6. ***Grief and bereavement (NGB and CGB)***: Increased attention was recently drawn to the potential for the medicalization of personal and social problems as a result of changes to the psychiatric manual, the DSM-V (Diagnostic Statistical Manual of Mental Disorders, Version 5), regarding guidelines and criteria for depression. Prior

versions of the DSM advised physicians not to diagnose major depressive disorder after the death of a loved one, even if all other criteria were met. The removal of the “bereavement” exclusion was met with harsh criticism as it suggested that the depressive syndromes that result from bereavement do not differ from “ordinary” occurrences of depression. The treatment of personal or social problems as medical problems has been questioned extensively. The case for Grief and Bereavement included two UpToDate entries: *Grief and Bereavement in Adults: Management* and *Complicated Grief in Adults: Treatment*.

7. ***Intimate partner violence: (IPV)***: Intimate partner violence (IPV) is a complex social and health issue. The physician’s role in supporting a patient experiencing abuse are often initiated when IPV is detected or disclosed. Physicians and health care workers are increasingly encouraged to talk about, screen for, and provide options for intervention when intimate partner violence is disclosed (American College of Obstetricians and Gynecologists, 2012; Cronholm, Fogarty, Ambuel & Harrison, 2011; Society for Obstetricians and Gynecologists of Canada, 2009). While preventing IPV and ensuring supports and resources are in place for IPV victims is recognized as a priority and a potential outcome of the medicalization of IPV, the issues underlying these actions and potential consequences of these actions are numerous and complex. As such, the role of health care workers in identifying and providing intervention options for IPV has been debated extensively (Cole, 2000; Wathen & MacMillan, 2012). The entry analysed for the IPV case is titled *Intimate Partner Violence: Intervention and Patient Management*.

Because the most common types of questions encountered in the clinical setting address the treatment of illnesses and conditions (Crowley et al., 2003), all entries chosen for

the multiple case study address treatment options. Individual analysis was followed by cross-case analysis. The triangulation between the seven cases, comprised of eight topics, highlight themes that transcend the cases, as well as themes that are unique to specific cases, were of interest.

It is important to note here that UpToDate is an internet-based evidence resource and researchers face a number of challenges in conducting a content analysis of internet-based resources (Weare & Lin, 2000). First, internet-based content consistently includes multiple hyperlinks to additional material. These hyperlinks may be considered similar to “see also” references in a print source; however, the immediacy of the hyperlinked content encourages the reader to shift from the initial content to the supplementary reading. Moreover, the dynamic nature of Internet resources adds additional challenges to analysis. Any content captured may be edited or completely rewritten in minutes. This makes any particular snapshot of the content somewhat arbitrary (Weare & Lin, 2000). While UpToDate updates are not continual, and in fact can be quite slow (Prorok et al., 2012; Jeffrey et al., 2012), in this study the web content was captured as a PDF to address the dynamic nature of the web-based data and ensure that the content analysed could be consistent throughout the study (as a PDF, see Appendices A to G). Although UpToDate entries were updated over the course of the study, the PDF of the captured entry was used for analysis.

Research Questions

Multiple case study research begins with core questions, but sub-questions are likely to evolve over the course of data collection and analysis and, eventually, will help to inform the themes that evolve from the data. It should be noted that the core research questions in case study research: (a) are open-ended, evolving, and non-directional, (b) reinforce the purpose of the research, (c) and are often ‘what’ or ‘how’ questions, rather than ‘why’

(Cresswell, 201; Agee, 2009).

The following six research questions initially made up the base of the analysis and met the criteria for research questions that are appropriate when using the case study method:

a.) What types of information sources do clinical experts include/privilege when developing content for the summary source, UpToDate? b.) What information is overlooked or excluded by clinical experts when developing content for the summary source UpToDate? c.) How is *evidence* situated in the entries for UpToDate? d.) How is *expertise* situated in the entries for UpToDate? e.) How is *the patient* situated in the entries for UpToDate? f.) How are these processes understood in the five concepts of the Circuit of Culture?

Throughout the course of the analysis minor alterations were made to the research questions. For example, it was not anticipated that expertise would be tied so directly to the authors. Specifically, the entries heavily used phrases such as ‘In our experience’ and ‘we suggest.’ The authors prominently presented and described expertise as their own so in turn, the fourth question evolved from ‘How is *expertise* situated in the entries for UpToDate?’ to ‘How is *author* situated in the entries for UpToDate?’ In addition, the final question changed from ‘How is *the patient* situated in the entries for UpToDate?’ to ‘How is the *patient-physician relationship* situated in the entries for UpToDate?’ This change largely evolved from the inability to disentangle the two entities from the relationship as described in the text. The final six research questions informing the analysis were:

1. What types of information sources do clinical experts include/privilege when developing content for the summary source, UpToDate?
2. What information is overlooked or excluded by clinical experts when developing content for the summary source UpToDate?
3. How is *evidence* situated in the entries for UpToDate?

4. How is *expertise* situated in the entries for UpToDate?
5. How is *the patient-physician relationship* situated in the entries for UpToDate?
6. How are these processes understood in the context of the five concepts of the Circuit of Culture?

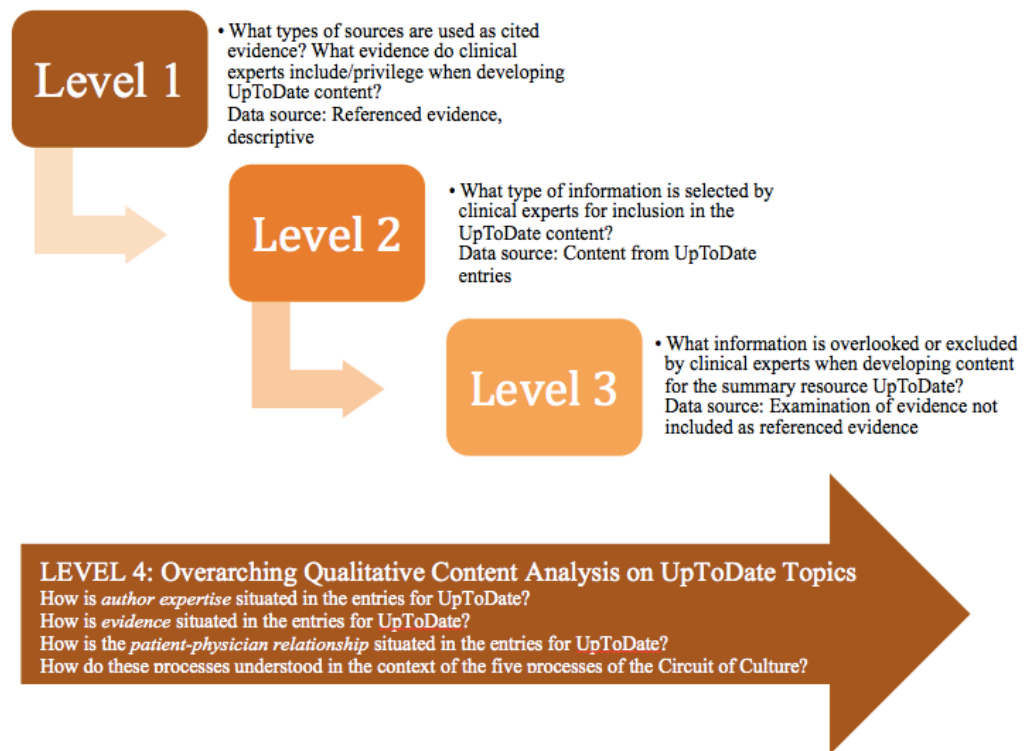


Figure 5: Data Collection and Analysis Schematic

Four levels of analysis, as presented in Figure 5, addressed the five research questions described above. The Level 1 and Level 3 analysis focused on the availability and inclusion of evidence in UpToDate while the Level 2 analysis focused what content is included in each UpToDate entry. Then, an overarching qualitative content analysis of the eight entries making up the seven cases was performed as a means to better understand how evidence, expertise and the patient is situated within the UpToDate entries. Finally, the process(es) was examined in the context of the five key elements of the Circuit of Culture.

Descriptive Data Extraction

Level 1 analysis relies heavily on the extraction of descriptive data from the referenced evidence. A core objective in this study is to understand what types of evidence sources are selected for inclusion as referenced evidence and what information is selected for inclusion in the entry. As such, along with the overall text of the UpToDate entry, key data sources for analysis were the referenced evidence of the eight entries. Referenced evidence refers to those articles or sources that have been listed in the topic citation list as evidence and appear in the reference list in the UpToDate entry. Descriptive information about the referenced evidence was gathered from the bibliographic record and the abstract. The full article was consulted when necessary. Information about when each case was downloaded, last update, and number of sources included as referenced evidence is presented in Table 2.

Entry Title	Download Date	Review current	Last Updated	# of References
Acute otitis media in children	Sept 2015	Aug 2015	Jan 31, 2014	82
Androgenetic alopecia in men	Nov 2015	Oct 2015	July 21, 2015	41
Irritable bowel syndrome in adults	Jan 2015	Dec 2014	Oct 2, 2014	84
Fibromyalgia in adults	Oct 2015	Oct 2015	Aug 28, 2015	91
Chronic fatigue syndrome	Nov 2015	Nov 2015	Jul 30, 2015	46
Grief and bereavement	Dec 2015	Nov 2015	Aug 6, 2015	20
Complicated grief	Oct 2015	Nov 2015	Aug 6 2015	30
Intimate partner violence	Nov 2015	Oct 2015	Apr 28, 2015	24

Table 2: Number of Sources Cited as Referenced Evidence

Descriptive data were mined from the evidence sources. The data extraction form was created for this study and web-based, making data entry more portable and easier using

form tools including: checklists, radio buttons and open text. Further the web-based form allowed the data to be easily exported to multiple formats (PDF, Word, Excel, SPSS) (see Appendix H). Descriptive data were collected not only to describe the content and the referenced evidence that make up the UpToDate topic information, but also to identify relationships between the evidence and the entries in relation to five primary elements:

1. *Publication Source*: The titles of publication sources for each article cited within the eight entries were recorded. The publication title for each referenced evidence was also compared to the list of 466 core journals identified by UpToDate for hand-searching. Hand-searching refers to manually searching through select journal titles from cover to cover for articles and citations relevant to a topic. Hand-searching aims to identify articles that may be missed due to limitations in indexing practices. Since the proliferation of digital publishing, hand-searching is now mostly done online but still requires the careful review of online tables of content and online article-by-article browsing.
2. *Date of publication*: The month (if available) and year of publication of the references were recorded for each source cited across the eight entries.
3. *Location of Study, if applicable*: For research studies, the country where the study took place was recorded. The country location(s) of data collection was recorded, not the home institution of the author. If data were collected in more than one country, it was recorded as multinational, also capturing the individual countries.
4. *Authorship, professional/academic background*: To understand the relative proportions of professional backgrounds that contribute to the UpToDate

evidence base, the authors' professional backgrounds were noted. Each cited reference was given a weighting of one, and the background of each author of the reference was assigned proportional weighting based on the number of authors contributing to the cited reference. For example, a paper with a single physician author would be assigned a value of 1.0 for physician background and a paper co-written by a basic scientist, a nurse and two physicians, would be assigned a value of .25 for the background for nurses and basic scientists and .5 in the physician background. No difference of weighting was given for order of authors.

5. *Type of Evidence:* In order to gain a better understanding of the type of evidence included in UpToDate, each cited reference was analysed for the level of evidence from Haynes' 6S model,' (e.g. Study; Synthesis); Type of Resource (e.g. Quantitative Research; Systematic Review); and Research Design, if applicable (e.g., RCT, Longitudinal). If the evidence/source cited was not recognized under the 6S Model, this was recorded with details about the type of resource (e.g. public health website).
6. *PICO Elements of Clinical Question:* The PICO framework identifies the Patient/Problem, Intervention, Comparison, and Outcome of the clinical question answered by the study. All identifiable elements of the referenced evidence were recorded. It was anticipated that certain PICO elements of the clinical question will have more or less importance in the entry depending on the topic and the question addressed. Using the PICO framework helped to separate and identify the features of the clinical question, as well as assist in identifying relevant evidence not included in the entries.

The conclusions of the study were also recorded. In incidences where all relevant information could not be captured by the abstract, the full-text of the referenced evidence was used.

Evidence Not Selected. A survey of the literature was conducted to better understand the corpus from which the referenced evidence was selected. In addition to understanding what is included as evidence, as Bowker and Star (2000) note, there is value in understanding what has not been selected or has been omitted from the entry. The content of UpToDate is claimed to follow “a hierarchy of evidence consistent with most evidence-based resources” (UpToDate, “Editorial Policy,” 2017). Specifically,

[w]hen current, high-quality systematic reviews are available, UpToDate topics and recommendations rely heavily on these reviews. When such reviews are unavailable, UpToDate summarizes the key studies bearing on the clinical issues at hand. (UpToDate, “Editorial Policy,” 2016)

To gain an understanding of the body of available evidence from which authors select systematic reviews and clinical trials, a purposeful search was conducted in PubMed.

Specifically, the PubMed portlet, which links clinical trials to the systematic reviews, which subsequently cite them, was used (see Figure 6).

Am J Gastroenterol. 2009 Jun;104(6):1489-97. doi: 10.1038/ajg.2009.156.

A treatment trial of acupuncture in IBS patients.

Lembo AJ¹, Conboy L, Kelley JM, Schnver RS, McManus CA, Quilty MT, Kerr CE, Drossman D, Jacobson EE, Davis RB.

Author information

Abstract

OBJECTIVES: This study aimed to compare the effects of true and sham acupuncture in relieving symptoms of irritable bowel syndrome (IBS).

METHODS: A total of 230 adult IBS patients (75 % females, average age: 38.4 years) were randomly assigned to 3 weeks of true or sham acupuncture (6 treatments) after a 3-week "run-in" with sham acupuncture in an "augmented" or "limited" patient-practitioner interaction. A third arm of the study included a waitlist control group. The primary outcome was the IBS Global Improvement Scale (IBS-GIS) (range: 1 - 7); secondary outcomes included the IBS Symptom Severity Scale (IBS-SSS), the IBS Adequate Relief (IBS-AR), and the IBS Quality of Life (IBS-QOL).

RESULTS: Although there was no statistically significant difference between acupuncture and sham acupuncture on the IBS-GIS (41 vs. 32 % , P = 0.25), both groups improved significantly compared with the waitlist control group (37 vs. 4 % , P = 0.001). Similarly, small differences that were not statistically significant favored acupuncture over the other three outcomes: IBS-AR(59 vs. 57 % , P = 0.83), IBS-SSS (31 vs. 21 % , P = 0.18), and IBS-QOL (17 vs. 13 % , P = 0.56). Eliminating responders during the run-in period did not substantively change the results. Side effects were generally mild and only slightly greater in the acupuncture group.

CONCLUSIONS: This study did not find evidence to support the superiority of acupuncture compared with sham acupuncture in the treatment of IBS.

Save items

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Cited by 3 systematic reviews

Effectiveness of acupuncture to treat irritable bowel syndrome: a [World J Gastroenterol. 2014]

Review Acupuncture for treatment of irritable bowel syndr [Cochrane Database Syst Rev. 2012]

How large are the nonspecific effects of acupuncture? A meta-analysis [BMC Med. 2010]

Similar articles

Adequate relief in a treatment trial with IBS patients: a prospective [World J Gastroenterol. 2009]

Acupuncture for irritable bowel syndrome: a blinded placebo-con [World J Gastroenterol. 2005]

Review Acupuncture for irritable bowel

Figure 6: PubMed Portlet to Identify Citing Systematic Reviews

By using the portlet, systematic reviews that address clinical questions with similar elements of PICO (i.e.: Patient, Intervention, Comparison, Outcome) to referenced clinical trials in the entry could be identified.

Additionally, the size and nature of the body of qualitative research available across the eight topics was of interest. While clinical trials, especially randomized controlled trials, are privileged in the EBM hierarchy, qualitative research studies are rarely included in these, and rarely recognized as components of evidence for practice. While qualitative research is often overlooked in evidence hierarchies, this type of research provides empirical accounts of the lived experience of health conditions from the patient perspective (Al-Busaidi, 2008). In health-care, qualitative research provides insight about how patients experience, navigate, and respond to health challenges through empirical accounts of such events (Dancet, et al, 2011; Given, 2008). Because the current study was interested in the ways that the patient and patient-centred care is situated within evidence-based medicine and in turn, the ways that patients and their experiences are situated within UpToDate, an understanding of the availability of qualitative research was sought. Targeted literature searches were performed to identify qualitative research on the eight topics. Qualitative findings are presented in single qualitative studies and meta-analyses. Table 3 provides an overview of the search strategies used in PubMed to identify qualitative evidence. The searches were limited to those articles where the topic or condition is assigned as a major subject heading (denoted in PubMed as [Majr]) by PubMed in order to identify focused and highly relevant articles.

Case	Medical Subject Heading assigned to condition	Date Limiter	Strategy for Qualitative Studies	Strategy for Meta-Analysis
AOM	"Otitis Media"[Majr]	08/2015	AND "Qualitative	AND (("meta
AGA	"Alopecia"[Majr] AND "male"[MeSH Terms]	10/2015	Research"[Mesh] AND ("therapy"[Subheading] OR "therapy"[All Fields] OR "treatment"[All Fields]	synthesis" OR "metasynthesis") OR ("Meta- Analysis" [Publication Type] or "meta-analysis" and qualitative))
IBS	"Irritable Bowel Syndrome"[Majr]	10/2015	OR "therapeutics"[MeSH Terms] OR "therapeutics"[All Fields])	
FIB	"Fibromyalgia"[Majr]	11/2015		
CFS	"fatigue syndrome, chronic"[Majr]	11/2015		
N/CGB	((("Grief"[Majr]) OR "Bereavement"[Majr])	11/2015		
IPV	((("Domestic Violence"[Majr])	10/2015		

Table 3: Search Strategies to Identify Availability of Qualitative Evidence

The targeted searches for systematic reviews and qualitative research are not intended to be comprehensive, but rather to gain a general sense of the body of literature from which authors select evidence for inclusion in UpToDate. This is particularly of interest because UpToDate “follows a hierarchy of evidence consistent with most evidence-based resources” but lacks clear guidelines for the selection of evidence for UpToDate entries. Searches for systematic reviews help to gain an understanding of whether the searches for evidence in UpToDate follow the guidance of evidence based medicine that it is only when “every other

S fails (ie, no system, [summaries,] synopses, or syntheses)” that it is appropriate to look for original studies (Haynes, 2001, p. 37). Identifying the availability of qualitative research helps to gain an understanding of the prominence of the patients’ accounts of illness experiences in comparison to physician experiences in treating such conditions.

Overarching Qualitative Analysis

As noted earlier, the goal of this research was not only to identify and analyze what is explicitly cited and stated in UpToDate entries but also to understand what is implied by the manner in which content is expressed, and how, if at all, this relates to the core constructs in the Circuit of Culture. As such, a key component of the study is the overarching analysis of the texts that make up the seven cases. The qualitative content analysis was undertaken to identify themes and patterns in the ways in which the authors of the entries present the content they have selected for inclusion (Berg, 1995, 2007). Because this type of analysis has not been previously done, inductive analysis was critical to allow data analysis and concept development to occur simultaneously. The inductive approach allowed themes to emerge from the data iteratively, rather than relying on pre-determined themes. Qualitative content analysis was used for each entries making up the seven cases in an attempt to make inferences about three particular phenomena of interest: certainty, expertise, and the position of the patient, then relate these to the Circuit of Culture.

In order to facilitate valid and reliable inferences, a systematic and transparent procedure was followed and documented. To develop the codes and categories inductively, the constant comparative method outlined by Strauss and Corbin (1990) was used as a guide for analysis. Initially, the texts of the entries were read and coded with general descriptions of the content. This process focused on “breaking down, examining, comparing, conceptualizing and categorizing the data” (Strauss & Corbin, 1990, p. 61) At this open

coding stage, many descriptors, categories and a wide range of codes were recorded to describe the various elements of the data (Berg, 1995). Axial coding, where connections between the initial codes and categories are made and recorded, followed, where new higher order concepts emerged, evolved and were ultimately labelled (Strauss & Corbin, 1990, p. 96). Core themes emerged from axial coding and extensive documentation of what falls beneath the broader themes was recorded. Finally, once the core themes were identified, the data were analysed as a whole with the core themes and the Circuit of Culture constructs in mind. Key content or phrases that support and confirm the core themes were selected from the text and noted. Outlying divergent statements were also selected and recorded. Multiple readings of the entries with the core themes and subheadings were needed in order to ensure reliable coding. This overarching qualitative analysis was assisted by the use of the qualitative analysis software NVivo (v. 10).

Chapter 3: Results

This multiple case study analysis included seven topics, where two of the cases, i.e., those related to bereavement, were combined in the cross-case analysis. These cases represented varying levels of contestation, complexity, and certainty. This section first analyses the cases individually, followed by the cross-case analysis. Data sources analysed for each case included: the related main professional entries for each topic, the referenced evidence of the main entries (descriptive analysis only), and the patient information in Basic and/or Beyond the Basics format, when available. Each case contained one main entry, with the exception of Grief and Bereavement, which contained two interrelated entries. A brief introduction to each topic leads each case, including an overview of issues that are discussed and debated about the topic. A descriptive analysis of the references cited in each of the cases is then presented, followed by the textual analysis. Across the seven cases, three broad higher-order categories emerged from the textual analysis that address the initial research questions about certainty, expertise, and the role of patient: *Situating the Authors*, *Situating the Evidence*, and *Situating the Patient-Physician Relationship*.

The analysis of the patient information entries was conducted to evaluate how these align with the main UpToDate entry for professionals, specifically in relation to the representation of certainty and uncertainty of evidence and the framing of the patient-physician relationship, including decision-making responsibilities. The analysis of the patient information focused on the section addressing treatment in order to best align the patient and professional content for comparison.

Table 4 provides an overview of the topics and data sources analysed, including the review date (re: currency) and word counts of the analyzed data.

Topic		Main	Basics	Beyond
Case		Word Count	Word Count	Word Count
#		<i>Review</i>	<i>Review</i>	<i>Review</i>
		<i>Current</i>	<i>Current</i>	<i>Current</i>
1	Acute Otitis Media	6176 words	732 words	1539 words
AOM		08/2015	10/2015	10/2015
2	Androgenetic Alopecia	3693 words		1430 words
AGA		10/2015	N/A*	12/2015
3	Fibromyalgia	7489 words	534 words	3371 words
FIB		10/2015	12/2015	12/2015
4	Chronic Fatigue Syndrome	3847 word	736 words	1369 words
CFS		11/2015	12/2015	12/2015
5	Irritable Bowel Syndrome	5374 words	460 words	3202 words
IBS		11/2015	12/2015	01/2016
6	Normal Grief and Bereavement	2182 words		
GRF		11/2015	N/A	N/A
	Complicated Grief	2669 words		
		11/2015	N/A	N/A
7	Intimate Partner Violence	3679 words		
IPV		10/2015	N/A	N/A

*N/A: UpToDate does not provide patient information at this level (Basics or Beyond the Basics)

Table 4: Overview of Topics and Entries Analysed

Case Study Analysis: Acute Otitis Media

Acute Otitis Media (AOM) is a painful ear infection that causes the middle ear to become inflamed. AOM is a common illness in children. More than two-thirds of children will experience AOM before the age of three (Vergison, Dagan & Arguedas, 2010). AOM has a clear organic cause, and the cause and validity of the illness is not contested. However, while AOM is the diagnosis for which children are most frequently prescribed antibiotics, the necessity for and role of antibiotics in treating AOM is heavily debated. Because children can recover spontaneously without treatment, one option for care is observation with comfort measures, i.e., watchful waiting with analgesics. The other primary strategy for care is to treat AOM with antibiotics although there is “strong evidence that antibiotics provide minimal benefit” (Hansen, Howlett, Del Mar & Hoffmann, 2015). The caregiver’s understanding of and desire for treatment with antibiotics has been shown to be a key influence in the likelihood of antibiotics being prescribed (Cockburn & Pit, 1997; Hansen et al.; McNulty, Nichols, French, Joshi & Butler, 2013). The debate is further magnified when considering the current focus on reducing the use of antibiotics in order to prevent development of antibiotic resistant bacteria. In a 2015 editorial on antibiotics and AOM, Del Mar, Venekamp, and Sanders explain: “any recommendation that may increase the use of antibiotics in primary care will contribute to antibiotic resistance, which is now a serious threat to global public health” (p. 1574).

To guide physicians in providing care for children with AOM, the American Academy of Pediatrics (AAP) and American Academy of Family Physicians (AAFP) developed a clinical practice guideline in 2004. The organizations updated the guideline in 2013. The document provides recommendations to primary care clinicians for the management of children from six months through 12 years of age with uncomplicated AOM.

The guidelines present both observation and antibiotics as options for care of children with AOM over six months of age. The presentation of both options and the perceived lack of decisiveness and clear position by guidelines has been criticized (Nikolopoulos, 2014). The debate about the best approach to antibiotics in AOM pervades and is addressed in the UpToDate entry, *Acute Otitis Media in Children: Treatment*.

Descriptive Analysis

The AOM case contained 82 cited references ranging in date of publication from 1980-2015. Fewer than one quarter ($n=18$, 22%) of the references were published between 2010 and 2015. The vast majority (74%) of cited references were from UpToDate's list of core journals. The journal most commonly cited in the AOM main entry was *Pediatric Infectious Disease Journal*, a key journal identified by UpToDate.

This UpToDate entry contained evidence situated in three levels of the 6S hierarchy: Summary, Synthesis, and Study (Figure 7). Of the 82 references, there are also 15 (18%) cited that are not recognized as evidence in the 6S hierarchy: non-systematic/narrative reviews ($n=8$); public websites ($n=2$); editorials/commentaries ($n=3$), textbooks ($n=1$) and case reports ($n=1$). The majority of referenced evidence (59%) were studies; all 48 studies were quantitative, 21 of which were RCTs.

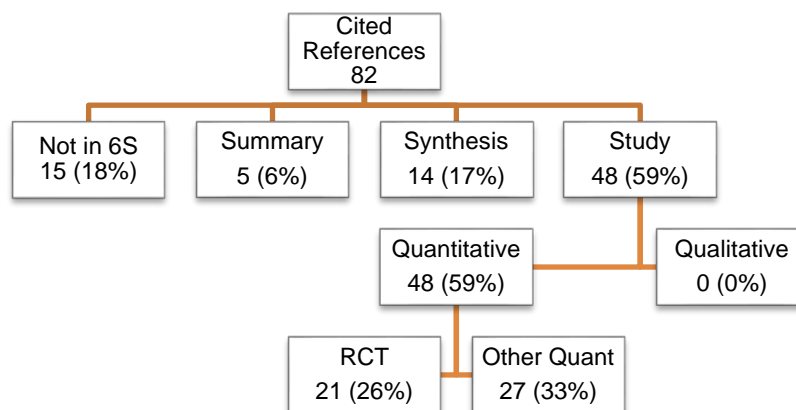


Figure 7: Types of Evidence in the AOM Entry

More than half of the cited studies were conducted in the United States ($n=27$, 56.3%). Three studies were multinational, all with partnerships with locations in the United States (two studies collaborating with sites in Canada and one with a site in Chile). Fourteen studies took place in European countries: (United Kingdom ($n=4$); France ($n=3$); Israel ($n=3$); Finland ($n=2$); and Italy ($n=1$); Denmark ($n=1$)); and one study each took place in Canada, Australia, Costa Rica and Japan.

The 82 cited references were written by a total of 376 authors. Based on the number of authors contributing to the paper, a proportional weighting was assigned for the background of each author. Across the 82 papers, the highest known proportional representation (.56) of the authors had a Medical Doctor (MD) background (see Figure 8).

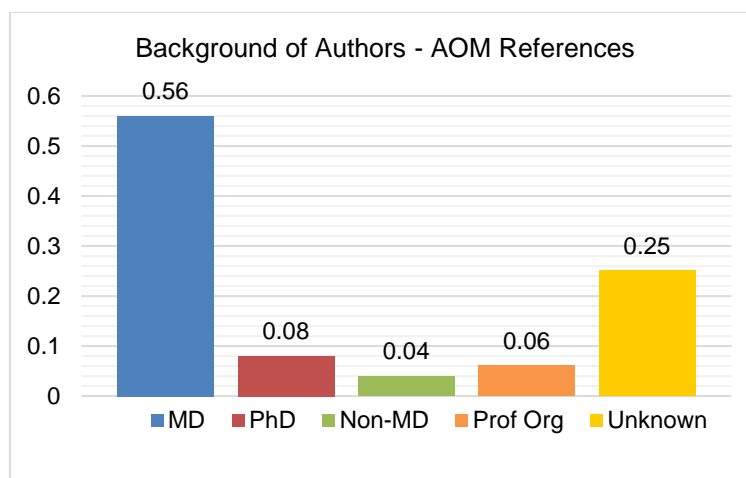


Figure 8: Relative Contributions by Author Background

Textual Analysis

Situating the Authors. The content of the AOM case is connected closely with the expertise of the authors. Most prominently, the authors share their expertise through their recommendations. The authors explicitly communicate their recommendations to the reader as their own position: “We recommend treatment to reduce ear pain in children with AOM whether or not they are treated with antibiotics” (AOM). Using the phrase ‘we recommend’ or ‘we suggest’ extensively, the authors make it overt that their guidance is developing out of

their own expertise and understanding. For example, they provide the following recommendation:

For children with AOM and tympanic membrane perforation, we suggest oral rather than topical antibiotic therapy. We suggest amoxicillin 90 mg/kg per day orally divided in two doses (we suggest a maximum of 3 g/day) as the preferred first-line oral therapy. (AOM)

The authors commonly provide specific details about the ways in which treatment options are enacted (e.g., the timing and allocation of medication dosages) by way of their own recommendations/suggestions. In addition to details about the execution of treatment regimens, the authors frequently connect their recommendations to specific patient features and circumstances. For example:

We suggest that children <2 years, children with AOM and tympanic membrane perforation, and children with a history of recurrent AOM be treated for 10 days. We suggest that children ≥ 2 years without tympanic membrane perforation or a history of recurrent AOM be treated for five to seven days. (AOM)

Follow-up for children whose symptoms have resolved depends upon the child's age and underlying medical problems, particularly language delay or learning problems. We suggest that:

Children <2 years be seen 8 to 12 weeks after diagnosis (by which time middle ear effusion will have resolved in 80 to 90 percent); many such children will already have a routine healthcare visit scheduled within this time frame

Children ≥ 2 years who have language or learning problems be seen 8 to 12 weeks after diagnosis

Children ≥ 2 years who are without language or learning problems be followed up at their next health maintenance visit, or sooner if there are concerns regarding persistent hearing loss (AOM)

The specific details about treatment, which vary depending on the individual patient's circumstances (e.g., age, medical history, presence of language and learning issues), are often provided by way of a recommendation by the authors.

There are 22 incidences where the authors utilize the phrase 'we suggest' or 'we recommend' to promote their approach to AOM through their own expertise. On selected

occasions, the authors followed up their recommendation with published evidence, which supports their recommended approach:

We suggest oral ibuprofen or acetaminophen for pain control in children with AOM [...] In a multicenter trial, 219 children (one to six years of age) with AOM were treated with antibiotics and randomly assigned to receive ibuprofen 10 mg/kg three times per day, acetaminophen 10 mg/kg three times per day, or placebo. (AOM)

We do not suggest pre-flight treatment with antihistamines or decongestants. In a randomized trial, predeparture administration of pseudoephedrine did not decrease ear pain, but was associated with increased drowsiness. (AOM)

The authors' endorsements of particular treatment options are presented first and then reinforced by clinical trials.

In addition to providing explicit recommendations, the authors also provide accounts of their own practices. The authors describe the approach to treatment that they take when treating children with AOM:

We generally treat children <2 years, children with tympanic membrane perforation, and children with recurrent AOM for 10 days. We generally treat children ≥ 2 years without a history of recurrent AOM for five to seven days. (AOM)

Through the accounts of their own routine practices (e.g., length of treatment based of patient characteristics), authors make implicit recommendations when treating patients and like the explicit recommendations, also often address the tailoring of treatment to individual patients.

In this case there is a noteworthy instance where the authors' steady presentation of their own recommendations by the phrase 'we recommend' or 'we suggest' was relinquished when the approach shifted from the prescription of antibiotics to observation. The authors provide guidance for four subgroups of children with AOM:

We recommend that children <6 months with AOM be treated immediately with an appropriate antibiotic.

We suggest that children six months to two years with AOM be treated immediately with an appropriate antibiotic;

We suggest that children ≥ 2 years who appear toxic; have persistent otalgia

for more than 48 hours; have temperature $\geq 102.2^{\circ}\text{F}$ (39°C) in the past 48 hours; have bilateral AOM or otorrhea; or have uncertain access to follow-up be immediately treated with an appropriate antibiotic.

For children ≥ 2 years who are normal hosts (eg, immune competent, without craniofacial abnormalities) and have unilateral AOM with mild symptoms and signs and no otorrhea, initial observation *may be appropriate* [emphasis added] if the caretakers understand the risks and benefits of such an approach. (AOM)

In this quotation, the authors provide a clear recommendation for antibiotics for three subgroups of children with otitis media. However, in the fourth and final bullet, the authors shift from the pattern of providing a clear recommendation—using ‘we recommend’ or ‘we suggest’—to stating that the approach of delaying or forgoing antibiotic treatment “may be appropriate” (AOM). Following three clear recommendations which the authors appear to ‘own’, the authors appear not to endorse or support their final suggestion.

Later in the case the authors provide additional details with respect to observation as a possible approach to treatment:

We suggest initial observation as an alternative to antimicrobial therapy for children ≥ 2 years who are normal hosts (eg, immune competent, without craniofacial abnormalities), without otorrhea, and who have mild symptoms and signs of unilateral acute otitis media (AOM) (ie, nonsevere ear pain for <48 hours and temperature $<39^{\circ}\text{C}$ [102.2°F]). Clinicians who recommend initial observation should exercise rigor in diagnosing AOM similar to that in the research protocols that support the safety of this practice. (AOM)

In this quotation, the authors do not endorse the treatment, but rather frame observation as an *alternative* treatment for this subgroup of children. The authors further separate themselves from the approach by referring to “clinicians who recommend initial observation” (AOM). The authors’ lack of full endorsement for observation as a treatment option for AOM is significant because of its alignment, or misalignment, with key clinical practice guidelines discussed in the *Situating the Evidence* section.

Situating the Evidence. The summary level of evidence is described by Haynes

(2007) as an integration of “best available evidence from the lower layers (drawing on syntheses [i.e., systematic reviews] as much as possible) to provide a full range of evidence concerning management options for a given health problem” (Haynes, p. 6). Both UpToDate and clinical practice guidelines are located in the Summary level of evidence. As established in the *Situating the Authors* section, the authors of this entry do not appear to fully endorse observation as a treatment option for children over 6 months of age. In contrast, the 2013 iteration of the AOM Clinical Practice Guideline of the American Academy of Pediatrics (AAP) and American Academy of Family Physicians (AAFP) recommends that for children as young as six months with unilateral AOM, “physicians should either prescribe antibiotic therapy or offer observation with close follow-up based on joint decision-making with the parent(s)/caregiver” (Lieberthal et al., 2013). The authors of the case acknowledge that their perspective counters this Clinical Practice Guideline:

The 2013 American Academy of Pediatrics (AAP) and American Academy of Family Physicians (AAFP) guideline recommends immediate treatment for children <6 months, children with severe signs or symptoms (defined by moderate or severe ear pain, ear pain for ≥ 48 hours, or temperature $\geq 39^{\circ}\text{C}$ [102.2°F]) and bilateral AOM in children <24 months of age. The 2013 AAP/AAFP guideline recommends either immediate treatment or observation (with pain control) for children between 6 and 24 months with unilateral nonsevere AOM and for children ≥ 24 months with unilateral or bilateral nonsevere AOM. *However, given the additional analysis now available showing a high rate of treatment failure among children <24 months with unilateral nonsevere AOM, we suggest that such children be treated with antimicrobial therapy.* (AOM, emphasis added)

The authors, here, describe the recommendations that are provided by the AAP and AAFP, which include options for both immediate treatment and observation, then highlight evidence that contradicts observation as a treatment option. In turn, they propose the alternative suggestion, the prescription of antimicrobial therapy for children less than 2 years of age. The preference for antimicrobial therapy aligns with their recommendation stated earlier: “We suggest that children six months to two years with AOM be treated immediately with an

appropriate antibiotic” (AOM). The authors also draw attention to other clinical practice guidelines that counter their recommendation: “Guidelines from other countries (e.g., the Dutch College of General Practitioners) recommend a no or delayed antibiotic strategy for most children with AOM” (AOM). Although the authors appear not to endorse initial observation as a treatment strategy, the authors repeatedly make clear that the guidelines affirm the option for observation. There is a willingness by the authors to position themselves counter to the published clinical practice guidelines.

In addition to highlighting the conclusions of clinical practice guidelines from the Summary level of evidence, the authors summon evidence from the Study and Synthesis level of the 6S hierarchy to exemplify certainty within the AOM case:

A 2001 meta-analysis concluded there is no evidence to support any particular antibiotic regimen versus another for treatment of AOM. (AOM)

Individual randomized trials that used stringent diagnostic criteria and experienced otoscopists to make the diagnosis of AOM and appropriate antibiotic regimens to treat AOM indicate that children younger than two years benefit from antibiotic therapy. (AOM)

The presence or absence of evidence is highlighted as a source of certainty in these examples. Throughout the case, there is wide variance in the amount of information that is provided about the referenced evidence from these levels, ranging from no details about the study to scant descriptions to extensive reports. In the quotations below, the variance in the extent of descriptions is demonstrated:

In a randomized trial, predeparture administration of pseudoephedrine did not decrease ear pain, but was associated with increased drowsiness. (AOM)

In a multicenter trial, 219 children (one to six years of age) with AOM were treated with antibiotics and randomly assigned to receive ibuprofen 10 mg/kg three times per day, acetaminophen 10 mg/kg three times per day, or placebo. On the second day of illness, fewer children who received ibuprofen or acetaminophen had pain (7 and 10 percent, respectively, versus 25 percent among placebo recipients); the reduction in pain was only statistically significant for ibuprofen. (AOM)

While the type of study design is included in both descriptions, it is only in the second quotation that details about the study's patient population (i.e., age and number), intervention (i.e., ibuprofen with dosage), comparators (i.e., placebo) and outcome (i.e., pain relief) were provided. Details about all elements of the PICO clinical question were included in the second quotation, while the first quotation only highlighted the basic outcomes of the study.

Descriptions of meta-analysis and systematic reviews also included varying levels of detail. Examination of the reporting of synthesis level of evidence provides a good example of the ways that the results and conclusions of a study or review influenced the level of description and detail by the authors. More detail about meta-analyses and systematic reviews that supported the prescription of antibiotics were provided than those that did not support antibiotic prescription. The single meta-analysis that demonstrated benefit of antibiotic care was described in a paragraph:

In a 2006 meta-analysis of individual data from six randomized trials (1643 children age six months to 12 years), children who were younger than two years who had bilateral AOM and children with otorrhea benefited most from antibiotic therapy. Among children younger than two years with bilateral AOM, 25 percent (95% CI 14-36 percent) fewer children treated with antibiotics than with symptomatic care continued to have pain and/or fever on days three to seven of illness. Among children with otorrhea, 36 percent (95% CI 19-53 percent) fewer children treated with antibiotics than with symptomatic care continued to have pain and/or fever on days three to seven of illness. (AOM)

The description of the meta-analysis includes details about the four PICO elements (i.e., patient, intervention, comparators, and outcome) of the investigated clinical question, as well as statistical results. In contrast, the description of five systematic reviews that do not support the use antibiotics is considerably shorter:

Systematic reviews and meta-analyses suggest that many children with AOM do well, even without antibiotic therapy, and that the benefits of antibiotics are modest. (AOM)

The authors cite five systematic reviews in the sentence quoted above. While the authors note that the intervention assessed was antibiotics in children, extensive details about the PICO elements are not provided, with the exception of a brief indication that the outcomes of the study found that “the benefits of antibiotics are modest” (AOM). The authors also follow-up the statement with critique of the conclusions:

However, many of the studies included in the meta-analyses had increased risk of bias (related to nonstringent diagnostic criteria, inclusion of children with mild disease, exclusion of patients <2 years of age, use of an inappropriate antibiotic or inappropriate dose, etc), making the results difficult to interpret. (AOM)

The authors highlight in this excerpt some of the shortcomings of the research, including bias within the study selection. The authors favour details about the systematic review supporting the use of antibiotics. The way in which these two systematic reviews containing conflicting findings are handled accentuate the authors’ ability to select what details about the evidence are brought to the fore.

The inclusion of commentary on the available evidence is common throughout the AOM case. The authors repeatedly provide critiques of the body of evidence available for AOM:

Randomized trials comparing immediate versus delayed antibiotics have used different outcome measures (eg, parental satisfaction, rate of filled prescriptions, etc) and types of follow-up (eg, telephone versus office examination). (AOM)

In this example, the authors highlight that the research studies evaluating AOM treatments often do not measure the same outcomes. In addition to the inconsistent outcomes across research studies, the authors’ commentaries also highlight methodological shortcomings of specific research studies including a lack of placebo, atypical dosing regimes, and unreliable diagnostic criteria. The authors also comment on insufficiencies in the research base as a whole. In particular, they draw attention to multiple areas where evidence is lacking or is

inconsistent:

Most clinical trials and standard pediatric practice provide a 10-day course of an oral antimicrobial agent for the treatment of AOM. However, some data suggest that a shorter course (ie, seven days) may be adequate. Unfortunately, many of the studies comparing short- and long-term antibiotic therapy have significant limitations that preclude definitive conclusions. (AOM)

These therapies have been proposed, but there are no placebo-controlled trials that directly address their effectiveness. (AOM)

The authors are transparent about gaps or inconsistencies in the current literature on AOM, giving rise to some uncertainty. In two instances within this entry, the authors fill in the lack of evidence in the research literature with their own recommendation:

Interventions to equalize middle ear and atmospheric pressure have not been well studied in controlled trials. We suggest that children be awake during descent and chewing gum or food (or sucking on a pacifier or bottle if they are too young to chew gum or food) to open the Eustachian tube and facilitate equalization of middle ear pressure. (AOM)

There are no randomized trials to guide treatment of recurrent AOM in children. [...] When recurrence occurs within 30 days of completion of antimicrobial treatment for the previous episode, we suggest [list of antibiotics]. (AOM)

The authors provide suggestions for care in the absence of evidence. This practice of authors ‘filling in’ where there is a lack of evidence aligns with the description of the work of authors and editors from UpToDate (UpToDate, “Physician Authors and Editors,” 2016).

Situating the Patient-Physician Relationship. The clinical practice guideline from the AAP/AAFP, which is referenced in the entry, states that the decision on which of the two approaches, observation or antibiotics, is adopted for a patient occurs “after joint decision-making with the parent(s)/caregiver” (Lieberthal et al., 2013, p. e965). In contrast, in the main UpToDate entry the clinician, rather than the patient, is positioned at the center of that choice:

When treating such children, practitioners should weigh the potential symptomatic benefit against the reported adverse events and potential for prolongation of middle ear effusion. (AOM)

In the quotation above, the practitioners are the decision-makers who assess multiple factors in order to make a choice. Physicians' need to consider specific patient characteristics is highlighted by the authors: "The choice of strategy depends upon the age of the child and the laterality and severity of illness" (AOM). Here, it is clear that the decision should take into consideration traits and characteristics of the patient; however, the responsibility for decision-making appears to rest with the physician. The focus on the physician in the decision-making process, and the subsequent absence of the patient/caregiver, runs counter to the AAP/AAFP guidelines that emphasize joint-decision making between the clinician and parent/caregiver (Lieberthal et al., 2013). Even when the factors are largely related to patient preference or patient context, overt acknowledgement and identification of the patient is absent in the text:

When the decision is made to treat acute otitis media (AOM) with antimicrobial agents, the selection among available drugs is based upon: Clinical and microbiologic efficacy; Acceptability (taste, texture) of the oral preparation; Absence of side effects and toxicity; Convenience of the dosing schedule; Cost. (AOM)

The decision-making for treatment is presented as the responsibility of physicians in consideration of the patient circumstances and preferences. The patient experience was treated much like patient preferences in that it was disconnected from the patient. The focus is not on patient experience, but rather the resolution of symptoms.

There are three instances in the AOM case where the caretakers of children with AOM are specifically mentioned. All three are in relation to the caretakers' need to understand the risks and benefits of observation:

When the initial observation strategy is chosen, caretakers must understand the risks and benefits, and appropriate follow-up must be ensured so that

antibiotic therapy can be initiated if symptoms worsen or persist after 48 to 72 hours. (AOM)

As demonstrated in the excerpt above, the authors only refer to caretakers when emphasizing the need for caretakers to comprehend the risks and benefits of not initiating antibiotics immediately. The caretaker's need for awareness of risks and benefits was only discussed in relation to observation therapy but not the alternative, antibiotic therapy. The effect of antibiotic resistance on the patient or the public is minimally addressed in the entry:

“Although the child is at higher risk for a nonsusceptible pathogen, we suggest high dose amoxicillin-clavulanate as initial therapy, even if the child received amoxicillin-clavulanate for the previous episode” (AOM). Antibiotic resistance is primarily discussed in relation to the resistance and domination of certain bacteria to particular antibiotics, but not in relation to the impact or responsibility of the patient:

Macrolide or lincosamide antibiotics can be used to treat AOM in children who have had an immediate type 1 hypersensitivity reaction (anaphylaxis, angioedema, bronchospasm, or urticaria) to amoxicillin or other beta-lactam antimicrobial agents. However, macrolide or lincosamide resistance is common (approximately 25 to 35 percent) among isolates of *S. pneumoniae*, and macrolides and lincosamides generally are not effective for eradication of *H. influenzae*. (AOM)

Trimethoprim-sulfamethoxazole, macrolides (eg, erythromycin-sulfisoxazole, azithromycin, clarithromycin), and lincosamides (eg, clindamycin) are not recommended for AOM that fails to respond to treatment with high-dose amoxicillin. Pneumococcal surveillance studies indicate that resistance to these agents is substantial). (AOM)

Antibiotics resistance is addressed through underscoring the antimicrobial activities of different antibiotics: physicians' and patients' responsibility to prevent antibiotics resistance is not addressed. The authors advise physicians to caution patients about the risks of observation; however, the side effects or risks of antibiotics are not included as key components of the physicians' education for AOM caregivers.

Patient Information. UpToDate provides patient information in two forms, *The Basics* and *Beyond the Basics*. The two patient entries were analysed to evaluate how the patient information entries align with the main professional UpToDate entry in relation to the representation of certainty and uncertainty of evidence and the framing of patient-physician relationship, including decision-making responsibilities. The analysis of the patient information is focused on the sections addressing treatment of acute otitis media in order to best align the patient and professional content for comparison.

As discussed, two strategies for care are available when treating AOM in children. Both treatment approaches are presented in patient information entries. In *The Basics*, the two treatments options for AOM are outlined as such:

Doctors can treat ear infections with antibiotics. These medicines kill the bacteria that cause some ear infections. But doctors do not always prescribe these medicines right away. That’s because many ear infections are caused by viruses — not bacteria — and antibiotics do not kill viruses. Plus, many children get over ear infections without antibiotics. (AOM Basics)

In this excerpt from *The Basics* patient information, the rationale behind each choice is described. The cause of AOM and the effects of antibiotics primarily dictate this choice. This explanation of choice is followed by an explanation of what children commonly are and are not prescribed antibiotics.

Doctors usually prescribe antibiotics to treat ear infections in infants younger than 2 years old. For children older than 2, doctors sometimes hold off on antibiotics. Your child’s doctor might suggest watching your child’s symptoms for 1 or 2 days before trying antibiotics if: Your child is healthy in general; The pain and fever are not severe. (AOM Basics)

The recommendations outlined here align with author recommendations to prescribe antibiotics for children under the age of two. In contrast, the 2013 clinical practice guideline of the AAP/AAFP “recommends either immediate treatment or observation (with pain control) for children between 6 and 24 months with unilateral nonsevere AOM” (AOM). The

patient information, while presenting both options for care, the specifics of the two treatment options align closer with the authors' recommendations than with the AAP/AAFP guidelines.

The Basics version of the patient information does align closely with the AAP/AAFP in terms of a shared decision-making process between health care professional and caretaker:

You and your doctor should discuss whether or not to give your child antibiotics. This will depend on your child's age, health problems, and how many ear infections he or she has had in the past. (AOM Basics)

The physician and the caregiver are presented as shared decision-makers. This emphasis on joint decision-making is only present in the basic information. In contrast, decision-making in the *Beyond the Basics* patient information is not presented as a shared process. The choice is based on choosing the *best* treatment for the patient: "The 'best' treatment depends on the child's age, history of previous infections, degree of illness, and any underlying medical problems" (AOM Beyond). These four factors that dictate the best treatment are followed by short explanations about who is most likely to receive observation or antibiotics based on these four factors. For example, the following explanation about how age influences the likelihood of antibiotic prescription:

Antibiotics are usually given to infants who are younger than 24 months or who have high fever or infection in both ears. Children who are older than 24 months and have mild symptoms may be treated with an antibiotic or observed to see if they improve without antibiotics. (AOM Beyond)

The appropriateness of antibiotics for children who are younger and or who have more significant symptoms is highlighted (aligning with the authors' recommendations, not the AAP/AAFP guidelines). A similar description of who is best suited for observation (i.e., those who are older, healthy and have less severe symptoms) is also included in the entry. In the *Beyond the Basics* entry, the notion that there is a "best" treatment based on medical status and history places a great deal of decision-making responsibility with the physician because of the implied need for the physician's expertise to identify the most suitable

treatment.

Additional roles of the caregiver highlighted in both entries include ensuring symptom identification, pain control, and proper follow-up. The importance of monitoring and follow-up is emphasized when observation is adopted as the treatment approach.

In substantial contrast to the UpToDate entry, the risks of antibiotics are put forth in the *Beyond the Basics* patient information:

Antibiotics can have side effects such as diarrhea and rash, and overusing antibiotics can lead to more difficult to treat (resistant) bacteria. Resistance means that a particular antibiotic no longer works or that higher doses are needed next time. (AOM Beyond)

These side effects are not emphasized in the main entry for professionals.

The patient information does not reflect the same preference for antibiotics that the authors of the main entry inferred. The patient information resources present both observation and antimicrobial therapy as options for treatment. However, antibiotics for children between 6 months and 2 years of age are favoured over the AAP/AAFP guidelines for the choice between antibiotics or observation. Further, the patient information provides insight into some of the potential side effects and outcomes of antibiotic prescribing. There is also variance within the two patient information sources concerning with whom the responsibility for decision-making sits. Specifically, *The Basics* accentuate the need for shared decision-making between patient and physician. In contrast, the presentation of a “best” treatment in *Beyond the Basics* implies that physician expertise is needed to identify the best option. There are substantial inconsistencies across the main professional entry, *The Basics* patient information, and the *Beyond the Basics* patient information.

Case Analysis: Androgenetic Alopecia

Androgenetic alopecia (AGA) is a common form of hair loss and is often referred to as male pattern balding. In AGA, hair is lost in a well-defined pattern beginning above both temples and over time, the hairline recedes to form a characteristic 'M' shape. While androgenetic alopecia can affect both men and women, the analyzed UpToDate main entry, *Treatment of Androgenetic Alopecia in Men*, only addresses the condition in men. A separate entry for AGA in women is included in UpToDate. AGA affects 30% of Caucasian men by the age of 30 and the incidence of AGA increases with age with up to 80% of men affected by the age of 70 (Ellis, Sinclair & Harrap, 2002; Yip, Rufaut & Sinclair, 2011). While alopecia in men is a common process that accompanies aging, the societal imperatives regarding maintenance of the appearance of vigour and vitality has led to a demand for intervention to treat this common process. Although balding is a normal process of aging, androgenetic alopecia is a condition often diagnosed and treated by physicians (Ellis, Sinclair & Harrap, 2002; Moynihan, 2002).

Descriptive Analysis

The AGA case contained 41 cited references ranging in publication date from 1987 to 2015. Twelve of the 41 references (29%) were published between 2010 and 2015. The majority (63%, $n=26$) of cited references were from UpToDate's list of core journals. The most commonly cited journal in the AGA main entry was the *Journal of the American Academy of Dermatology*, a core UpToDate journal.

The UpToDate entry for AGA contained three types of evidence from the 6S hierarchy: Summary, Synthesis, and Study (see Figure 9). Twenty-two per cent ($n=9$) of the cited references were not recognized as evidence in the 6S hierarchy. These nine references were made up of seven non-systematic reviews, a case report/brief, and a drug information

brief. Only one summary and one synthesis (systematic review) were cited in the entry.

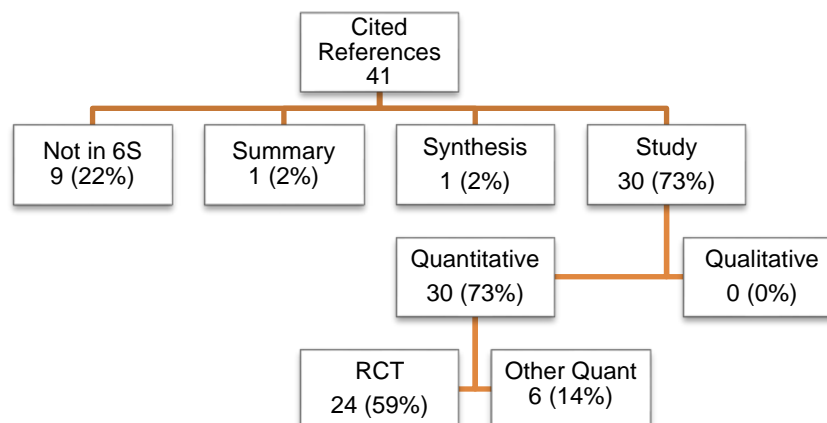


Figure 9: Types of Evidence in AGA Main Entry

Approximately three quarters of the cited references ($n=30$) were studies, all of which were quantitative, with 24 RCTs and most conducted in the US ($n=20$, 67%). Two multinational studies were cited, both in partnerships with locations in United States. Three studies took place in European countries (Germany ($n=2$), Turkey ($n=1$)), and one each in Canada, Japan, Iran, and India. It is unknown where one study of the 30 studies was conducted.

The 41 cited references were written by a total of 203 authors. Across the 82 papers, the highest known proportional representation (.51) of the authors had a Medical Doctor (MD) background.

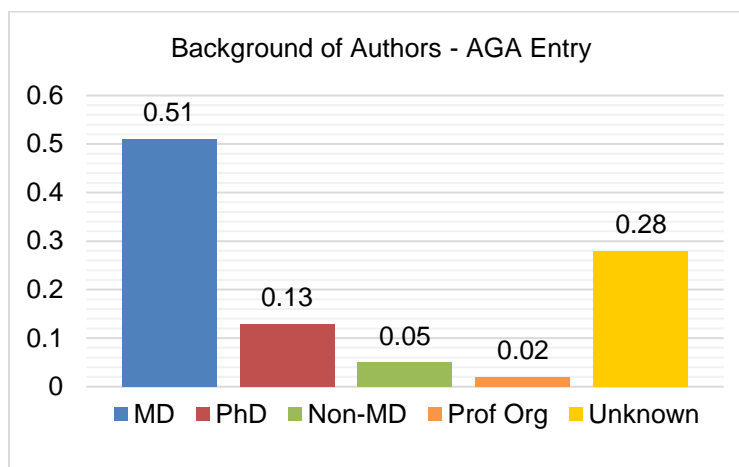


Figure 10: Relative Contribution by Authors' Background in the AGA main entry

Textual Analysis

Situating the Authors. While the use of ‘we’ is supported by the Editorial Policy of UpToDate and is common throughout the previous case (AOM), in the AGA case, the authors did not overtly acknowledge themselves in the content. Instead, the authors presented the information without explicit recognition of themselves as a source of expertise.

The authors only make one reference to themselves as authors and experts:

For male patients with androgenetic alopecia who desire treatment, we suggest treatment with oral finasteride (1 mg/day) over topical minoxidil. Treatment with minoxidil 5% solution or foam is an alternative first-line therapy that may be preferred by patients who prefer to avoid systemic therapy. The response to treatment with both agents is variable. No high quality randomized trials have directly compared their efficacies. (AGA)

In this quotation, which appears in the *Summary and Recommendation* section, the authors provide guidance to the reader to use one treatment over another. By making use of the ‘we suggest’ statement, the authors make explicit that this recommendation comes from their own endorsement, aligning with UpToDate policy (UpToDate, “Editorial Policy,” 2016).

Concurrently in the statement, the authors acknowledge that the evidence base to support their recommendation is not strong.

There is content in the main entry for which the source of the knowledge is ambiguous; it may be emerging from the authors’ expertise, but there is no explicit acknowledgment as such. For example, the authors note that: “[m]en utilizing minoxidil for androgenetic alopecia *should* be advised of the following: [List of patient information needs]” (AGA). There is no reference to where this information originates and the use of the word ‘should’ frames this as guidance. The source of the expertise, experience, or evidence is not made explicit.

Situating the Evidence. In the absence of situating themselves in the content, the authors present the evidence as the primary source of certainty for the effectiveness of

treatments for AGA. The body of evidence available to the authors is the basis for justifying treatment selections:

In addition to improved hair counts, other factors, such as increases in hair thickness, pigmentation, and length may contribute to the perception of improved scalp coverage during therapy. This concept is supported by a randomized trial that followed men treated with finasteride for up to 192 weeks and found that net improvements in hair weight were greater than improvements in hair count. (AGA)

Here, the authors draw from a randomized trial for support. The authors also highlight the existence of a seemingly broad research base as a means to support the two first-line treatments:

Topical minoxidil and oral finasteride are the therapeutic agents that have been most extensively studied for the treatment of androgenetic alopecia in men. Both drugs have demonstrated efficacy and high tolerability in placebo-controlled randomized trials, supporting their status as first-line agents. (AGA)

The authors evaluate treatments based upon type and breadth of research available, often underscoring the volume of research available: “In comparison to finasteride, fewer studies have evaluated the efficacy and safety of dutasteride in male androgenetic alopecia” (AGA). They note the lack of a broad research base and bring attention to areas where the evidence is insufficient. In turn, they highlight the need for more research evaluating novel therapies, comparing between treatment options, appraising the effectiveness of combination therapies, and assessing treatment side effects.

The highlighted lack of significant research and understanding about the risk for sexual dysfunction and male breast cancer as a result of a first-line AGA treatment is noteworthy. The authors state that little is known about sexual dysfunction as a side effect of finasteride and the need for more research:

Additional studies are needed to validate these findings and evaluate the frequency with which persistent sexual dysfunction might occur. (AGA)

Nevertheless, finasteride is identified as a first-line therapy.

The majority (73%) of the references cited in the AGA entry were quantitative studies, and more than half were RCTs. The details provided about the studies varied greatly. Few or no details were provided for some (e.g., “A randomized trial of 326 men found that the drug was efficacious for frontal scalp hair thinning” (AGA)) while others were detailed extensively:

Data from an evaluator-blinded randomized trial of 99 men with midfrontal and/or vertex androgenetic alopecia that compared finasteride 1 mg/day with the 2% formulation of minoxidil are less straightforward. Although patients and evaluating clinicians were more likely to perceive increased hair growth at three months with minoxidil, at 12 months, finasteride was associated with significantly greater increases in hair counts, and the differences in patient and evaluator global assessments of clinical response were not statistically significant (62 versus 56 percent improved on blinded evaluator assessment) (AGA).

In the largest randomized trial that compared the 5% and 2% solutions, 393 men with androgenetic alopecia were randomly assigned to treatment with 5% or 2% topical minoxidil solution or placebo. After 48 weeks of therapy, 5% minoxidil was significantly better than the 2% solution or placebo in terms of change from baseline in nonvellus hair count (increase in count of 18.6, 12.7, and 3.9 per cm², respectively), patient ratings of scalp coverage and treatment benefit, and investigator rating of scalp coverage. Treatment with 5% minoxidil was also associated with an earlier therapeutic response and an improvement in the patients' psychological perceptions of hair loss. However, patients treated with 5% compared with 2% minoxidil reported more pruritus and local irritation. (AGA)

The sole systematic review was cited twice in the AGA main entry with a focus on study outcomes:

A meta-analysis of placebo-controlled randomized trials identified moderate quality evidence in support of the use of finasteride for treatment of androgenetic alopecia in men. After 6 or 12 months of treatment, the mean percentage change in hair count was 9 percent higher among patients treated with finasteride compared with patients who were given placebo (95% CI 8-11 percent). This difference increased over time. After 48 months of therapy, the mean percentage change in hair count was 24 percent (95% CI 18-31 percent) higher in patients treated with finasteride. (AGA)

This systematic review is later cited when the side effects of sexual dysfunction are addressed in the AGA main case, stating: “A systematic review of nine trials with a total of 3570 patients found an overall absolute increase in sexual dysfunction of 1.5 percent” (AGA). Here, new information is provided about the review, including the number of studies and the number patients included. Both times the systematic review is cited, the authors highlight the type of evidence (i.e., systematic review) from which the knowledge emerges. In contrast, only one summary level resource was cited in the main entry of the AGA case and the authors made no indication of its level of evidence (i.e., summary) or type of resource (i.e., clinical practice guideline) when citing. The ‘Evidence-based (S3) guideline for the treatment of androgenetic alopecia in women and in men’ was published in the *Journal der Deutschen Dermatologischen Gesellschaft*. The main entry stated: “Hair shedding may occur at the initiation of treatment and is thought to occur as a result of the stimulation of telogen follicles to reenter the anagen phase” (AGA). While there is a parenthetical reference, there is no indication of the type of evidence from where the information emerges. There was also no acknowledgement of the type of resource that the information emerged from when information was cited from resources not recognized as evidence by the 6S hierarchy.

Situating the Patient-Physician Relationship. The patient’s experience of hair loss is the key driver for people to seek treatment for the condition. The authors acknowledge in the beginning and at the end of the main entry that hair loss is a normal process that has evolved into a medical issue due to non-medical concerns:

Although androgenetic alopecia is a benign and asymptomatic disorder, cosmetic concerns lead some patients to seek treatment. (AGA, repeated in summary)

AGA is a cosmetic, not medical, concern. While not explicitly denoted as an example of medicalization, the authors highlight that AGA poses no harm or risk to the patient. Beyond the recognition that it is “cosmetic concerns that lead some patients to seek treatment” (AGA), there is no explanation of how these cosmetic concerns affect the individual.

References to the AGA patient focus on the potential for and experience of side effects when receiving treatment. Specifically, the side effects of the two first-line treatments are discussed. The side effects of and precautions for minoxidil are described in single paragraph highlighting that few patients experience side effects and the most common are skin reactions and irritations. In contrast, the side effects of and precautions for finasteride are covered more extensively. The authors advise that physicians be aware of rare side effects including gynecomastia, testicular pain, and depression that “are more likely to occur with the typical 5 mg dose used to treat benign prostatic hypertrophy” (AGA). The authors also highlight uncertainty around the effect of treatment on the levels of prostate specific antigen, the risk of prostate lesions, and the risk for male breast cancer. While these and other precautions of finasteride are briefly acknowledged, more significant attention is paid to the effect of finasteride on sexual function. The information provided by the authors focus on the prevalence and persistence of the sexual side effects based on the published evidence:

A systematic review of nine trials with a total of 3570 patients found an overall absolute increase in sexual dysfunction of 1.5 percent. The risk for sexual side effects increases with age. Sexual side effects related to finasteride usually resolve after discontinuation of the medication. However, persistent sexual dysfunction after the discontinuation of finasteride was reported in a survey-based study of 71 men who associated their symptoms of sexual dysfunction with the use of finasteride for hair loss. The mean age of the study participants was 26 years and the mean duration of finasteride use was 28 months. Twenty percent of these men reported continued symptoms for greater than six

years after cessation of the medication. Moreover, a follow-up study of 54 of the interviewed men found that 9 to 16 months after the initial survey, 96 percent continued to report sexual side effects. Additional studies are needed to validate these findings and evaluate the frequency with which persistent sexual dysfunction might occur. Reductions in sperm count also may occur during treatment with finasteride. This effect reverses after drug discontinuation. (AGA)

This excerpt cites one systematic review and eight studies that identify and evaluate side effects related to sexual function. The authors do not address the impact of these side effects on patient experience, the likelihood of patient discontinuation of treatment due to these side effects, or ways that physicians might address these side effects, based on published evidence or clinical observation. Unlike other entries included in the multiple case study, the authors do not include their personal experiences, or their tacit knowledge, with patients as a source of knowledge.

In the AGA case, there is little acknowledgement of the interaction between physician and patient during treatment. The role of the physician in patient education when treating is referred to once within the entry: “Men utilizing minoxidil for androgenetic alopecia should be advised of the following: [list].” Patient education for minoxidol in AGA treatment includes the need for: proper application, continuous treatment to maintain effect, and recognition of the possibility of side effects. This one instance of patient education is the only indication of interaction between the patient and physician.

As stated in *Situating the Evidence*, the authors refer heavily to the results of studies as a key element for selecting treatments for patients; however, the authors do acknowledge the variability in patient preference that will influence the choice of treatments:

Treatment with minoxidil 5% solution or foam is an alternative first-line therapy that may be preferred by patients who prefer to avoid systemic therapy. (AGA)

The subsequent development of minoxidil 5% foam offered an alternative vehicle for drug delivery that is preferred by some patients. (AGA)

Preferences of patients are acknowledged as factors for consideration when deciding on a treatment plan; however, decision-making responsibility is not addressed explicitly within the entry.

Patient Education. In stark contrast to the main entry written for professionals, the difficulties of experiencing hair loss are overtly and extensively addressed. The entry states early in the entry that for “many people, losing their hair is a frustrating experience” (AGA Beyond). The challenging nature of the condition is described in the patient information as:

The psychosocial impact of hair loss can be severe for some people, especially women, since there is little understanding or acceptance of the condition. Women may have difficulty with issues of low self-esteem or feeling unattractive. (AGA Beyond)

In this quotation, women are also suggested to have a more difficult time with hair loss and in turn may suffer from low self-esteem and feelings of being unattractive. While the main entry for AGA addressed only treatment in men, there was acknowledgement that men are pushed towards treatment because of cosmetic, not medical, concerns. The expansion of the patient information to include women provided interesting contrast to the ways the psychosocial effects of hair loss factors are framed. The cosmetic concerns are not outlined in any detail in the main entry, but “low self esteem and feeling unattractive” may also describe the cosmetic concerns of men.

The entry contains additional guidance to help the patient navigate the psychological and social issues related to AGA:

If you are having difficulty with the psychosocial impact of losing your hair, speak to a healthcare provider about your feelings. Providers can offer support and may recommend that a patient work with a therapist, clinical psychologist, or support group; individual and group therapy can help patients adjust and cope with hair loss, and may also provide tips on cosmetic coverings. (AGA Beyond).

While the need for psychosocial support is recognized in the patient information, there is no acknowledgement of the need for additional support in the professional entry.

The two first-line treatments for men, minoxidil and finasteride, are discussed alongside a unique drug appropriate and safe only for women. Information about minoxidil includes how the treatment works, how to apply, what to expect (e. g. time to see effects; transience of effects after discontinuation). The lack of consistent results for the treatment is also acknowledged in the patient information.

Not all people benefit from minoxidil. The best results are seen when baldness has been present for less than five years, when it affects the crown (top) of the head, and when the area of hair loss is less than 10 centimeters in diameter. Studies have shown that 30 to 40 percent of men and women with crown hair loss experience cosmetically significant results with minoxidil. (AGA Beyond)

The inconsistent results across patients are acknowledged and in turn the attributes that increase the likelihood of success are highlighted. The side effects and precautions of the treatment area also made clear:

Minoxidil causes few side effects. Occasionally, the skin may become irritated. Body-wide side effects are possible if minoxidil is absorbed through cracks or cuts in the scalp. People with a history of heart disease, in particular, should watch for systemic side effects, such as an increased heart rate, swelling in the hands or feet, or weight gain. (AGA Beyond)

The information provided about finasteride is much briefer. Finasteride is described as “a pill that decreases the production of one of the hormones associated with androgenetic alopecia, resulting in an increased amount of hair covering more of the scalp” (AGA Beyond). The possible effect of sexual dysfunction covered at length in the main professional entry is briefly acknowledged:

Men can take finasteride by mouth at a dose of 1 milligram (mg) per day. Higher doses of finasteride (such as those used to treat some prostate conditions) can cause side effects including erectile dysfunction and decreased sex drive. However, such side effects are rarely seen with the 1 mg dose used

to treat hair loss. (AGA Beyond)

Few details about the sexual side effects for finasteride are presented in the patient information. The patient information communicates that the side effects are rarely seen in patients treated with finasteride for hair loss. In comparison, the authors of the main professional entry call upon a systematic review, which included 3570 patients to provide a rate of prevalence for sexual side effects of 1.5%. When comparing the main professional and patient entries subtle differences in the presentation of the psychological effects of AGA and the potential side effects emerged.

Case Analysis: Irritable Bowel Syndrome

Irritable Bowel Syndrome (IBS) affects the large intestine (colon) and is characterized by chronic abdominal pain, discomfort, bloating, and alteration of bowel habits. Diarrhea or constipation may predominate, or they may alternate. This variability has given rise to subtypes of irritable bowel syndrome: IBS-C (irritable bowel syndrome with constipation), IBS-D (irritable bowel syndrome with diarrhea), and IBS-M (mixed IBS with constipation and diarrhea). The cause of IBS is unknown and the diagnosis is symptom-based. Because of the multiple factors that are considered to be elements of the root cause of IBS, including psychological influences, Wessely and Hotopf (1999) described IBS alongside Fibromyalgia and Chronic Fatigue Syndrome as occupying “that grey area between medicine and psychiatry” (p. 430). Moynihan et al. present the diagnosis of IBS as an example of medicalization because of its portrayal of mild problems as serious illnesses that need to be treated aggressively with medications. However treatment of IBS is complicated by the variability in symptoms, the uncertainty in the cause, and its psychological elements.

Descriptive Analysis

The IBS case cited 89 references ranging in date of publication from 1984-2015. Fewer than half ($n=35$, 39%) of the references were published between 2010 and 2015. Fewer than one quarter of the cited references (22%) were from UpToDate’s list of core journals. *American Journal of Gastroenterology*, a core journal, was the most commonly cited, at 14 times.

The UpToDate entry contained three types of evidence from the 6S hierarchy: Summary, Synthesis, and Study (see Figure 11). Eleven of the 89 references (12%) cited are not sources recognized as evidence within the 6S hierarchy. Of these, seven are non-systematic/narrative reviews, two are drug profiles, one is a textbook and the other is the U.S.

Food and Drug Administration website. Three clinical practice guidelines (Summary level of evidence) were cited in the entry. Seventeen per cent of references cited ($n=15$) were systematic reviews, which are situated in the Synthesis level of the 6S hierarchy. Sixty of the 89 references (67%) of the references were quantitative studies ($n=60$), of which 50 were RCTs.

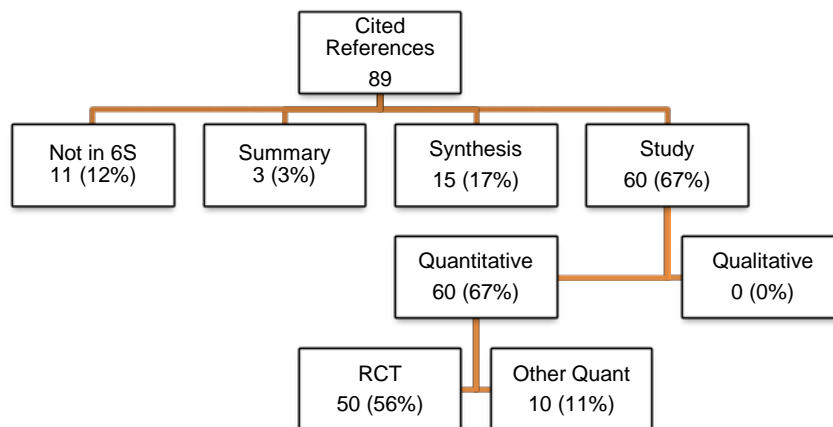


Figure 11: Type of Resources Cited in the IBS Main Entry

The United States ($n=26$, 43%) is the most frequent location of the cited individual studies. The remaining 34 studies took place across the globe: United Kingdom ($n=7$), Australia ($n=5$), China ($n=4$), Netherlands ($n=3$), Norway ($n=2$), Iran ($n=2$), France ($n=1$), India ($n=1$), Canada ($n=1$), Belgium ($n=1$), Italy ($n=1$), Lebanon ($n=1$), Spain ($n=1$), Sweden ($n=1$), Taiwan ($n=1$). There were two multinational studies spanning the United States and Canada, and multiple European countries.

The 89 references making up the IBS case were written by 534 authors. The relative contribution from the array of professional backgrounds of the authors was determined. Across the 89 papers, the highest known proportional representation (.33) of the authors had a Medical Doctor (MD) background followed by Basic Scientists (.08). The backgrounds of the authors of the articles cited in the IBS entry included professional organizations (.02) and non-physician (MD) health professionals (.03) (i.e., nurses, pharmacists, public health

professionals). Proportionally across all 46 papers, .54 of the backgrounds of authors were unknown.

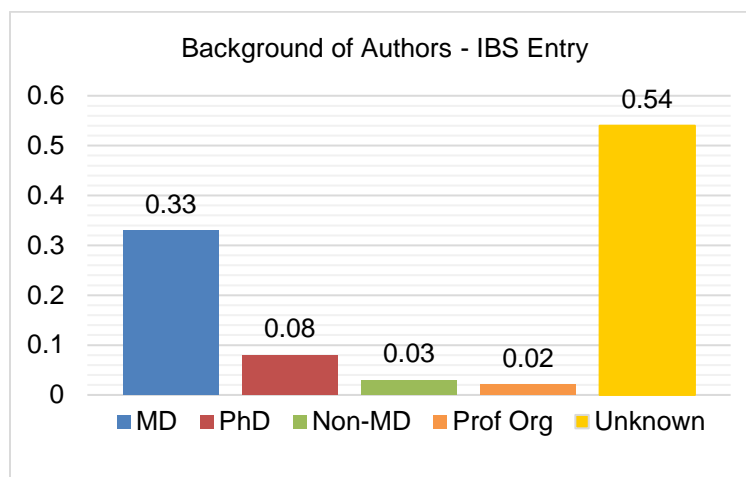


Figure 12: Relative Contribution by Authors' Background in the IBS main entry

Textual Analysis

Situating the Authors. The authors share their expertise and experience throughout the main entry of IBS, mainly through the provision of recommendations. The authors of the case share their expertise by way of clear recommendations for the care of patients. For example, the authors advise: “In patients with persistent abdominal pain despite antispasmodics, we recommend a trial of antidepressants” (IBS). In alignment with the guidance of the UpToDate *Editorial Policy*, author recommendations are clearly delineated by the phrases ‘we recommend’ or ‘we suggest.’

The authors focus many of their recommendations on providing specific details about treatment regimens. For example, they suggest specific details about the treatment regime for the pharmacotherapy, loperamide: “In patients with IBS-diarrhea (IBS-D), we suggest loperamide 2 mg 45 minutes before a meal on regularly scheduled doses” (IBS).

The authors provide details about the exact dosage and timing of the drugs as a

suggestion. The recommendations often provide guidance to the reader about how to implement potential treatments.

Overwhelmingly, the authors of the IBS case provide recommendations for treatments aimed at patients who have not responded to other initial therapies. The following examples demonstrate the recommendations for care following an unsuccessful treatment trial:

In patients with IBS with constipation (IBS-C) who have failed a trial of soluble fiber (eg, psyllium/ispaghula), we suggest polyethylene glycol (PEG). We treat patients with persistent constipation despite treatment with PEG with lubiprostone or linaclotide. (IBS)

We also suggest an empiric trial of a lactose-free diet in patients who complain of persistent abdominal bloating despite exclusion of gas-producing foods. (IBS)

While antibiotics should not be routinely recommended in all patients with IBS, in patients with moderate to severe IBS without constipation, particularly those with bloating, who have failed to respond to other therapies (eg, a diet low in fermentable oligo-, di-, and monosaccharides and polyols [FODMAPs], antispasmodics, and TCAs), we suggest a two-week trial of rifaximin. (IBS)

Because of the variability in IBS symptoms, the variability in treatment response, and the overall lack of clarity around IBS, multiple treatments aimed at alleviating symptoms often are attempted for a single patient. The authors provide their recommendations as to how physicians may progress and navigate through the treatment options, almost by trial and error. The possibility of repeated failed treatments led the authors to suggest treatments that lack strong evidence:

We suggest a two-week trial of a gluten-free diet in patients with diarrhea-predominant IBS (IBS-D) with significant abdominal bloating and flatulence whose symptoms have failed to improve with a low FODMAP diet and avoidance of gas-producing foods. However, there is limited evidence to support gluten avoidance in patients with IBS. (IBS)

The authors acknowledge that there is little evidence to support the suggestion to avoid gluten in patients with IBS however UpToDate supports the provision of recommendations when strong evidence is not available.

In addition to providing recommendations about treatments by way of phrases such as ‘we recommend’ or ‘we suggest’, the authors also provide details about what they do in their own practice. For example,

We initially start with 17 g of powder dissolved in 8 ounces of water once daily and titrate up or down (to a maximum of 34 g daily) to effect. However, side effects of bloating and abdominal discomfort limit the use of PEG. (IBS)

In patients with abdominal pain due to IBS, we use antispasmodics on an as-needed basis. (IBS)

The authors’ choice to present accounts of what occurs within their own practices gives rise to an implied endorsement, comparable to the explicit recommendations and suggestions for the treatment regime. Moreover, statements of the authors’ own practices are similar to the recommendations because they also address treatment options in light of failed treatment:

We treat patients with persistent constipation despite treatment with PEG with lubiprostone or linaclotide. (IBS)

In patients with persistent diarrhea despite antidiarrheals, we use bile acid sequestrants (eg, cholestyramine, colestipol, colesevelam). However, their use is limited by associated gastrointestinal side effects including bloating, flatulence, abdominal discomfort, and constipation. (IBS)

The authors provide accounts of specific follow-up treatments they have applied based on patients’ individual responses, more specifically lack of responses, to treatments.

Situating the Evidence. At the beginning of the entry, the alignment of the authors’ approach and CPG-based recommendations for treatment is made explicit: “Our

recommendations are largely consistent with the American College of Gastroenterology guidelines” (IBS).

As noted above, multiple treatments have been studied in an attempt to alleviate symptoms, but none has been found to address the symptoms in all patients. Throughout the case, the authors present evidence to support the array of treatment options evaluated:

The efficacy of linaclotide in the treatment of IBS-C has been demonstrated in two randomized controlled phase III trials. (IBS)

A 2009 meta-analysis concluded that the overall treatment effects of SSRIs were similar to TCAs. (IBS)

As demonstrated here, the type of study that has been called upon as evidence is used as an indicator of the strength of certainty. When the authors use recognized evidence resources, specifically systematic reviews or RCTs, the type of resource is often highlighted.

In addition, the authors provide varying levels of detail about the 60 studies and 15 systematic reviews cited in the case. Some research was cited with no description of the study details. For example, the following statement was followed by a parenthetical reference to a systematic review assessing the efficacy of probiotics in IBS: “Although [probiotics] have been associated with an improvement in symptoms, the magnitude of benefit and the most effective species and strain are uncertain” (IBS). This statement does not indicate that this information was derived from a systematic review or that 19 RCTs were included. In contrast, the following is the most comprehensive description of a systematic review in the IBS main entry:

A 2011 meta-analysis that included eight placebo-controlled trials of antidepressants in adults with IBS concluded that antidepressants were significantly more effective as compared with placebo in improving pain (54 versus 37 percent) and global symptoms (59 versus 39 percent). The number need to treat to benefit one patient was four. (IBS)

In this description, the study type (i.e., systematic review/meta-analysis) and number of studies included in the review were included, along with descriptions of the patients (i.e., adults with IBS), interventions (i.e., antidepressants), comparison (i.e., placebo), and outcomes (i.e., pain, global symptoms and number needed to treat). The descriptions of the synthesis level of evidence were much briefer than study descriptions in the IBS main entry. The most extensive description of a study was related to a trial for the pharmaceutical linaclotide. The long paragraph provides multiple details about the patient (number of subjects), intervention (dosage), and comparison (placebo) alongside extensive details about the outcome of the study. Outcomes included both the positive effects of the drug, as well as the adverse side effects. Thus, the authors are selective when calling upon evidence.

In addition to describing the research that provides evidence for treatment options, the authors also provide their own appraisal of the quality of research that is available:

However, the randomized trials included in the meta-analysis had a relatively short- term follow-up and the improvement in abdominal bloating in patients with IBS without constipation was modest. (IBS)

At times the authors suggest that readers should exercise prudence when considering the results of studies because of weaknesses in the research design:

However, the results of this study should be interpreted with caution due to methodological limitations and small sample size. (IBS)

The commentary on the research available goes beyond critiques of specific studies but also highlights the limitations of the wider research base:

Randomized trials evaluating specific pharmacologic agents have demonstrated their superiority as compared with placebo. However, there have been few controlled trials evaluating specific strategies for how these drugs should be used in conjunction with other types of treatment (eg, fiber therapy), how long they should be used, or whether they should be

given continuously or as needed. (IBS)

In this example, the authors' commentary highlights a lack of high-quality controlled trials evaluating how non-pharmacological and pharmacological treatments can be used together.

The authors often establish the relationship between their expertise and the chosen evidence in a consistent arrangement. They commonly present treatments by leading with their own recommendation or suggestion for treatment (as either an explicit recommendation or as a description of their own treatment practices), and then follow up the recommendation with evidence that supports their recommendation. For instance,

We suggest a diet low in fermentable oligo-, di-, and monosaccharides and polyols (FODMAPs) in patients with IBS with abdominal bloating or pain despite exclusion of gas-producing foods... Studies have demonstrated an improvement in IBS symptoms with FODMAP restriction. In one randomized trial, 25 patients with IBS were randomly challenged by graded dose introduction of fructose and fructans alone or in combination, or glucose for a maximum test period of two weeks. Patients receiving fructose and/or fructans were more likely to report inadequate symptom control as compared with patients receiving glucose (70 to 79 versus 14 percent). Symptoms were dose-dependent and mimicked the patients' baseline IBS symptoms. In another randomized, single-blind, crossover trial, 30 patients with IBS and 8 healthy controls were assigned to 21 days of a diet low in FODMAPs or a moderate FODMAP Australian diet followed by a 21-day washout period before crossing over to an alternate diet. Subjects with IBS, but not controls, had significantly lower overall gastrointestinal symptoms scores with an improvement in scores for abdominal pain, bloating, flatulence, and dissatisfaction with stool consistency while on a low FODMAP diet as compared with the moderate FODMAP diet and their diet at baseline. (IBS)

This same format is used when there is uncertainty within the evidence in spite of the authors' recommendation. A qualified recommendation to trial fibre in patients with IBS is followed by conflicting evidence:

The role of fiber in patients with IBS is controversial, but given the absence of serious side effects and potential benefit, psyllium/ispaghula should be considered in patients with IBS whose predominant symptom

is constipation. As some patients may experience increased bloating and gas, we suggest a starting dose of psyllium of one-half to one tablespoon daily. The dose should then be slowly titrated up based on response to treatment.

A 2011 systematic review that included 12 studies found no beneficial effect

for bulking agents over placebo in improving abdominal pain, global assessment or symptom scores. On subgroup analyses, there was no significant benefit with either soluble (eg, psyllium) or insoluble fiber (eg, methylcellulose). However, another meta-analysis that pooled data from the same trials and used a combined endpoint for abdominal pain and global IBS symptoms demonstrated that in six trials, psyllium was associated with a small improvement in symptoms as compared with placebo with a number needed to treat to prevent one patient with IBS remaining symptomatic of six (RR of persistent symptoms 0.76, 95% CI 0.63-0.96). (IBS)

While suggesting that fibre should be considered as treatment for IBS patients, the authors frame its use for the treatment of the constipation variant as controversial because of conflicting outcomes from two systematic reviews.

Situating the Physician-Patient Relationship. The clinician-patient relationship is explicitly mentioned three times in the IBS case. For example:

Establishment of a clinician-patient relationship and continuity of care are critical to the management of all patients with irritable bowel syndrome (IBS).

In all three instances, the authors call for the “establishment of a clinician-patient relationship” (IBS) with little explanation of what that relationship entails. In one instance, it is clarified that there is need for a *therapeutic* clinician-patient relationship

It is important to establish a therapeutic clinician-patient relationship to validate the patient's symptoms. Patients should also be counseled that although IBS does not increase their risk of malignancy, it is a chronic disease. (IBS)

Few details about what constitutes therapeutic clinician-patient relationship are included, beyond ensuring that the clinician validates the syndrome as real. The quotation also implies that patient education and counseling are key components; the section continues,

“The clinician should establish realistic expectations with consistent limits and involve the patient in treatment decisions” (IBS). This is the only instance in the entry where the patient’s role in decision-making is specified. While the clinician-patient relationship is mentioned in the IBS case, descriptions and guidance provided by the authors about what it entails are scant.

As seen in the above excerpts, the authors choose to use the term ‘clinician’, rather than ‘physician’. In one instance, they do acknowledge the need for care from someone other than a physician: “Low FODMAP dietary education should be provided by a trained dietician to avoid unnecessary dietary over-restriction and a nutritionally replete diet” (IBS). While the authors choose to use the broad term clinician, the majority of the care and treatment (e.g., pharmaceuticals) described in the case are delivered by physicians.

As discussed in the preceding two sections, there is very wide variation in IBS symptoms and experiences, and in patient responses to treatment. As such, the need to tailor treatment for the individual patient is featured prominently throughout the case: “Since IBS generally presents as a complex of symptoms, treatment should be based on the predominant symptom and subtype” (IBS), as is the emphasis on the need to adjust or change treatment approaches:

For the treatment of abdominal pain in IBS, antidepressants should be started at low doses. The initial dose should be adjusted based upon tolerance and response. Due to the delayed onset of action of antidepressants, three to four weeks of therapy should be attempted before increasing the dose. (IBS)

In patients with abdominal pain due to IBS, we use antispasmodics on an as-needed basis. In patients with IBS with constipation, we initiate antispasmodics only if the abdominal pain persists despite treatment of constipation. In patients with persistent abdominal pain despite antispasmodics, we recommend a trial of antidepressants. (IBS)

While there are recognized psychological factors associated with IBS, the

acknowledgement of these factors throughout the UpToDate entry is minimal. The authors only acknowledge these factors in relation to the need for transitory or supplementary treatments:

The use of anxiolytic agents in patients with IBS should be limited to short-term (less than two weeks) reduction of acute situational anxiety that may be contributing to symptoms. (IBS)

For patients with IBS in whom depression is a cofactor, serotonin reuptake inhibitors (SSRIs) can also be used. (IBS)

Patients with unrelenting symptoms that are associated with psychiatric impairment may benefit from behavioral modification in conjunction with antidepressants (IBS)

The psychological factors are not treated individually in relation to the patient experience but rather as a circumstance or conditions requiring additional treatment.

Patient Information. Both levels of patient information acknowledge that treatments “help alleviate symptoms but do not cure the condition” (IBS Beyond), which closely reflects the content of the main entry. The lack of cure is repeatedly highlighted in the patient information:

Although many drugs are available to treat the symptoms of irritable bowel syndrome, these drugs do not cure the condition. They are primarily used to relieve symptoms. (IBS Beyond)

Most people with IBS have the condition for the rest of their life. Even so, most people find ways to improve their symptoms. (IBS Basics)

In these quotations, the lack of cure is indicated, first, by the recognition that pharmaceuticals are used only as a means to alleviate symptoms, and second, by the assertion that IBS is a life-long condition. This absence of a known cure largely arises out of the fact that a clear cause of IBS has not yet been identified. As noted in the *Beyond the Basics* information, “there are a number of theories about how and why irritable bowel syndrome (IBS) develops” (IBS Beyond). The *Beyond the Basics* also presents an overview of six potential

causes for IBS.

Because of the many unknowns associated with IBS, the treatment plan for IBS is not clearly outlined for physicians. The subsequent need for patients to trial multiple therapies throughout their treatment is conveyed to patients in the two patient information sources. The trial and error approach is described in the *Beyond the Basics* entry as:

Treatments are often given to reduce the pain and other symptoms of irritable bowel syndrome, and it may be necessary to try more than one combination of treatments to find the one that is most helpful for you. Treatment is usually a long-term process; during this process, it is important to communicate with your healthcare provider about symptoms, concerns, and any stressors or home/work/family problems that develop.
(IBS Beyond)

The same message of perseverance through multiple treatments is articulated in Basics: “The key is to keep working with your doctor or nurse until the 2 of you find an approach that works” (IBS Basics). The need to try multiple treatments in sequence is also reflected in the main professional entry where the authors attempt to map out a strategy for physicians to navigate the treatment options based on treatment responsiveness. When discussing the trial and error approach the relationship between patient and physician is also accentuated. The *Beyond the Basics* entry also emphasizes that patients should communicate with the clinician about symptoms, concerns and life stressors affecting health. This presentation of treatment planning and decision-making as a joint process between patient and clinician is not as evident in the main professional entry.

The effects and overlap between stress and IBS is more upfront in the patient information. In *The Basics*, counselling is suggested “because stress and worry can make the condition worse” (IBS Basics). The *Beyond the Basics* entry presents the management of stressors as a collaborative process between clinician and patient.

The best approach for reducing stress and anxiety depends upon your situation and the severity of your symptoms. Have an open discussion with your

clinician about the possible role that stress and anxiety could be having on your symptoms, and together decide upon the best course of action. (IBS Beyond)

Once again, open communication and joint decision-making is emphasized in the *Beyond the Basics* information when addressing the stress and anxiety. This co-management of stress that is underscored in the *Beyond the Basics* is not reflected clearly in the main professional entry.

The strain that can develop in the relationship between physicians and IBS patients due to the chronicity and uncertainty of the illness is underscored in the patient information: “The chronic nature of irritable bowel syndrome and the challenge of controlling its symptoms can be frustrating for both patients and healthcare providers” (IBS Beyond). Because of the changing and chronic nature of IBS and the need to try many treatments in order to alleviate rather than cure the disease, frustration can develop in both patients and physicians.

Both *The Basics* and *Beyond the Basics* information provides an overview of habits and practices which patients can adopt to help with their symptoms, prior to pharmacological interventions or concurrently with pharmacological interventions. These lifestyle changes include dietary monitoring, dietary modifications, and incorporation of an exercise program. The *Beyond the Basics* patient information reflects the main professional entry in its advocacy for treating patients first with non-pharmacological lifestyle changes prior to introducing medications. The *Beyond the Basics* patient information communicates, “medications are reserved for people whose symptoms have not adequately responded to more conservative measures such as changes in diet and fiber supplements” (IBS Beyond). In contrast, *The Basics* entry does not indicate that there is an attempt to treat IBS with dietary and lifestyle changes prior to introducing medications; it introduces a list of possible

medications that may be used to treat IBS with:

How is IBS treated? — Medicines can ease the symptoms of IBS. But no treatment can cure the condition. Counseling might also help with IBS, because stress and worry can make the condition worse.

The medicines that can help with IBS symptoms include: [followed by the types of medications used in to treat IBS (eg. “Medicines called ‘antispasmodics’”). (IBS Basics).

While the *Basics* entry of the patient information does provide a list of lifestyle changes that may alleviate symptoms, there is no indication that these should be trialled prior to the introduction of medications. Only in the *Beyond the Basics* format of the patient information is the preference to try non-pharmacological approaches prior to medications underlined.

Case Analysis: Fibromyalgia

Introduction

Patients diagnosed with fibromyalgia have severe and often-debilitating symptoms, including distinctive tenderness on palpitation as well as widespread pain, fatigue, sleep disturbances, cognitive challenges, and depressive symptoms—all of which are medically unexplained. There is considerable controversy about the legitimacy of diagnosis (Wolfe, 2009). The scepticism by physicians, sociologists, medical historians, even family members is grounded in the perception that the diagnosis of fibromyalgia has arisen from the medicalization of discomfort in modern society, the need for labelling and diagnosis in order to access health and wellness supports, and the substantial power of the pharmaceutical industry (Wolfe). In response to the scepticism about the diagnosis of Fibromyalgia, patient advocacy groups, pharmaceutical companies, physician-specialists, professional organizations have fought hard to have fibromyalgia recognized as a “real disease,” and have been able to advocate for the development of criteria for diagnosis by the American College of Rheumatology (ACR) and an International Classification of Disease (ICD) code by the World Health Organization. These changes enable patients to provide proof of condition to employers, colleagues and family, as well as a diagnosis that is recognized and compensated by insurance companies and government agencies.

While organizations and associations increasingly recognize fibromyalgia as a real illness, researchers and clinicians continue to search for the cause of the symptoms of fibromyalgia. Proposed contributing factors include psychological, genetic, neurobiological, and environmental origins. Because of the unknown cause and the possibility of a psychological component to the condition, there are challenges in clearly defining the medical profession’s approach to patients diagnosed with fibromyalgia. As a result, the

controversy extends beyond the diagnosis to treatment. Critics suggest that treatment of fibromyalgia prolongs and preserves the diagnosis rather than ameliorates it. According to Hayden (2003),

The treatment acts, dripping with empty promises of elucidation and unproved promises of palliation, are iatrogenic. I would further suggest that these circular treatment acts will exacerbate whatever mood or thought disorder is complicating the plight of these patients. (p. 1669)

The treatment is viewed as a self-perpetuating cycle in which more (not fewer) complications develop.

Descriptive Analysis

The main entry for fibromyalgia written for professionals contained 91 cited references ranging in date of publication from 1986-2015. Fewer than half ($n=37$, 41%) of the references were published between 2010 and 2015. The majority (73%) of cited references were from UpToDate's list of core journals. The most commonly cited journal was *Arthritis and Rheumatology*, cited 17 times. UpToDate identifies *Arthritis and Rheumatology* as a core journal.

UpToDate's main entry addressing the treatment of fibromyalgia contained four types of evidence within the 6S hierarchy: Summary, Synopsis of Synthesis, Synthesis, and Study (see Figure 13). Only seven references (8%) cited in the entry were sources that are not recognized as evidence in the 6S hierarchy: All seven of these references were non-systematic/narrative reviews. The largest proportion of references was from the study level of evidence ($n=60$), all of which were quantitative. Thirty-two of the 60 studies cited in the FIB case were randomized controlled trials.

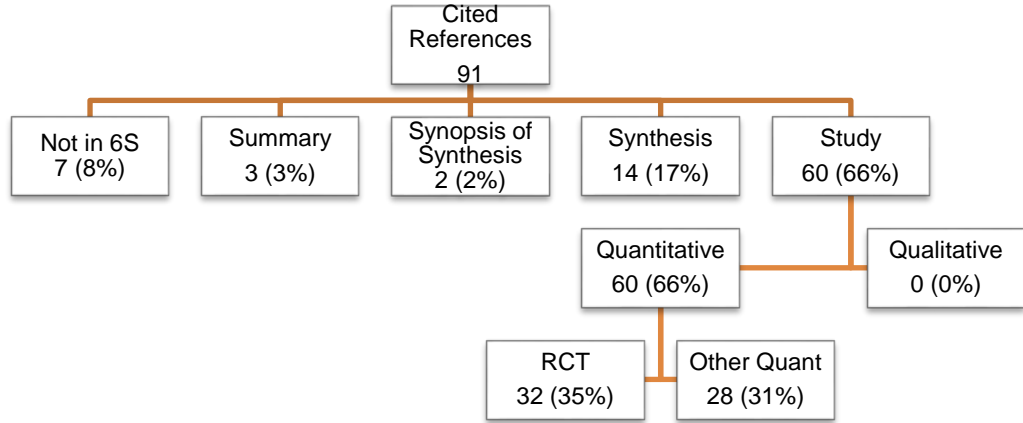


Figure 13: Types of Evidence in FIB Main Entry

The greatest proportion of empirical studies in the FIB case were conducted in North America with 32 studies conducted in the United States (53.3%) and 11 (18.3%) in Canada. Seven studies (12%) were conducted in Spain. Other European locations for these studies the United Kingdom ($n=2$), Turkey ($n=2$), and Denmark ($n=1$). One study was conducted in South Korea and four were multinational.

The 91 references included in the fibromyalgia entry were written by a total of 531 authors. Across the 91 papers, the highest known proportional representation (.41) of the authors had a Medical Doctor (MD) background (see Figure 14).

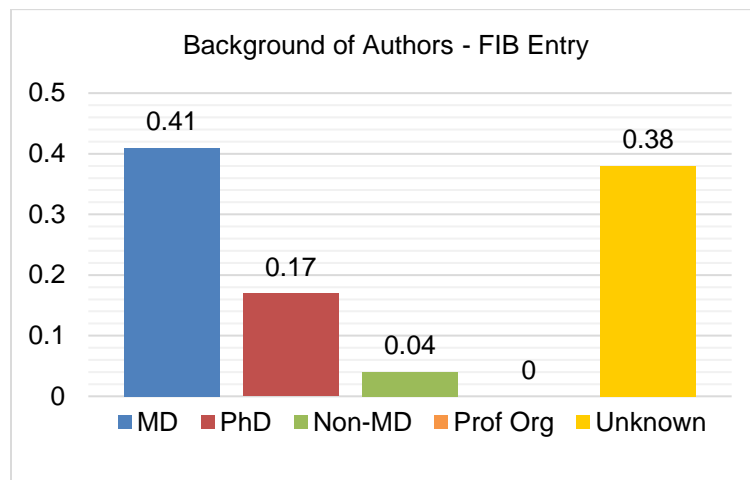


Figure 14: Contributions by Authors' Backgrounds for FIB main entry

Textual Analysis

Situating the Authors. Within the context of the many unanswered questions about fibromyalgia, physicians and specialists persevere in their attempts to treat the symptoms of fibromyalgia. It is also within this context of uncertainty that the authors of UpToDate share their personal expertise about the treatment of fibromyalgia. The authors' knowledge and experiences are consistently positioned as central to the content presented in the fibromyalgia main entry.

Aligning with UpToDate's policy, the authors of the FIB entry share their expertise by way of explicit recommendations for treatment. The authors' recommendations often provide specific details about how to deliver treatment regimens. For example, the authors provide recommendations about dosage and timing for tricyclic medications:

We suggest initiating therapy with a low dose of a tricyclic medication (eg, amitriptyline 10 mg) at night time, especially since these drugs are effective, widely available, and far less costly for most patients than some of the newer agents. (FIB)

In addition to the specific information about dosage and timing, the authors also highlight the accessibility of the drug treatment, information that is not often provided in the published research. In their recommendations, the authors provide extra information about the exact patient for whom the treatment is best. The authors provide information that facilitates a tailoring of the treatment based on the preferences, needs, and context of the patient:

In patients who do not respond to trials of low-dose tricyclics or who have intolerable side effects, we advise a trial of pregabalin, duloxetine, or milnacipran, depending upon the patient's symptoms. (FIB)

In patients unresponsive to or intolerant of amitriptyline and in patients with more severe sleep disturbance in addition to pain, we suggest the use of pregabalin. (FIB)

The authors here provide suggestions of ways to tailor care for individuals based on the

patient's symptoms and responsiveness.

In addition to explicit recommendations, the authors further integrate their personal expertise into the UpToDate entry by providing accounts of what occurs in their own practice. For example, the authors share their approach to patient counselling to encourage exercise in fibromyalgia patients:

We counsel patients regarding the importance of exercise for reconditioning and for functional capacity, and caution that a temporary increase in myalgias may occur upon initiating an exercise program. (FIB)

As demonstrated in this quotation, these descriptions of treatment practices from their own experience serve as an endorsement for the approach, albeit not explicitly. The authors also provide accounts of what occurs in their own practices when there is a lack of evidence:

We use gabapentin, for which evidence is more limited, as an alternative to pregabalin in patients for whom cost of the medication or regulatory requirements limit the use of pregabalin. We begin with a dose of 100 mg at bedtime before titrating the dose upwards as tolerated and as required. The recommended dose is 1200 to 2400 mg/day, based upon the study described below. As with pregabalin, some patients may respond to lower doses. (FIB)

In this quotation, there is no explicit recommendation for the drug gabapentin; however, the authors' communication of their own practices to prescribe the drug is an implicit recommendation of this approach in light of the limited evidence available.

The details about the authors' approaches to care are often directly tied to tailoring treatment for individuals. For example, they provide guidance on how to administer two pharmacological treatments in order to meet the needs of specific patients:

Milnacipran is an alternative to duloxetine in patients with severe fatigue in addition to pain. We initiate therapy with 12.5 mg each morning, gradually titrating as tolerated to 50 mg twice daily. Some patients will require a higher dose; up to 100 mg twice daily may be needed ... In those patients with more severe problems with sleep, we use pregabalin taken at bedtime. (FIB)

In patients unresponsive to or intolerant of amitriptyline and in patients with more severe sleep disturbance in addition to pain, we suggest the use of pregabalin. We begin with a dose of 25 to 50 mg at bedtime before adjusting the dose upwards as tolerated to the recommended dose of 300 to 450 mg/day. Some patients may respond to lower doses, such as 100 to 300 mg/day, and do not require further dose escalation. (FIB)

Treatments are adjusted to address patients' individual preferences, socioeconomic status, symptom presentation, drug reactions and tolerability, or treatment responsiveness.

The authors broaden the experiences and expertise they bring into the fibromyalgia entry by sharing with the reader some of the acquired knowledge from their experiences in treating patients:

In our experience, patients generally have a better response to treatment when they understand that they are not harboring some infectious agent over which they have no control. (FIB)

In our experience, sustained responses are seen in most patients receiving duloxetine who initially benefit from treatment, when such patients are followed for more than one year on continued therapy. (FIB)

The authors set apart information derived from their clinical experience by explicitly using the phrase 'in our experience'.

The authors of this entry take such acquired knowledge and experience one step further to compare their practice-acquired knowledge to the results and conclusions of the published research. Specifically, the authors reveal to the reader where the approaches and conclusions of research and their own practice diverge:

Various doses of cyclobenzaprine have been used in placebo-controlled trials, including 10 mg in the morning and 20 mg at night, 10 mg three times daily, 10 mg in the morning and 30 mg in the evening, and 10 to 40 mg daily as needed. We usually start with doses of 10 mg near bedtime and increase as tolerated to the larger doses. In patients who find an initial dose of 10 mg too sedating, we reduce the dose to 5 mg before bedtime. (FIB)

In this example, the authors provide an overview of dosages used in research and contrast them with the unique approach that they have developed within their own practice. In other incidences, the realities of applying the conclusions of clinical research to practice are highlighted. The following quotation succeeds a statement extolling the benefits of exercise in fibromyalgia patients citing six published articles:

In practice, it has been difficult to start and maintain fibromyalgia patients in a structured cardiovascular exercise program, because patients generally perceive that their pain and fatigue worsen as they begin to exercise. (FIB)

Here, the authors contrast the research showing the benefits of exercise against their own experience in practice where patients are hesitant to start and sustain an exercise program because they perceive that exercise worsens their condition. This experience, however, does not preclude the authors from recommending “an exercise program, including aerobic conditioning, stretching, and strengthening” (FIB) as one of three key components of the initial treatment for fibromyalgia. While many drugs administered on their own appear to benefit patients in clinical trials, in the authors’ clinical experience no great benefit arises from a single medication.

Despite the clinical trial efficacy, in “real-world experience” the majority of fibromyalgia patients do not achieve great benefit from any single medication. (FIB)

Here, the authors explicitly contrast the results of clinical trials and the realities of everyday life outside of the structured inquiry.

Situating the Evidence. The authors’ recommendations and experiences are central to the content in the fibromyalgia main entry. In turn, evidence is used to support the authors’ recommendations and approaches. The authors often share their

recommendations and practices at the outset of each section and then follow-up with an acknowledgement of the research that supports their approach:

In patients unresponsive to or intolerant of amitriptyline and in patients with more severe sleep disturbance in addition to pain, we suggest the use of pregabalin. We begin with a dose of 25 to 50 mg at bedtime before adjusting the dose upwards as tolerated to the recommended dose of 300 to 450 mg/day. Some patients may respond to lower doses, such as 100 to 300 mg/day, and do not require further dose escalation.

The efficacy and safety of pregabalin has been evaluated in randomized trials and in systematic reviews and meta-analyses. In a 2010 meta-analysis involving three randomized trials and a total of 1890 patients, those allocated to receive pregabalin in any one of three doses (600, 450, and 300 mg daily) were significantly more likely to respond to treatment, defined as a ≥ 30 percent reduction in pain score, compared with patients receiving placebo (odds ratios 1.7, 95% CI 1.27-2.29, 1.92, 95% CI 1.49-2.12, and 1.53, 95% CI 1.18-1.98, respectively). (FIB)

Here, the authors offer their expertise as recommendations for the drug preglabin and accounts of their practices with dosages and tolerability, then follow up their expertise with studies that support the efficacy and safety of their approach.

The authors select studies and systematic reviews which provides evidence for their approach:

In patients unresponsive to or intolerant of amitriptyline and in patients who have severe fatigue or who require concomitant drug therapy for depression in addition to pain, we suggest treatment with duloxetine in place of amitriptyline. It is also available in many countries for the treatment of depression and of diabetic neuropathy. Duloxetine should be used in the morning at breakfast. The usual starting dose in patients with fibromyalgia is 20 to 30 mg/day, which is gradually increased to the recommended dose of 60 mg/day... The benefits of duloxetine in fibromyalgia have been shown in a 2014 systematic review that identified six randomized trials involving 2249 patients in which duloxetine was compared with placebo. On meta-analysis of the data, duloxetine (60 mg daily) was significantly more likely than placebo to reduce pain by at least 50 percent at 12 weeks (RR 1.57, 95% CI 1.20-2.06) and at 28 weeks (RR 1.58, 95% CI 1.10-2.27). The number needed to benefit at 12 weeks was 8 (95% CI 4-21). The efficacy of duloxetine in patients with fibromyalgia was initially demonstrated in two multicenter trials of 12 weeks' duration. As an example, in one trial, pain was reduced by at least 30 percent in a significantly greater proportion of patients receiving duloxetine (60 mg

once or twice daily) compared with those taking placebo (55 and 54 versus 33 percent, respectively). (FIB)

In this example the authors select a systematic review and two randomized controlled trials to demonstrate the effectiveness of duloxetine in treating fibromyalgia patients. They bring attention to two trials that initially demonstrated the drug's effectiveness, and select one systematic review for which to provide details. The authors are transparent at times that they have selected the evidence based on what they have deemed the best approach to treatment.

The level of detail about the evidence that the authors call upon for support varies greatly. There are evidence sources for which few or no details about the studies are provided. In other instances, extensive details are included:

In randomized trials, [milnacipran] improved pain and global wellbeing more than placebo. As an example, in one trial, 1196 patients were randomly assigned to treatment with one of two doses of milnacipran or to placebo [50]. Primary outcomes were improvement in a composite of pain, patient-reported global status, and self-reported physical function after 15 weeks of treatment. A greater than 30 percent improvement in the composite measure was significantly more likely among those receiving milnacipran at either dose (100 mg/day or 200 mg/day) than among the placebo group (OR 1.79, 95% CI 1.14-2.8, and 1.75, 95% CI 1.11-2.75, respectively). Greater improvements in individual component scores (ie, pain, global status, and physical function) were also noted in the milnacipran-treated patients compared with the placebo group. As an example, patient-reported pain (on a 100 point scale) improved from baseline levels by a statistically greater degree in the patients receiving milnacipran than those receiving placebo (-15.7 and -17.4 versus -13). Adverse effects leading to discontinuation of study drug were more common in the milnacipran-treated subjects than in the placebo group (19 to 24 percent versus 9.5 percent, respectively). Commonly reported adverse effects were nausea, headache, and constipation. (FIB)

In this description of a single study, extensive details are included about the intervention (i.e., dosage), comparison (i.e., placebo) and the outcome (i.e., improvements, side effects), as well as the number of patients involved.

The effectiveness of treatments, especially drug treatments, is a focus in the presentation in evidence; however, the limitations of particular treatments are also highlighted within the FIB case:

Although all of these agents, including amitriptyline, duloxetine, and milnacipran, are considered as first-line medications by experts on fibromyalgia, a 2012 meta-analysis of antidepressants used for fibromyalgia found that only a minority of patients experienced substantial improvement with these drugs and that adverse side effects were common. Moderate degrees of benefit were seen in pain and sleep, but effects on fatigue and quality of life were small. (FIB)

Here, the authors acknowledge that there are limitations to the efficacy of drug treatments for fibromyalgia.

Occasionally in the fibromyalgia case, the authors extend the description of the evidence beyond describing features of the study to include a commentary on the evidence, whether studies or synthesis. For example, they highlight that conclusions may be weak due to methodological shortcomings: “The strength of the conclusions was limited, to some degree, by the lower methodological quality of the amitriptyline trials” (FIB). In addition to calling attention to the limitations of particular evidence sources, the authors also point out where the corpus of literature on the treatment of fibromyalgia is lacking:

Strength training and flexibility exercises have not been extensively studied; However, there is some evidence of benefit from strength training in some small trials that used several different types of resistance training programs. (FIB)

The efficacy of these drugs compared with placebo has been demonstrated in randomized trials and meta-analyses, but there have been few direct comparisons of one with another, particularly with the older drugs. (FIB)

At the end of the main professional entry, the authors’ overall approach is compared to Clinical Practice Guidelines created by panels of experts:

Our approach is generally consistent with the recommendations of various expert panels and with the guidelines from professional organizations that have been proposed for treatment of adults with fibromyalgia. Most of these guidelines preceded the regulatory approval of pregabalin, duloxetine, and milnacipran for fibromyalgia treatment. (FIB)

In this quotation, the clinical practice guidelines to which the authors refer are sponsored by the European League Against Rheumatism and the Canadian Pain Society with the Canadian Rheumatology Association, and two guidelines that were not sponsored by an organization but authored by experts in the field. Both the Clinical Practice Guidelines and UpToDate entry are considered to be evidence within the Summary level of evidence within the 6S hierarchy.

Situating the Patient-Physician Relationship. The main professional entry for fibromyalgia starts with the following description: “Fibromyalgia is a chronic pain disorder that is challenging to treat.” From the outset of the entry, the challenging nature of the fibromyalgia is acknowledged. The authors of the case are explicit that the goal of treatment is not cure but rather, symptom reduction:

Treatment of fibromyalgia is directed at reducing the major symptoms of this disorder, including chronic widespread pain, fatigue, insomnia, and cognitive dysfunction.

They underscore that patients are going to continue to experience the symptoms of fibromyalgia when they are receiving treatment:

Most patients with fibromyalgia continue to have chronic pain and fatigue, although most longitudinal long-term studies of outcome in fibromyalgia have been from tertiary referral centers. One study of 538 patients followed at six referral centers found that pain, fatigue, sleep disturbances, anxiety, and depression were essentially unchanged over a follow-up period of approximately eight years. Similarly, in the author’s experience at a referral rheumatology center, there has been little change in the patients’ symptoms. (FIB)

The authors use both the evidence base and their personal experience to support the chronicity and perseverance of symptoms even with treatment and advise that “patients need to appreciate that their symptoms will wax and wane but that the pain and fatigue generally persist” (FIB).

The authors also point out that ambiguity exists about what type of health care professional is responsible for treatment—the specialist or the primary care physician:

The issue of who should be in charge of the treatment of patients with fibromyalgia has been controversial. Most specialty groups recommend that the initial management of patients with fibromyalgia can and should be carried out in the primary care setting. Ideally, treatment should include an integrated, multidisciplinary nonpharmacologic and pharmacologic approach, but there have been relatively few trials that have formally evaluated such a combined approach to therapy. (FIB)

Physiotherapists, psychologists, psychiatrists are all acknowledged as be potential members of a multidisciplinary approach to care. The challenges that patients face in receiving a diagnosis of fibromyalgia complicate the ownership of professional responsibility for care and affects the patient experience.

Most patients have had fibromyalgia for years before the diagnosis is finally made. They often have undergone multiple diagnostic evaluations and have consulted with many different specialists. Some patients may feel rejected by the medical profession, while others may fear that a life-threatening illness will eventually be found. (FIB)

The authors acknowledge that, for many patients, their contact with health care professionals has not always been positive or affirming. While the fibromyalgia controversy is well documented, the authors allude to, but do not overtly acknowledge, that doctors and other health care professionals who have previously cared for patients may not accept the diagnosis of fibromyalgia as legitimate. The authors situate their position in this argument by emphasizing that patient education must include reassurance that the illness is real. In the main professional entry for this case they identify

reassurance and validation as key to the patient-physician relationship. However, they also emphasize that patients must understand the condition is not progressive or life-threatening:

Reassurance that fibromyalgia is a real illness – The patient must be reassured that fibromyalgia is a real illness and is not imagined or “in your head.” The benign nature of the disorder should also be emphasized. As an example, patients must be told that this is not a deforming or deteriorating condition and that it is neither a life-threatening nor a cosmetic problem. (FIB)

This passage highlights the challenge of balancing the validity of the condition with its relatively benign nature. Other elements of patient education include the role of stress and mood disorders, the role of sleep disorders and sleep hygiene, the role of exercise, the prognosis for fibromyalgia, and the lack of evidence of persistent infection. Patient education “should also include family members” (FIB). The authors emphasize that patient education should reassure patients that “the great majority of patients live normal and active lives.” In contrast, the prognosis section underscores that there is “little change in patients’ symptoms” for those receiving treatment and fibromyalgia patients report a high incidence of being work-disabled. Multiple tensions within the patient-physician relationship are highlighted in this entry, particularly with respect to ensuring balance in messages to patients.

Patients’ role in treatment includes their engagement in non-pharmacological approach to treatments, including adopting proper sleep routines, exercise programs, relaxation techniques, and cognitive behavior therapy. The authors indicate that some patients respond so well to non-pharmacological measures that they do not require medications. They emphasize the importance of the patient maintaining a positive outlook to improve prognosis. Because of the complexities involved with this condition,

the treatment trajectory for fibromyalgia appears to be primarily the responsibility of the primary care physician, not the patient.

Patient Education. UpToDate provides patient information in two formats for fibromyalgia, *The Basics* and *Beyond the Basics*.

The level of comprehensiveness and sophistication of the *Beyond the Basics* patient information for fibromyalgia is noteworthy. As well as being lengthy, the level of sophistication and knowledge required to understand the content appears to be much higher than other *Beyond the Basics* patient information entries. Indeed, the information provided appears not to be directed towards the patient, but rather at physicians who provide patient education. For example, the entry states: “Balanced and accurate patient information is critical to allow fibromyalgia patients to take charge of their illness and to best manage this disorder” (FIB). In contrast, *The Basics* patient information is targeted at patients and has a comparable level of sophistication and complexity to the other similar entries.

Patients often seek medical care to be find a cure for an illness, however for patients with fibromyalgia, there is no cure currently available. The patient information included in *The Basics* clearly communicates that while physicians are able to treat the symptoms of fibromyalgia, they cannot cure it.

Some people seem to get over fibromyalgia. But in most people it cannot be cured. Even so, people can learn to deal with the condition and lead fairly normal lives. Fibromyalgia does not get worse over time, and it is not life-threatening. (FIB Basics)

In light of the lack of cure, patients are asked to “deal with the condition” (FIB Basics). This same requirement for patient acceptance of the condition and its symptoms are communicated in the *Beyond the Basics*:

It is important to have realistic expectations concerning the ability to function

and manage the condition over the long term. Symptoms often wax and wane over time, yet some degree of muscle pain and fatigue generally persist. Nevertheless, most people with fibromyalgia improve, and most patients lead full, active lives. (FIB Beyond)

(The same passage appears verbatim in the main entry for medical professionals).

In these entries the authors communicate that the uncertainty surrounding the cause of fibromyalgia extends beyond treatment: “Despite ongoing research, the cause, diagnosis, and optimal treatment of fibromyalgia are not clear” (FIB Beyond). In order to treat fibromyalgia, a multi-professional team approach is advocated. The members of the team include: “A doctor; A physical therapist; Someone trained in mental health (such as a social worker or counselor)” (FIB Basics). The *Beyond the Basics* entry echoes this roster of health care professionals, but places the patient as a member of the team: “Optimal treatment of fibromyalgia should include the patient, clinician, physical therapist, mental health professional, and other healthcare professionals” (FIB Beyond). The call for a multi-professional approach appears in the main professional entry but the patient is positioned as member of the health care team only in the *Beyond the Basics* entry.

Both pharmacological and non-pharmacological treatments are addressed in the patient information sources. *The Basics* entry indicates that patients will work with their team to find the right treatment combination:

There are medicines and strategies to help with the symptoms of fibromyalgia. But there is no one treatment that works for everyone. You and your healthcare team will need to work together to find the right mix of treatments for you. In general, treatment can include: Medicines to relieve pain, improve sleep, or improve mood; Physical therapy to learn exercises and stretches; Relaxation therapy; Working with a counsellor. (FIB Basics)

A collaborative approach to finding a combination of medications and non-pharmacological treatments is stressed. Few specifics about medication options are provided in *The Basics* although it includes a request for patients to “Be open to medicines” that are often described

for depression or seizures because “they work on the brain areas that deal with pain” (FIB Basics). In addition to a willingness to consider medications, the authors also encourage patients to become more active even though their symptoms may be aggravated initially.

In contrast, in *Beyond the Basics* the details provided about the medications used to treat fibromyalgia are extensive. For instance,

As of 2011, three medications had been approved by the FDA for the treatment of fibromyalgia. These included pregabalin, an alpha-2-ligand inhibitor, as well as duloxetine and milnacipran, which are selective norepinephrine and serotonin reuptake inhibitors. However, older medications that are generic or have not been as extensively studied may also be effective. (FIB Beyond)

Here, the level of detail and advanced language is striking. There are many instances in the description of medications in *Beyond the Basics* patient information in which extensive background knowledge of medical terminology, medications, and biochemistry would be necessary for patients to understand the content. For example, “Although cyclobenzaprine is considered to be a muscle relaxant, its chemical structure and mode of action are very similar to those of amitriptyline” (FIB Beyond). The descriptions of the medications are comprehensive and complex; however, there is little information provided about for which patients the medications are best suited and how these decisions are made. Unlike the patient information provided in *The Basics*, the need to tailor treatment to the patient and how such decisions are made are not addressed in *Beyond the Basics*.

The *Beyond the Basics* patient information for fibromyalgia places exercise under the heading “Complementary and Alternative Treatments of Fibromyalgia.” As in *The Basics* the expectation for exercise to initially worsen symptoms is shared. Other complementary and alternative treatments include relaxation therapies, hypnosis, biofeedback, cognitive behaviour therapy, acupuncture, and Tai chi and yoga.

As highlighted in the main professional entry, the importance of maintaining a good

attitude in light of the diagnosis of fibromyalgia and the related experiences is emphasized in both patient entries. *The Basics* entry addresses the patient by offering the following words of encouragement: “It is also really important that you try not to be too negative about your life. Your outlook has a big effect on how you feel pain. Do your best to be positive” (FIB Basics). Similarly, the *Beyond the Basics* section ties the positive attitude of patients to their prognosis stating: “One of the most important factors in a person's long-term prognosis is the person's ability to take charge, to avoid ‘catastrophizing,’ and to learn to cope well with symptoms while remaining as active as possible” (FIB Beyond). In both patient entries, one of the primary roles of patients is to try to maintain a positive outlook.

Case Analysis: Chronic Fatigue Syndrome

Chronic Fatigue Syndrome (CFS) is an illness characterized by persistent fatigue for at least 6 months, and is often accompanied by several other symptoms including headaches, muscle pain, insomnia, and concentration issues. The condition is complex and not well understood. There is no clear cause identified and no effective diagnostic test developed for CFS. As such, it is diagnosed through symptom identification. Chronic fatigue syndrome, irritable bowel syndrome and fibromyalgia are closely linked and many individuals concurrently meet the symptomatic criteria for two or three of these conditions. The lack of cause and diagnostic test has led to questions about and challenges to the legitimacy of the diagnosis of CFS. Some health care professionals argue that a diagnosis of CFS may be self-validating, self-reinforcing and potentially a self-fulfilling prophecy (Huibers & Wessely, 1996). Treatment of CFS is aimed at symptom relief, not cure; however, attempts to find effective treatments, even for symptom relief, have not been successful.

In February 2015, the United States Institute of Medicine (IOM) published a report renaming Chronic Fatigue Syndrome as Systematic Exertion Intolerance Disease (SEID), as well as proposing a redefinition of the diagnostic criteria for CFS. The change to SEID has been met with some hesitation among patients and health care professionals (Jason, Sunnquist, MacManimen & Furst, 2015). Nevertheless, the authors of the IOM report hope that one outcome of the name change will be a shift in the perception of the disease and an overall increase of the acceptance of the condition (Institute of Medicine, 2015). While the term disease in the name implies a pathological mechanism, the authors of the IOM report acknowledge that no disease process has yet been identified.

Descriptive Analysis

The authors of the CFS entry cite 46 references ranging in date of publication from

1986-2015. Fewer than one quarter ($n=10$, 22%) of the references were published between 2010 and 2015. Forty-one of 46 references (89%) are published in UpToDate's core journals. The most common journals cited in the Chronic Fatigue Syndrome main entry was *The Lancet* (cited seven times) and *American Journal of Medicine* (cited seven times), which are both identified as core journals by UpToDate.

The UpToDate entry for CFS contains three types of evidence recognized by the 6S hierarchy: Synopsis of Synthesis, Synthesis, and Study (see Figure 15). Seven of the 46 references (15%) cited fall outside of the 6S hierarchy. All seven of the references that are not types of evidence included in the 6S hierarchy are non-systematic/narrative reviews. Only two references in the CFS case are systematic reviews, which are situated in the Synthesis level of the 6S hierarchy. Thirty-three of the 46 references are quantitative studies. Approximately half ($n=24$, 52%) of all references cited in the CFS case are randomized controlled trials.

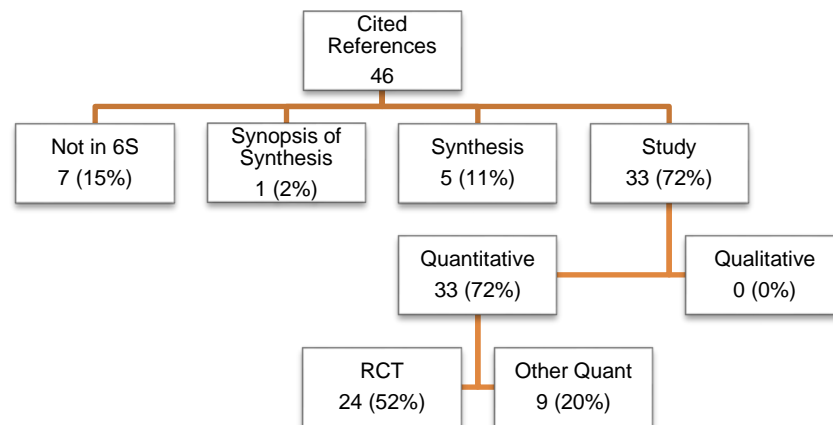


Figure 15: Types of Evidence in CFS Main Entry

The studies took place primarily in the United States and United Kingdom with 12 of 33 (36%) from the US and 11 of 33 (33%) from the UK. Three studies took place in the Netherlands and two in Belgium. There was one multinational study spanning the United

States and multiple European countries. One study each took place in Australia, Denmark, and Norway. It is unknown where one older study took place.

The 46 references making up the CFS case were written by 259 authors. Across the 46 papers, the highest known proportional representation (.32) of the authors had a Medical Doctor (MD) background followed by Basic Scientists (.25). Proportionally across all 46 papers, .38 of the backgrounds of authors were unknown (Figure 16).

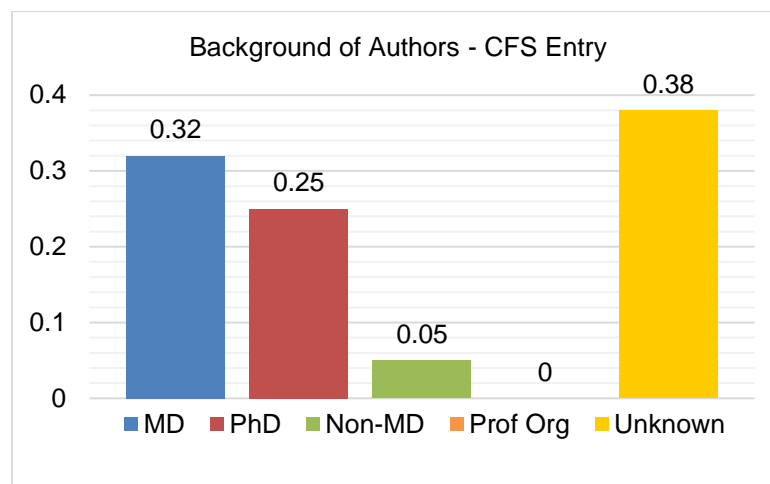


Figure 16: Relative Contribution by Authors' Background in the CFS main entry

Textual Analysis

Situating the Author. While the UpToDate Editorial Policy encourages the authors and editors of UpToDate to make explicit recommendations for treatment, the authors of the CFS entry did not center the content on their own recommendations for treatment. The authors make use of the phrase 'we (do not) recommend' in only one instance:

In a small double-blind, placebo-controlled crossover study that included 14 patients with CFS/SEID, modafinil, a selective wakefulness-promoting agent, had a mixed effect on cognition; had no effect on fatigue, quality of life, or mood; and had a negative effect on mental flexibility and motor speed. We do not recommend this agent. (CFS)

In this quotation, the authors provide information on a small RCT assessing the effectiveness of the drug modafinil followed by their own opposition to the use of the drug. This is the

only use of the ‘we recommend’ phrase in the CFS case. Although the authors do not concentrate on explicit recommendations, they do provide two accounts of their own clinical practices. In one instance, the authors simply affirm that they urge patients to push themselves when engaging in physical activity: “We encourage the patient to gently push himself or herself” (CFS). In the other instance, the authors provide a more extensive description of their approach to treating CFS as a form of neurally- mediated hypotension:

We do not routinely perform tilt table testing on our patients with SEID/CFS since it is expensive, moderately uncomfortable, and without proven utility. However, after carefully explaining to a patient that the efficacy is not established, we are willing to try atenolol alone or with fludrocortisone, if the patient wishes. We start with low doses which are increased slowly over several weeks. (CFS)

The authors do not center the content on their explicit recommendations; however, by providing accounts of their own practices, there is an implied endorsement of the approach.

In the CFS case, the authors used the term ‘we’ in one additional context, noting that “if the cause is organic, we do not yet know how to find it or treat it” (CFS). In this example, the use of ‘we’ places the authors within that community of clinicians and researchers. Similarly, the authors encourage clinicians to “... emphasize that we have considerable knowledge and experience with SEID/CFS” (CFS). The authors use ‘we’ not to describe themselves as authors, but rather to describe themselves as part of the collective of researchers and clinicians.

Situating the Evidence. Throughout the case the authors make it clear that there have been many attempts to find an effective treatment for chronic fatigue syndrome but there is no cure and there has been little success in finding a treatment that will alleviate symptoms. In the introduction of the main entry for CFS, the authors point out that the evidence has identified only two therapies that produce what they describe as ‘meaningful benefit’.

Many therapies have been tried in chronic fatigue syndrome (CFS), also called

systemic exertion intolerance disease (SEID), but only counseling therapies (eg, cognitive behavioral therapy) and graded exercise therapy appear to produce meaningful benefit. (CFS)

They note further that “neither of these modalities are curative. There is no known specific medical therapy for CFS/SEID” (CFS). The variety of options for delivery of these two non-pharmaceutical treatments is shared by way of the evidence that supports the approach. For example, cognitive behaviour therapy can be provided individually or in a group.

Another way to administer CBT is in a group setting. In a randomized trial, cognitive behavioral group therapy was more effective than enhanced usual care (defined as management by a primary care physician or medical specialist) at improving physical functioning, bodily pain, and vitality at 16 months among patients with a variety of somatic syndromes, including CFS/SEID; the patients who received cognitive behavioral group therapy participated in nine three and a half hour sessions over four months. CBT appears to be more useful than participation in a support group. In one three-arm trial, 278 patients were randomly assigned to CBT, a support group, or no active intervention with follow-up at 8 and 14 months. The CBT group had significantly improved fatigue severity, strength, overall sense of improvement, and lower sickness profile scores compared with the other groups at both time points. (CFS)

The efficacy of CBT through group therapy is demonstrated by two randomized trials with two different types of comparisons (i.e., usual care and non CBT support groups).

The demonstration of the efficacy of CBT and graded exercise therapy relies heavily on individual studies, citing only one systematic review on these treatments.

In the CFS entry, substantial attention is paid to the research examining the treatments that have been trialed but have not demonstrated efficacy or for which the efficacy remains uncertain. The lack of proven effective treatments is made transparent. Throughout the case, the authors make clear that many treatments have been trialed but there has been little success:

A number of medications and special diets have been evaluated in patients

with CFS/SEID, but none has proved successful. Among the modalities that have been tried are serum globulin, arituximba, acyclovir, galantamine, fluoxetine, and other antidepressants, methylphenidate and modafinil (stimulants), glucocorticoids, amantadine, doxycycline, magnesium, evening primrose oil, vitamin B12, Ampligen, essential fatty acids, bovine or porcine liver extract, dialyzable leukocyte extract cimetidine, ranitidine, interferons, exclusion diets, BioBran MGN-3 (a natural killer cell stimulant), and removal of dental fillings. (CFS)

After this extensive list of trialed and ineffective treatments, the authors go on to describe the evidence that has not been able to yield results to support the use of certain therapies in the treatments of CFS. For example, the association of CFS with the Epstein Barr virus infection lead researchers to try an antiviral drug but showed no benefits: “A controlled trial of intravenous and oral acyclovir was based upon the possible association with Epstein-Barr virus infection. The outcome showed no benefit of treatment” (CFS). In some instances, the authors provided details about specific trials. For example, the authors describe an RCT that assessed the efficacy of galantamine, a drug has been used in Alzheimer patients, in treating fibromyalgia.

In the largest and best-designed randomized, double-blind, controlled trial that has been performed for the treatment of CFS/SEID, 434 patients at multiple centers were randomly assigned to one of four doses of galantamine or placebo. At 16 weeks, there was no benefit from galantamine in the primary end point (improvement in the Clinical Global Impression Scale) or in any secondary end points. (CFS)

The authors selected this study because it *best* demonstrated the effect of the drug on fibromyalgia, and in turn, they also provided details about the patients, intervention, and outcomes of the study were provided. The authors describe in varying level of detail the evidence that refutes the many possible treatments that have been trialed as potential therapies for CFS.

Over half of the referenced evidence cited in the case were studies; however, the length of descriptions and amount of detail that the authors provided varied greatly across the

24 studies. The extensiveness of the details extended from only parenthetical reference to minimal details about one or two of the study's PICO elements to extensive details about all four PICO elements of a study. A single trial for rituximab was described in the following paragraph:

In a double-blind, placebo-controlled trial, 30 patients with CFS/SEID were randomly assigned to receive rituximab (500 mg/m²) or saline, given twice two weeks apart. There were no differences in the primary endpoint, defined as effects on the fatigue score at three months after the intervention. However, a major or moderate response, defined as lasting improvements in self-reported fatigue score during follow-up, was seen in 10 of 15 patients (67 percent) who received rituximab and in 2 of 15 patients (13 percent) who received placebo. The mean duration of response within a one-year follow-up period among the 10 responders in the rituximab group was 25 weeks (range 8 to 44 weeks). There were no differences in B cell levels between patients in the rituximab group who achieved a response compared with those who did not achieve a response. (CFS)

In these examples, the authors highlight the study design (i.e., randomized controlled trial) and provide details about all four PICO patients (i.e., 30 patients with CFS), intervention (500 mg/m² rituximab), comparison (i.e., saline) and outcomes (i.e., fatigue, B cell levels) of the study in order to demonstrate the effectiveness or lack of effectiveness of the therapies tested in the trial. In contrast, a study evaluating patient beliefs and outcomes was described as: "In one study, belief in a viral cause of the illness was associated with prolonged functional impairment" (CFS).

The authors' descriptions of the evidence in the CFS main entry extend beyond the description of the patient, intervention, comparison and outcome to include commentary or analysis of the research study itself. For example, they point out when studies examining drug treatments were not designed as a randomized controlled trials: "Although these results appeared intriguing, these studies were not placebo controlled, blinded, or randomized" (CFS). The authors suggest caution in interpreting the results based on the study design.

In addition to providing analysis of individual studies, the authors also highlight overarching issues with the interpretation and application of the body of research examining treatment for CFS. For example,

A major problem with evaluating the effect of therapy in CFS/SEID is that the symptoms fluctuate over time, may remit spontaneously, and are subject to substantial response rates to placebo. (CFS)

The authors also draw attention to insufficiency of evidence to support treatments. The description of rituximab treatment provides a good example of how they caution readers about the need for additional study despite the presence of positive results from a single study.

Though intriguing, these findings are too preliminary to support the use of rituximab, a drug that can cause immunosuppression and serious complications. This study needs to be repeated with a larger number of patients. (CFS)

The repeat this caution with respect to the use of the drug rintatolimod.

Rintatolimod is an investigational immune modulator and antiviral drug that has been approved for the treatment of CFS/SEID in Canada and Europe. It improved measures of exercise performance in two randomized trials; however, the clinical implications were unclear. Treatment with this drug should be considered experimental until more studies have been done. (CFS)

Although rintatolimod is approved for the treatment of CFS in Canada and Europe the authors advise that it should be considered 'experimental' until more research is completed. The clinical implications are considered to be unclear despite approval of the drug for treatment of CFS in Canada and Europe. The lack of clear understanding of what is considered to be 'sufficient' research is underscored in the CFS case.

The authors acknowledge that the body of CFS studies often yields conflicting conclusions. In addition to commenting on the uncertainty regarding the long-term prognosis for the condition, they also point out divergent results found with respect to specific treatments.

Intramuscular immunoglobulin injections appeared to be beneficial in one small controlled trial. However, this finding is in contrast to the more general experience. Controlled trials of intravenous immune globulin yielded conflicting and unimpressive results with a high incidence of adverse effects. (CFS)

Interestingly, in this instance the authors note that the benefits shown in one study do not align with others results but provide few details about the specifics of the cited research, yet they include other examples in which they provide considerable detail about the conflicting results. For example,

The results of studies evaluating glucocorticoids have also been inconsistent. A double-blind, randomized, placebo-controlled trial of 25 to 35 mg/day of oral hydrocortisone for 12 weeks in 70 patients showed modest benefit at the expense of adrenal suppression. By comparison, in a randomized crossover trial, clinical improvement was observed in response to 5 to 10 mg/day of hydrocortisone among 32 patients with chronic fatigue but without a comorbid psychiatric disorder. No adrenal suppression was observed, but the duration of therapy was only one month. (CFS)

Here, by providing the descriptions of two studies, the authors highlight the inconsistent conclusions in the evaluation of glucocorticoids. Differences in the patients (i.e., number, comorbidities), and interventions (i.e., dosage), and outcomes (i.e., adrenal suppression) are noted as a means to demonstrate inconsistency in the evidence base.

Situating the Patient-Physician Relationship. While the authors acknowledge in one instance that there is an opportunity for interprofessional care: “Graded exercise therapy should be supervised by a physical therapist or exercise therapist” (CFS), the primary focus of the content is the provision of care from a physician. The relationship between the patient and physician is acknowledged in the case as an important element of treatment. Under the heading ‘Treatment,’ the authors include three subheadings: the two treatments judged to be effective (i.e., Cognitive Behaviour Therapy and Graded Exercise Therapy), and ‘Supportive Approach’. The authors advise physicians to “establish rapport with the patient to be able to

provide support and reassurance” (CFS). They describe six specific elements that comprise a supportive approach. For example, one bullet describes the physician’s role in validating the patient’s experience and diagnosis:

Explain to the patient that the severity is variable but can be completely incapacitating and that the symptoms are real. CFS/SEID is a real illness, and the symptoms are not due to malingering. Because of the lack of laboratory abnormalities, most patients struggle with the validity of their disease (as do many of their clinicians) and may experience feelings of guilt. The patient must believe that you understand that they have a real disease or you will not be able to help them. (CFS)

Physicians’ confirmation of CFS as a ‘real illness’ is repeatedly highlighted as a critical element of the physician-patient relationship. In addition to validation, the authors emphasize the importance of being honest, addressing patients’ concerns without engaging in unhelpful debates and demonstrating a commitment to patients’ treatment process. The physicians’ adoption of a supportive approach is identified as a key component of a treatment regime for patients.

Within the section advocating for a supportive approach to treatment, the ways in which CFS can challenge the relationship between patient and physician are also interspersed. For example, the authors acknowledge that these patients are often time-consuming: “It is often tempting to avoid such patients, since they can take up a great deal of time” (CFS). Further, they point out that CFS patients have complex needs and encourage the physicians to: “Accept the fact that you will not be able to satisfy all patients with this disease” (CFS). They also acknowledge that patients’ desire to understand the cause of CFS can strain the relationship and they advise physicians to “Avoid debate over the psychogenic versus organic origin of symptoms” (CFS) because there is no benefit to the patient. While the importance of demonstrating support for patients is emphasized, the authors also concede that providing care for CFS patients can be challenging for physicians.

Patient Information. The transition from healthy individual to patient with CFS is described in both patient information entries, *The Basics* and *Beyond the Basics*. For instance:

Chronic fatigue syndrome is hard to deal with, because people who get it were usually active before. They did not tend to worry about being sick. Then, all of sudden, they feel tired and can't figure out what is wrong with them. Even the doctor often can't find a cause for the symptoms. And to make matters worse, other people sometimes think their symptoms are "all in their head." This can make people with chronic fatigue syndrome feel angry, helpless, and sad. (CFS Basics)

Both patient information sources also repeatedly validate the existence of the illness.

If you have chronic fatigue syndrome, try to remember that you have a real medical condition. You are not imagining your symptoms, and your problem is not "made up." Scientists have not yet figured out how to explain or cure chronic fatigue syndrome, but they do know that it is real. (CFS Basics)

Here, the intention is to reassure patients that CFS is a 'real medical condition' and that, while scientists do not yet know the cause or cure of CFS, they too believe it to be real. In the *Beyond the Basics* entry, there is recognition that the condition may not be a physical abnormality but rather may originate in the mind.

There is no point to debating whether symptoms of CFS/SEID originate in your mind or are the result of a not-yet identified abnormality. If the cause is in your mind, the symptoms are no less real (a difficult concept for some patients and/or their families). If the cause is an abnormality in your body, it is not yet known how to find it or treat it. (CFS Beyond)

The importance of validation by the patient's own health care professional is asserted repeatedly in *The Basics* and *Beyond the Basics*.

The most important thing you can do to deal with your condition is to find a doctor or nurse whom you trust and like and who believes that your condition is real. Only that way can the 2 of you work together to figure out how best to deal with your symptoms. (CFS Basics)

In both entries the need for physicians to accept CFS as a real condition is emphasized as 'the most important' element of their treatment. The *Beyond the Basics* information also

emphasizes the importance of building a relationship that “include[s] trust on both sides and a willingness to believe that CFS/SEID is both real and disabling” (CFS Beyond). Both patient information sources emphasize the necessity for finding a health care provider who is ‘willing’ to believe that CFS is real; however, there is also recognition that many healthcare providers are not knowledgeable about the condition.

Living with CFS/SEID can be frustrating because most people, including healthcare providers, have a limited understanding of why or how CFS/SEID develops. In addition, there are limited treatment options. (CFS Beyond)

In light of the lack of cure, the goal of treatment for CFS is reduction of fatigue.

There is no cure for chronic fatigue syndrome (CFS), also called systemic exertion intolerance disease (SEID); the goal of treatment is to reduce symptoms of fatigue and help you to cope. Many therapies have been tried in CFS/SEID but none has been consistently successful. Cognitive behavioral therapy and graded exercise appear to be the most effective treatments. (CFS Beyond)

The content presented in this excerpt from *Beyond the Basics* (i.e., lack of cure, the goal to reduce fatigue, the many trialed therapies, and identification of cognitive behavioural therapy and graded exercise therapy as CFS treatments) aligns with the content presented in *The Basics* as well as the main entry. Short descriptions of cognitive behaviour therapy and graded exercise therapy are provided in both patient information sources.

Following the identification of the two proven therapies, both patient information sources highlight that other therapies have been trialed but with little success.

Researchers have also checked whether different medicines, supplements, and special diets help with chronic fatigue syndrome. So far, none of these approaches has proven helpful (CFS Basics).

Indeed, *Beyond the Basics* provides a list of five treatments that have been trialed and “not proven to improve symptoms of CFS/SEID include the following” (CFS Beyond, emphasis in original). The trials and unproven efficacy of multiple treatments are also

highlighted in the main CFS entry.

Particular attention is brought to the lack of a role for antibiotics in treating CFS. This matter is highlighted with considerable detail in both *The Basics* and the *Beyond the Basics* patient entry.

There is no role for antibiotics in the treatment of CFS/SEID, and there is the potential for serious side effects from prolonged use of antibiotics. Your doctor might offer you antibiotics, especially if you test positive for Lyme disease. But antibiotics do not work on chronic fatigue syndrome. And testing positive for Lyme does not mean that your symptoms are caused by Lyme disease. Plus, taking antibiotics for a long time when you do not need them can cause health problems. (CFS Beyond)

In this case, the content of the two patient information sources and the main entry written for professional are well-aligned.

Case Analysis: Grief and Bereavement

The question of whether grief arising from the death of a loved one is a natural human process or a serious condition that may require medical attention is longstanding (Breen & O'Connor, 2007; Engel, 1961; Glass, 2005). In 1917, Freud explored this very tension in his classic essay "*Mourning and Melancholia*" and distinguished between two different responses to loss. Mourning while painful and difficult, was recognized to be also time-limiting, natural, and normal. In contrast, melancholia affects one's sense of self-worth, and is long-lasting and pathological. This distinction between 'normal' and 'abnormal' grief has been discussed for a century, and in turn, the ways in which physicians and health care professionals treat grief have also been debated.

A change to the foundational psychiatric text, the Diagnostic Statistical Manual of Mental Disorders (DSM), in 2013, may start to define treatment of grief more clearly and affect the way grief is understood and, in turn, how the medical profession handles grief. In the fifth edition, a feature termed the "grief exemption" or "bereavement exclusion" was removed (American Psychiatric Association, 2013). Prior to 2013, bereavement was the only life event or stressor specifically excluded from a diagnosis of major depression in DSM-IV. In removing the so-called bereavement exclusion, clinicians can diagnose major depression in persons who have experienced the death of a loved one after only two weeks of depressive symptoms. The goal of the change is to identify individuals who require treatment for major depression, which has been triggered or precipitated by the death of a loved one. However, the unintentional effect of this proposed change could be the medicalization of grief and an increase in the labelling of healthy, but grieving people with a psychiatric diagnosis.

Further complicating the treatment and handling of grief and bereavement is the proposed disorder of 'complicated grief'. Complicated grief disorder, officially named

‘persistent complex bereavement disorder’ by a DSM working group, is a proposed disorder assigned to individuals experiencing grief that is prolonged, intense and debilitating. Grief is considered prolonged if patients have not demonstrated adaptation to the loss and integration of bereavement into their lives by six months (Bonanno et al., 2002). Complicated grief is differentiated from other mental disorders including major depression and post-traumatic stress disorder.

In consideration of this context, the case study on grief and bereavement includes two UpToDate entries written by the same authors: *Grief and Bereavement in Adults: Management* (NGB) which addresses the treatment of what is often coined normal grief and bereavement, and *Complicated Grief in Adults: Treatment* (CGB), which addresses the treatment of complicated grief in adults. The two entries were chosen to represent the single case because the degree of medicalization was a key factor in the selection of cases; as such, the overlap across and the distinction between the two entries is very important.

Descriptive Analysis: Normal Grief and Bereavement (2015)

The normal grief and bereavement (NGB) entry includes 20 cited references, the fewest number of references across the eight entries analysed. The 20 references were all published between 2000 and 2014 with more than half ($n=11$, 55%) published between 2010 and 2015. Only seven of the 20 references were published in UpToDate’s core journals.

Half of the references ($n=10$) cited in the NGB entry are not recognized as types of evidence within the 6S hierarchy classification (see Figure 17). All six studies cited in the main entry for the NGB were quantitative, of which four were randomized controlled trials. The locations of study for the six studies were the United Kingdom ($n=2$), United States ($n=2$), the Netherlands ($n=1$), and one multinational spanning the United Kingdom and the United States. Two systematic reviews were cited, as well as two summary level resources.

The two summary resources included in the NGB main entry were clinical practice guidelines.

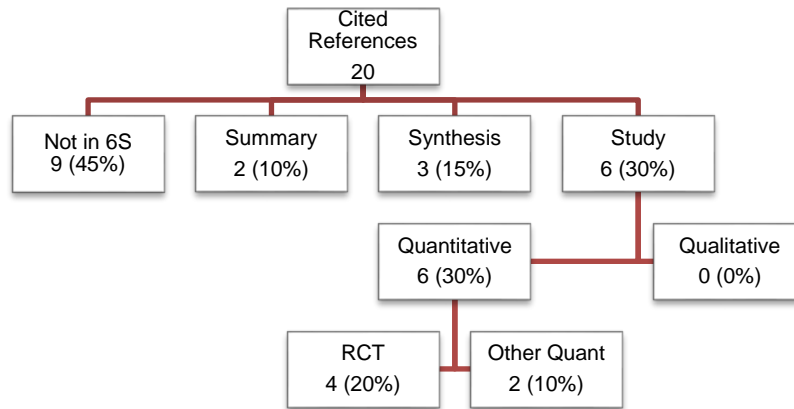


Figure 17: Types of Evidence in NGB Main Entry

The 20 references included in the main entry for NGB were written by a total of 88 authors. Across the 20 papers, the highest known proportional representation (.41) of the authors had a Basic Scientist (PhD) background. The relative proportion of authors with a Medical Doctor (MD) background was .24. The proportion of authors where the background authorship was unknown was .29 (see Figure 18).

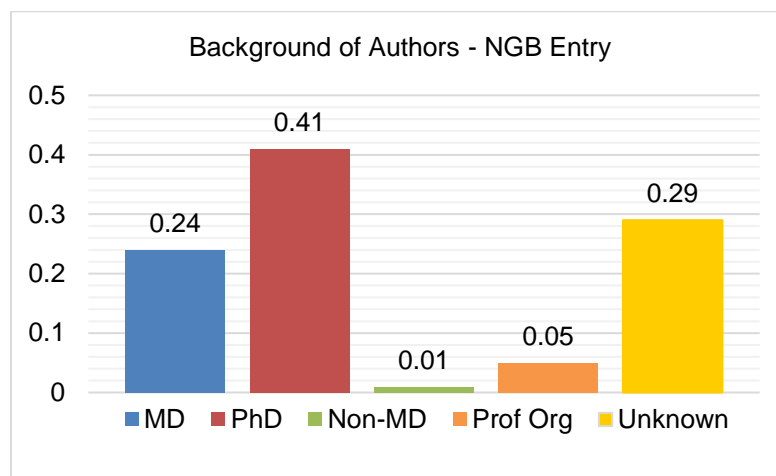


Figure 18: Relative Contributions by Author Background for NGB main entry

Descriptive: Complicated Grief (CGB, 2015)

The main professional entry addressing complicated grief (CGB) cited 30 references.

There is minimal overlap of references across the NGB and CGB entries (only two sources were cited in both entries). The 30 references were published between 1998 and 2015. Seventy per cent ($n=21$) were published between 2010 and 2015. Only nine of the 30 references (30%) were published in UpToDate's core journals. The most commonly cited journal was *Death Studies*, which is not identified as a core journal by UpToDate.

Seventy-seven per cent of references ($n=23$) cited in the CGB entry were studies; all but one was quantitative. Eleven of the 22 quantitative studies were randomized controlled trials. Three systematic reviews were cited. Only four references cited (13%) in the CGB entry were not sources of evidence recognized as evidence by the 6S hierarchy classification.

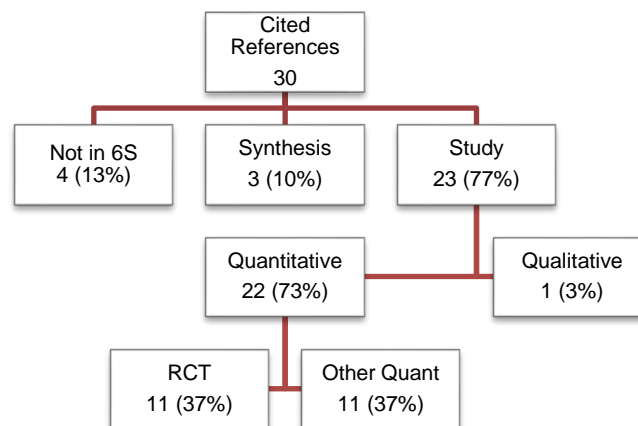


Figure 19: Complicated Grief and Bereavement in Adults: Treatment (CGB)

The 30 references included in the main entry for CGB were written by a total of 127 authors. Across the 30 papers, the highest known proportional representation (.35) of the authors had a Basic Scientist (PhD) background. The relative proportion of authors with a Medical Doctor (MD) background was .24. The proportion of authors whose background was unknown was .36.

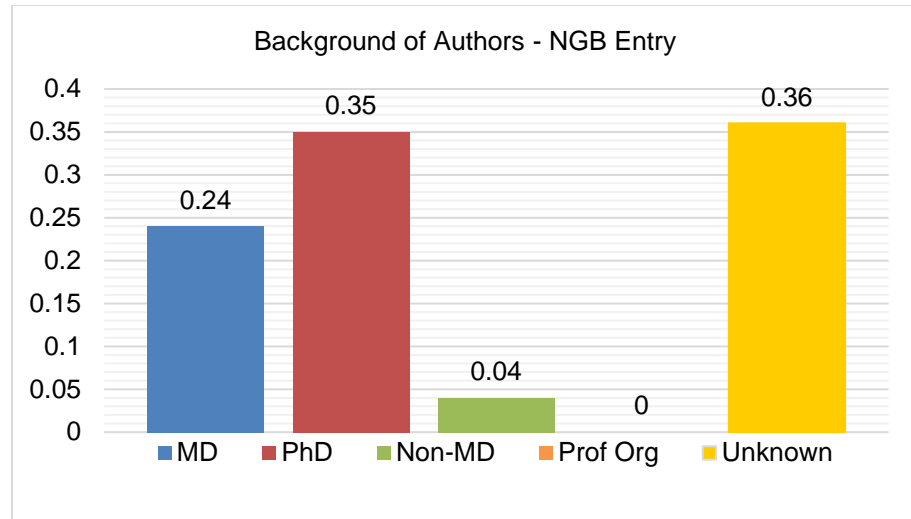


Figure 20: Relative Contributions by Author Background for NGB main entry

Textual Analysis

Situating the Author- Normal Grief and Bereavement (NGB, 2015). In the main entry for NGB the authors do not readily provide their recommendations, nor do they readily position their expertise within the content. The authors provide explicit recommendations only three times in the entry. For example, the authors offer their recommendation for treatment for bereaved patients who do not have mental disorders: “For bereaved individuals who do not have mental disorders, we suggest not routinely administering grief counseling or other psychotherapies” (NGB). In one additional instance, the authors provide their endorsement for treatments *implicitly* by describing their own approach to care: “For bereaved individuals who do not have mental disorders, we generally do not use benzodiazepines” (NGB). Their strategy to avoid prescription of these psychotropic drugs is reinforced more explicitly later in the entry by using the phrase ‘we suggest.’ Explicit recommendations are infrequent in the main entry for NGB.

There are sections of the NGB entry where the source of the knowledge is unclear. The authors do not always attribute the information to themselves or to published materials. For example, the authors describe patients’ experience before and following death:

If possible, clinicians should summon families prior to an expected death. If this is not possible and the patient dies, the clinician should promptly call immediate family members who are not present at the bedside in order to inform them, express condolences, answer questions, and offer them the option of viewing the body. (NGB)

For patients who are worried about their reaction to the death, education may be helpful. As an example, patients without mental disorders may be alarmed by hallucinations of the deceased, and can be reassured that this is not a manifestation of psychotic illness. Some people worry about the intensity or uncontrollability of emotions; this too is a typical feature of acute grief. (NGB)

In the first excerpt the authors provide guidance about what the clinician *should* do prior to the death of a patient. In the second the authors advise physicians about how patients might react when faced with the death of a loved one, and how best to respond to such reactions. The sections without any attribution to a source, neither evidence nor expertise, often relate to the role of the physician, as demonstrated in the first excerpt, or the experience of the patient, as demonstrated in the second excerpt. The ambiguity of the source of knowledge and the nature of the information provided suggests that the authors are providing implied guidance and recommendations based on tacit knowledge gained through their own experience.

Situating the Author- Complicated Grief and Bereavement (CGB). In the *Complicated Grief* entry, the (same) authors are more forthcoming with their own recommendations and refer predominantly to their own expertise through their explicit recommendations. Seven recommendations made by the authors in the CGB explicitly use the phrase ‘we recommend’ or ‘we suggest,’ as encouraged by the Editorial Policy of UpToDate. The recommendations endorse specific therapies and are often followed up by published evidence.

For patients with complicated grief, we recommend CBT adapted for complicated grief as first-line treatment. CBT has been widely studied and multiple randomized trials indicate that CBT targeted for complicated grief is

efficacious; the evidence supporting CBT includes head-to-head trials comparing CBT with other active treatments (rather than waiting list controls or usual care). As an example, a 12-week trial compared CBT with grief counseling in 54 patients, and found that improvement of complicated grief was greater with CBT and that its clinical effect was large. (CGB)

Not all recommendations were followed by evidence. For example, the authors provide guidance for physicians caring for patients who have not responded to cognitive behaviour therapy:

If patients are not responding to first-line treatment with complicated grief therapy or other forms of CBT targeted for complicated grief, we suggest re-evaluating patients with respect to psychosocial problems that can derail treatment, and addressing any such problems. As an example, patients may have serious financial, occupational, or interpersonal problems such as lawsuits related to the death, disability due to incapacitating symptoms, or conflicts with family members in settling the estate. (CGB)

The lack of clarity about the origin of information included in the CGB entry is common. In one instance, the authors infer their endorsement of treatment through accounts of their typical practice. In the Summary and Recommendations, the authors reinforce their endorsement of complicated grief therapy by describing their choice of this therapy in their own practice stating “We typically use a form of CBT called “complicated grief therapy” (CGB). While the authors do not overtly share their recommendation using ‘we recommend,’ their account of their typical practice endorses the practice implicitly.

Situating the Evidence, Normal Grief and Bereavement (NGB, 2015). Almost half of the references cited (9 of 20) in the entry for NGB are not types of evidence recognized within the 6S hierarchy of evidence. Six quantitative studies were cited in the NGB entry. The authors provided short description of two of the six studies cited in the NGB entry, both were randomized controlled trials:

A six-week randomized trial compared diazepam (2 mg, up to three times per day) with placebo in 30 individuals who were bereaved within the past two weeks; patients were allotted 20 tablets for the entire study. Outcomes were comparable at the end of the treatment and at the six-month follow-up. (NGB)

A subsequent randomized trial compared psychoeducation (four sessions, each lasting two hours, administered during home visits) with no intervention in 83 individuals bereaved through suicide; improvement of depressive symptoms (including suicidal ideation) and complicated grief symptoms in the two groups was comparable. (NGB)

As shown in the excerpts, the category of high quality trial (i.e., randomized controlled trial) was highlighted in both descriptions. The information about the intervention, comparison, and outcomes was provided; however, information about the patients was scant. Both descriptions describe studies in which the intervention did not result in a meaningful benefit.

The NGB main entry cited three synthesis level evidence sources, the meta-analysis comparing the efficacy of various grief interventions including counseling, psychotherapies, and support groups with control groups. Short descriptions were provided about all meta-analysis. A meta-analysis evaluating grief interventions with usual care was described briefly as:

A meta-analysis of nine trials compared interventions (eg, support groups) intended to prevent complicated grief with control conditions (eg, usual care or minimal treatment) in 1545 bereaved individuals, and found that the incidence of complicated grief was comparable. (NGB)

Once again, the authors are transparent that these interventions are not beneficial to the patient. Despite the outcomes of this meta-analysis and other research showing no benefit to grief interventions for normal grief and bereavement, the authors go on to explain when grief counselling can be helpful:

However, grief counseling can be helpful specifically for bereaved individuals who request it, and may also be helpful when it is coupled with other efforts that are focused upon new activities as well as experiences intended to restore one's life. (NGB)

The authors assert that grief counselling can be helpful for those who request it, citing a 2007 systematic review.

Finally, two World Health Organization (WHO) clinical practice guidelines were

cited. The guidelines cited addressed the use of benzodiazepines. The authors' aversion to using benzodiazepines was compared to the WHO guidelines: "Our approach is consistent with treatment guidelines from the World Health Organization" (NGB). The citation of clinical practice guidelines was used as a means to further validate their recommended approach.

Situating the Evidence, Complicated Grief (CGB). In contrast with the NGB main entry, the authors rely heavily on studies as evidence for the content presented in the complicated grief main entry. Specifically, 23 of the 30 cited references (77%) were studies - the highest proportion across the eight main entries analysed for this multiple case study.

The authors present their recommendation for first-line therapy for complicated grief as cognitive behaviour therapy (CBT) adapted for complicated grief. The strength of their recommendation is directly connected with the evidence.

CBT has been widely studied and multiple randomized trials indicate that CBT targeted for complicated grief is efficacious; the evidence supporting CBT includes head-to-head trials comparing CBT with other active treatments (rather than waiting list controls or usual care) For example, a 12-week trial compared CBT with grief counseling in 54 patients, and found that improvement of complicated grief was greater with CBT and that its clinical effect was large" (CGB)

This approach of acknowledging a larger body of evidence and then selecting examples from the body was also used when describing a specific therapy called "complicated grief therapy":

Evidence for the efficacy of complicated grief therapy includes randomized trials that studied the treatment in different age groups:
One trial compared complicated grief therapy with interpersonal psychotherapy in 95 patients (mean age approximately 48 years). Both treatments were administered in 16 weekly sessions, and patients were allowed to continue antidepressants initiated prior to study intake. Response occurred in more patients who received complicated grief therapy than interpersonal psychotherapy (51 versus 28 percent).
A second trial by the same principal investigator, using similar methods, compared complicated grief therapy with interpersonal psychotherapy in 151

patients (mean age approximately 66 years). More patients responded to complicated grief therapy than interpersonal psychotherapy (70 versus 32 percent), and response was sustained six months post-treatment. (CGB)

The authors select two studies from the body of randomized trials for which to provide descriptions that included details about the patients, intervention, comparators and outcomes of the study as well as the study design (i.e., randomized controlled trials). Study design is a common element highlighted in the CGB entry. The authors' preference for randomized trials is implicit in the entry.

No randomized trials have demonstrated that antidepressants are efficacious for complicated grief, and these drugs are often not used. However, several small observational studies suggest that these drugs may be helpful. (CGB)

The authors highlight that while observational studies *suggest* efficacy, randomized trials have not *demonstrated* efficacy. When describing three observational studies, the authors present outcomes with tempered certainty using words such as *suggest* and *may* (be helpful).

The authors provided a short description of one of the three synthesis level evidence sources.

Randomized trials indicate that the best treatment for complicated grief is psychotherapy that is specific for complicated grief. As an example, a meta-analysis of five trials compared psychotherapies (eg, cognitive-behavioral therapy [CBT]) adapted for complicated grief with control conditions (eg, nonspecific supportive psychotherapy) in 368 patients. Improvement was greater with psychotherapies adapted for complicated grief and the clinical benefit was moderately large. In addition, one study followed patients beyond the end of treatment and found that improvement remained greater in patients who received active treatment. However, the heterogeneity across the five trials was large. (CGB)

In this excerpt, the authors highlight that the meaningful clinical benefit of delivering psychotherapies specific for complicated grief. They also emphasize one of the five studies that demonstrated that improvements extended beyond the duration of the treatment. The two other systematic reviews cited in the entry appeared only as parenthetical references in a list

of possible treatments for non-responsive patients. In addition to proof of efficacy, descriptions of the way in which cognitive behaviour therapy is designed and delivered are provided in the CGB entry.

The second-line treatment, behavioural activation, is presented more briefly in the CGB main entry. Much less explanation about what behavioural activation is or how it is delivered is included. Only one randomized controlled trial was described in order to demonstrate the efficacy of behavioural activation in complicated grief:

Evidence for the efficacy of behavioral activation includes a 12-week randomized trial that compared behavioral activation with a waiting list control in 25 patients; after 12 weeks, patients in the control group received behavioral activation. Behavioral activation was administered in 12 to 14 individual sessions, and included education about complicated grief, self-monitoring of activities, identifying patterns and reinforcers of avoidant behavior, and scheduling alternative rewarding activities. Improvement was greater with active treatment; among the 25 patients, response at posttreatment occurred in 45 percent. At the follow-up assessment 12 weeks after treatment ended, response was observed in 60 percent of patients. In addition, symptoms of depression and PTSD also improved. (CGB)

Interestingly, the account of the behavioural activation therapy included in this study description is the only explanation of the intervention in the main CGB entry.

Cognitive behaviour therapy and behavioural activation are considered the first- and second-line therapies and, as such, the authors provide evidence of their efficacy. When these first- and second-line therapies fail, the presentation of evidence and the strength of evidence provided in the entry are markedly reduced. When these therapies fail, the authors suggest an amalgamation of approaches including: education about complicated grief, counseling and support, encouragement, correcting dysfunctional thoughts, anticipating anniversary dates, antidepressant medications. With the exception of the use of antidepressants, for which the authors state a lack strong evidence, these approaches are not situated within a body of evidence but rather are only presented as a list in the CGB main entry. Following failure of

these interventions, another list of possible therapies is presented.

For patients with complicated grief who do not respond to this combination of interventions, we suggest interpersonal psychotherapy, narrative therapy, meaning making therapy, psychodynamic psychotherapy, family therapy, eye movement desensitization and reprocessing, or art therapy. (CGB)

While no descriptions of these therapies or descriptions of the evidence supporting these therapies are provided, each of these therapies does include at least one parenthetical citation, either a systematic review or a study.

Situating the Patient-Physician Relationship, NGB

The authors of the normal grief and bereavement entry address the normalcy of the grief process by declaring that many people do not require treatment when they are going through the processes of grief and bereavement.

Acute grief does not typically require treatment. Most bereaved individuals are resilient and grief is transformed and integrated during a natural adaptive process that typically unfolds with the support and encouragement of close family and friends, as well as clergy. (NGB)

The resiliency of bereaved individuals is highlighted alongside the need for the support and encouragement of others. Grief, as a natural process that does not require treatment but rather support, is reinforced throughout the case and informs the way in which the patient-physician relationship is described in the main entry for NGB.

While it is often not necessary for physicians to provide treatment for the bereaved, the authors do emphasize that patients often welcome the physician's acknowledgement of and support for their loss. Throughout the entry, the authors provide strategies and tactics for physicians to support the bereaved.

Support from clinicians for acute grief typically includes empathic listening, information about the wide range of typical grief symptoms, reassurance, and monitoring. Condolence letters, telephone calls, attending the funeral or memorial service, and home visits may be helpful as well. (NGB)

Clinicians are advised also to be aware of social and environmental issues that may hamper the bereavement process:

Clinicians can guide bereaved patients in managing social or environmental problems that supervene in the aftermath of a loss and become the focus of thoughts and behaviors. As an example, if a widow is left with insufficient funds to support herself, her partner's affairs are in disarray, or she is ostracized or blamed after the death of a loved one, these situations demand attention because they may interfere with adaptation, trigger a depressive or anxiety disorder, or lead to complicated grief. (NGB)

To further assist physicians, the authors provide suggestions for what to say to grieving patients and identify times and ways that physicians can support their patients through the grieving process.

The physician is not positioned as the main source of bereavement support, but rather a natural one.

Primary care clinicians are a natural source of support for bereaved individuals and typically view bereavement care as important and satisfying; however, many clinicians feel inadequately trained. (NGB)

The limitations of physicians' comfort in treating patients is also underscored when the entry addresses the need to rule out other conditions including "Suicidal ideation and behaviour; Complicated grief; and Other mental disorders, such as major depression, posttraumatic stress disorder (PTSD), insomnia disorder, and anxiety disorders" (NGB). The authors advise that: "Primary care clinicians who are not comfortable diagnosing and treating mental disorders should refer patients to mental health clinicians" (NGB). The entry acknowledges that while physicians can be a helpful source of support, clinicians often feel underprepared to treat the bereaved, especially when complications and comorbidities develop.

Through the identification of opportunities for support throughout the bereavement support, the authors also provide insight into the experiences of the patient. Patient

experiences are exposed through the description of ways in which patient education and patient encouragement can assist patients and:

For patients who are worried about their reaction to the death, education may be helpful. As an example, patients without mental disorders may be alarmed by hallucinations of the deceased, and can be reassured that this is not a manifestation of psychotic illness. Some people worry about the intensity or uncontrollability of emotions; this too is a typical feature of acute grief. (NGB)

Encouraging patients to maintain regular patterns of activity, sleep, exercise, and nutrition may help adaptation to the loss. Bereaved individuals may forget to care for themselves and may withdraw socially. If the deceased person lived in the same house, meals can trigger intense feelings of missing the person. Patients may eat food that a loved one especially enjoyed in order to feel close to the person, or avoid foods that serve as reminders of the loss. Sleep can be disrupted as well. (NGB)

The intensity and uncontrollability of the patient emotions and reactions are described, as well as the resulting effect on daily life. More extensive descriptions of the patient experience are covered in the related UpToDate entry *Grief and Bereavement: Clinical Features*, however by exploring the opportunities for the physician to provide support, physician observation of the patient experience is also underscored.

Situating the Patient-Physician Relationship, CGB

Complicated grief is acute grief that becomes “unrelenting, intense, and functionally debilitating” (CGB). Unlike normal grief and bereavement, the authors claim that complicated grief requires treatment. The patient-physician relationship in complicated grief is dictated by the goal of treatment, which is outlined in the CGB entry as “resolving grief complications and fostering adaptation to the loss” (CGB). The authors reinforce that the goal of the treatment is not the elimination of all symptoms. They provide indicators of when the treatment is successful including improved emotion regulation, an ability to envision a positive life, and engagement in activities and relationships.

One of the keys to providing treatment is educating the patient about complicated

grief as a disorder. The education is intended to assist patients by validating their experience and providing a diagnosis:

Many patients with complicated grief are discouraged by the prolonged acute grief and feel hopeless, and are relieved to receive the diagnosis as well as education about the disorder. In addition, family and friends who initially were supportive may be critical and tired of trying to help because they do not realize the patient has a treatable condition. (CGB)

The authors reinforce the validity of complicated grief as ‘real’ by describing it as a “treatable condition” (CGB). Patient education and validation of complicated grief as a disorder is presented as a key attribute of the patient-physician relationship.

First- and second-line therapies for complicated grief are identified in the CGB treatment entry. Physicians are encouraged to treat patients first with cognitive behaviour therapy adapted for grief. If patients fail to respond, behavioural activation is suggested as the second line treatment. Prior to moving onto second line treatment clinicians are encouraged to assess for “psychosocial problems that can derail treatment” (CGB). Issues that may arise may relate to legal, occupational or financial problems as a result of the death. Physicians are encouraged to “address any such problems” (CGB). The complexity of the grieving patient is acknowledged by the authors stating:

In addition, many patients with complicated grief have comorbid major depression, anxiety disorders, PTSD, or substance use disorders. If a disorder other than complicated grief is more salient, treatment should refocus upon the primary problem. (CGB)

Repeatedly, complicated grief is framed as “a unique and recognizable condition that can be differentiated from other mental disorders” (CGB), however, the presence of complex psychosocial issues and comorbidities do raise questions about the simple description of complicated grief as a *treatable condition*.

The responsibility for delivery of the first- and second- line treatments is ambiguous in the CGB entry. No clear indication is provided about what type of professional delivers

these treatments and what relationship exists between the patient, the primary care providers, and the treatment provider.

UpToDate does not provide patient information for either normal or complicated grief.

Case Analysis: Intimate Partner Violence

Intimate Partner Violence (IPV) describes physical, sexual, and emotional abuse by a current or former partner or spouse; it is differentiated from bi-directional conflict in relationships. Most victims of IPV are female; most perpetrators are male. Alongside the risk of death, very significant non-fatal outcomes and consequences include injuries and disabilities; mental health and behavioural consequences; and poor reproductive health (WHO, 2010). Because of the serious and pervasive health impacts, intimate partner violence is increasingly recognized as a public health concern requiring physician awareness and involvement.

Physician support for a patient experiencing abuse is often initiated when IPV is detected, disclosed, and “diagnosed.” Physicians and health care workers are increasingly encouraged to talk about, assess risk, and provide options for support when intimate partner violence is disclosed (American College of Obstetricians and Gynecologists, 2012; Cronholm, Fogarty, Ambuel & Harrison, 2011; Society for Obstetricians and Gynecologists of Canada, 2009). Preventing IPV and ensuring supports and resources are available to those experiencing abuse is recognized as a priority, and the potential issues and consequences that emerge from these actions are numerous and complex. As such, the role of health care workers in identifying and providing intervention options for IPV has been debated extensively (Cole, 2000; Wathen & MacMillan, 2012).

Descriptive Analysis

The authors of the IPV case cite 28 references ranging in date of publication from 1984-2015. Almost half ($n=13$, 46%) are published between 2010 and 2015. Forty-six ($n=13$) are published in UpToDate’s core journals. The most commonly cited journal in the IPV case was *The Lancet*, cited four times.

The UpToDate entry for IPV contains three types of evidence from the 6S hierarchy: Summary, Synthesis, and Study (see Figure 21). Half of the references ($n=14$) cited in the IPV case are not sources recognized as evidence within the 6S hierarchy; five non-systematic/narrative reviews; four public websites, three published reports, a textbook and a resource manual. Five systematic reviews (Synthesis level), are cited, along with seven studies, including one qualitative, two RCTs and four non-RCT quantitative studies. Six of the seven studies took place in the United States and one in Australia.

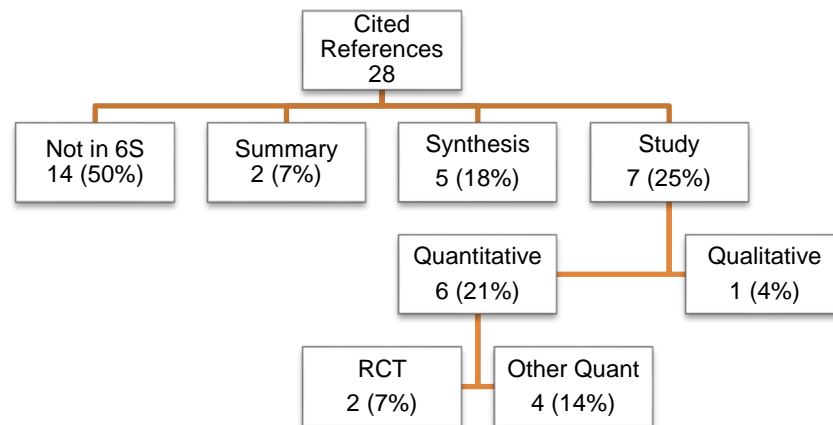


Figure 21: Types of Evidence in IPV Main Entry

The 28 references cited in the IPV case were written by a total of 108 authors. Across the 46 papers, the highest known proportional representation (.22) of the authors was from professional organizations. Proportionally, medical doctors comprise .17 of the authors and other health professionals made up .21 of the authorship. The relative proportion of authors who are Basic Scientists is .20 (see Figure 22). Proportionally across all 46 papers, .21 of the authors' backgrounds are unknown.

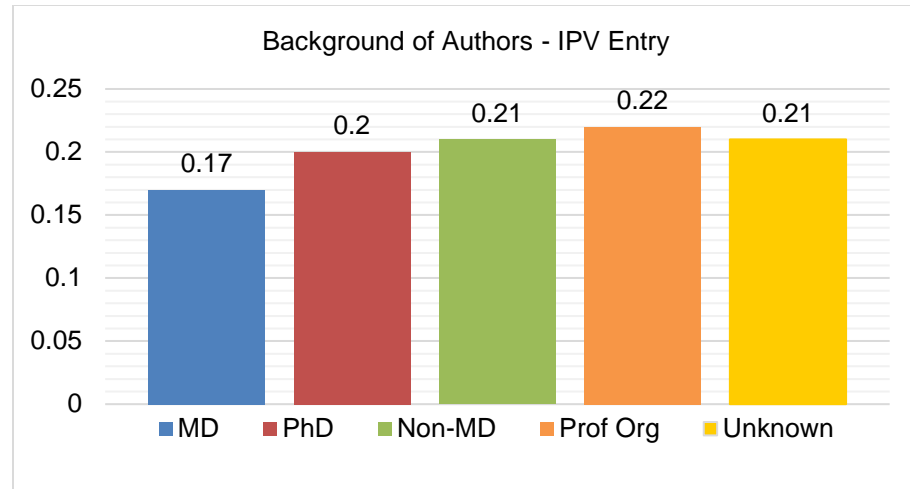


Figure 22: Contributions by Authors' Backgrounds for IPV main entry

Textual Analysis

Situating the Authors. The authors of the IPV case do not overtly locate themselves within its content. Unlike other cases, the authors never refer to themselves as “we” to designate content emerging from their own recommendations, practices, or expertise. Nevertheless, there are indications that selected guidance provided to the reader is based on authors' expertise.

Significant sections of the case are not anchored to a cited reference. For example, the authors provide the reader with sample phrases that may be used within the clinical encounter, e.g., “I want to help you through this in any way I can” (IPV). This type of advice commonly permeates the general literature on responding to IPV. Similarly, there are multiple instances of guidance and advice to the reader that align with general knowledge about supporting victims of IPV, without overt attribution as to where the advice originated:

The clinician should ask the patient how afraid they are and what they think are their immediate and future safety needs. Unfortunately, many people minimize or deny their danger. Clinicians may be surprised or frustrated with the severity of abuse patients are willing to tolerate and should understand that love and other family concerns, such as children in the home and economic factors, often confound the picture. (IPV)

Providers should assure the abused patient that they are available for support. In addition the patient should be offered referral for counseling about options and safety, often to an onsite or local domestic violence agency where available. Patients may be reluctant or resistant to talking with anyone else because of fears about safety. On subsequent visits, you may emphasize ongoing support and concern and ask the patient again to consider referral to someone who can help think about options. (IPV)

The authors provide the reader with guidance about how to communicate with and advocate for the IPV victim by explaining what the physician *should* do. They guide the physician through a patient encounter and offer insights into what the physician might expect when caring for victims of IPV. While the authors do not explicitly refer to themselves in this case, in the presence of advice and in the absence of published evidence, they do appear to be sharing their own experiences, knowledge, and expertise.

Situating the Evidence. As noted above, significant sections of the IPV case are not attributed to published evidence. The case contains only seven studies: two RCTs, four non-RCT quantitative studies (two U.S. National surveys, a tool validation, and a cohort/longitudinal study) and one qualitative study. (One RCT was misidentified as a meta-analysis in the UpToDate entry). The descriptions of the evidence used within the case vary in the amount of detail provided.

The case unusually contained one qualitative study (of two such studies in all the cases reviewed). No details about the study were provided other than its conclusion: “Attempting to or leaving a relationship with a perpetrator often increases the risk of injury. Providers should not encourage their patients to leave a relationship” (IPV).

Importantly, one of the key messages communicated in the IPV main entry is that there is little evidence that demonstrates meaningful benefits of IPV interventions: “The effectiveness of interventions for domestic violence has been studied and have shown limited benefits for most women” (IPV). The authors call upon a systematic review and clinical

practice guidelines to support this claim:

Studies have not shown conclusive benefits for advocacy or counseling interventions. A 2009 systematic review found insufficient evidence to determine if advocacy (providing information, support, and resource access) in healthcare settings is effective for women who live with their abusing partners. Intensive advocacy for women in shelters decreased physical abuse, but its effect on depression, quality of life, and psychological distress was uncertain. A subsequent multicenter trial randomized women who screened positive for IPV to an intervention of one to six counseling sessions or to no intervention. The response to a mailed survey at one year found no differences in the primary outcomes of quality of life, psychological health, or planning for safety, although the risk of depression was reduced in the intervention group. (IPV)

The 2013 World Health Organization guidelines concluded that, except for women who have spent at least one night in a shelter or for pregnant women experiencing IPV, there is insufficient evidence that interventions for IPV improve health outcomes.

While the conclusions of the systematic review and the clinical practice guidelines indicate that IPV interventions are not effective, the authors resist the notion that no intervention is necessary. Specifically, they state: “Counseling may strengthen the victim’s self-worth and provide ongoing support, although objective evidence to support these benefits is limited” (IPV). While there is not sufficient evidence to support the benefits of counselling, the authors suggest counselling as a means to provide support to the victim.

The authors do bring attention to areas of IPV research in which there have been conflicting results across studies, particularly regarding the efficacy of treatments for pregnant women:

In a 2012 meta-analysis of four trials, counseling interventions reduced IPV, improved birth outcomes for pregnant women, reduced IPV in the post-partum period, and reduced unsafe relationships and pregnancy coercion for women seen in family planning clinics. However, a subsequent 2014 systematic review looking at 9 studies concluded that there was insufficient evidence to assess the effectiveness of interventions for domestic violence on pregnancy outcomes due to the heterogeneity and poor quality of studies overall. (IPV)

Throughout the case the authors are transparent in describing research that addresses the care

of IPV as inconsistent and inconclusive.

The clinical practice guidelines from the World Health Organization, which occupy the summary level of evidence, are mentioned twice in the entry.

The World Health Organization issued guidance in 2013 for responding to intimate partner violence and sexual violence against women. The guidelines stress the importance of woman-centered care as first-line support, to include confidentiality when possible, privacy, nonjudgmental support, validation, and not pressuring the woman to leave the relationship. The guidelines incorporate recommendations for initial support, care for survivors, clinician training, healthcare policy, and mandatory reporting. (IPV)

The focus on a supportive, patient-centred approach to caring for the IPV victim is clearly conveyed in both the clinical practice guidelines and the UpToDate entry. The second reference to the guidelines addresses the lack of efficacy of IPV treatments. While not explicitly stated, the approach put forth by the authors does align with WHO guidelines.

Situating the Physician-Patient Relationship. The authors explicitly and repeatedly state throughout the case that providing care for the patient requires supports beyond the physician: “Care of the patient experiencing IPV requires a team approach involving medical, institutional, and community resources” (IPV). Potentially helpful supports include social workers, women’s shelters, legal aid, hospital or community advocates, and community hotlines. The willingness of physicians to connect IPV victims with support is dictated by patient needs and experience. In particular, the authors highlight the importance of readiness:

For patients who are not ready or are too fearful to proceed with referral, support and concern should be discussed on subsequent visits, and the patient should again be asked to consider referral to someone to help him or her think about their options. (IPV)

The authors emphasize that patients’ needs and experiences guide care as well as referrals.

The IPV main entry highlights that the focus of care in IPV is support: “Providers should assure the abused patient that they are available for support” (IPV). Throughout the

case, the authors provide clarification about what ‘support’ entails.

When IPV has been identified, the most important first consideration is to offer support to the patient. It is crucial that providers affirm their understanding of how difficult it must be for the patient to share this information, recognize the patient's strength in doing so, and provide assurance that they will be available to the patient for the future. This should be immediately followed by an assessment of the victim's safety. (IPV)

The authors describe the importance of physicians being able to demonstrate their understanding, compassion, and respect.

The immediate expression of empathy, acknowledgement, and continued ability to support and assist the patient are the most important components of care after a patient has disclosed abuse. (IPV)

The authors provide further guidance about how to deliver this type of support. Specifically, they list possible statements that will help the physician convey empathy, validation, and assistance.

The need for the clinician to recognize the uniqueness of patient experiences and situations is emphasized. Some differences across patients that are underscored in the entry include the level of danger victims are experiencing, as well as their readiness to change their situation, and the supports they have available. The authors are explicit that it can be challenging to provide care for victims of IPV. One of the key challenges is the clinicians’ disbelief that victims are willing to tolerate the abuse. While it may be difficult for physicians to understand the situations and choices of victims, the authors are very clear throughout the IPV case that decision-making is the right and responsibility of the patients: “Patients should be allowed to make autonomous decisions regarding health advice” (IPV). The authors reinforce the importance of this by calling on the WHO clinical practice guidelines outlining the need to provide the environment that will allow victims to make their own decisions.

The guidelines stress the importance of woman-centered care as first-line support, to include confidentiality when possible, privacy, nonjudgmental support, validation, and not pressuring the woman to leave the relationship.

(IPV)

The clinical practice guidelines reinforce the responsibilities of physicians to ensure patient autonomy. Within this context, the legal aspects of providing care for IPV are acknowledged as one caution and limitation to patient autonomy. The compounding safety and legal issues that arise when children are exposed to IPV are emphasized: “Health providers and law enforcement officers, as well as teachers and child care providers, are mandated reporters in most states” (IPV).

It is noteworthy that throughout the IPV entry, patients experiencing IPV are not limited to female victims. Although women are most at risk for experiencing IPV, the authors position the content as gender neutral, referring most often to their, and sometimes including both binary genders by referring to he/she or him/her.

UpToDate provides no patient information for intimate partner violence.

Cross-Case Analysis

Descriptive Analysis:

In this cross-case descriptive analysis, the 427 references cited across the eight professional entries that make up the multiple case study are examined. Comparisons across the seven cases and eight entries are highlighted.

Currency. One of the highly regarded benefits of online medical information is the capacity to update information with the most recent developments in a timely and efficient manner. In this way, new medical knowledge can be integrated into online point of care resources such as UpToDate, into clinical practice, and into a patient's care more quickly than ever before. According to its *Editorial Policy*, the content of UpToDate is "revised whenever important new information is published" (UpToDate, "Editorial Policy," 2016). Table 22 provides an overview of the publication dates of the references cited across the professional entries across the cases analysed in this investigation. All but the *Grief and Bereavement* (NGB) entry cited at least one publication published in the year of download, 2015. The two entries with the highest percentage of references published between 2010 and 2015 were the *Grief and Bereavement* (NGB) and *Complicated Grief and Bereavement* (CGB), both citing more than 50% of references published in a 5-year period prior to the review current date. It is noteworthy that these two entries were new entries in 2015 and are labelled version 1.0. In 2015, these two entries (NGB and CGB) replaced a single entry addressing all issues relating to bereavement. Because these two entries originated in 2015, older publications may not have been included in the entry with the result that the proportion of articles published in the last five years increased. In contrast, the two entries that have the lowest percentage of references published between 2010 and 2015, *Acute Otitis Media* and *Chronic Fatigue Syndrome*, are on versions 29.0 and 31.0 respectively. The high percentage

of articles published prior to 2010 in entries with a higher version number suggests that older articles may not be removed or updated when new versions are created.

UpToDate Main Entry	Review Current Date	Earliest Publication Year	Most Recent Publication Year	Most Common Year(s) (Mode)	2010-2015
Acute Otitis Media	08/2015	1980	2015	1999	22% (18/81)
Androgenetic Alopecia	10/2015	1987	2015	2002	29% 12/41
Irritable Bowel Syndrome	10/2015	1984	2015	2012	39% (35/89)
Fibromyalgia	11/2015	1986	2015	2008	41% (37/91)
Chronic Fatigue Syndrome	12/2015	1986	2015	2001	22% (10/46)
Grief and Bereavement	11/2015	2000	2014	2005; 2010; 2011; 2013	55% (11/20)
Complicated Grief	11/2015	1998	2015	2013	70% (21/30)
Intimate Partner Violence	10/2015	1984	2015	2015	46% (13/28)

Table 5: Overview of publication dates of references cited across the eight professional entries

Journal Titles. UpToDate provides a list of 466 key journals that are identified as highly relevant and of high quality, which warrant hand-searching by the community of physician-authors that is responsible for selecting the evidence to be included in UpToDate. Hand-searching is a method that involves the examination of the entire contents of preselected journals to identify articles of interest. In this study, these journals are referred to as UpToDate’s core journals. Across the eight entries, of the total 427 cited references, 402 were published articles from a total of 143 journal titles. Of the 143 journals cited, 43% ($n=62$) were part of UpToDate’s core journal list and represented 72% ($n=285$) of the 402 cited journal articles. The percentage of references from core journals in each of the eight entries is presented in Table 6. Eighty-nine per cent of references cited in the *Chronic Fatigue Syndrome* main entry were published in the core journals. For three topics, *Grief and Bereavement (normal)*, *Complicated Grief and Bereavement*, and *Intimate Partner Violence*, fewer than half of the references cited were published in the core journals.

	AOM	AGA	IBS	FIB	CFS	NGB	CGB	IPV	Total
	$n=82$	$n=41$	$n=89$	$n=91$	$n=46$	$n=20$	$n=30$	$n=28$	$n=427$
<i>% from</i>	74%	63%	70%	73%	89%	35%	30%	46%	67%
<i>Core Journals</i>	(61)	(26)	(62)	(66)	(41)	(7)	(9)	(13)	(285)

Table 6: Percentage of references cited from a core journal

The five most cited journals are listed in Table 7. Across the eight professional entries, the most commonly cited journal was the *Cochrane Database of Systematic Reviews*. This title is not always considered a journal; however, because of its inclusion in the list of journals hand-searched, it is considered a journal for this analysis. The second most commonly cited journal was *JAMA*. Across all the topics the most commonly cited journal is

included on the core journal list with the exception of the entries for *Normal Grief and Bereavement* (NGB) and *Complicated Grief* (CGB) where *Death Studies*, the most frequently cited journal is not included among UpToDate's core journals.

Entry	Most Commonly Cited Journal	Core
AOM	Pediatric Infectious Disease Journal (n=16)	Yes
AGA	Journal of the American Academy of Dermatology (n=13)	Yes
IBS	American Journal of Gastroenterology (n=14)	Yes
FIB	Arthritis and Rheumatology (n=18)	Yes
CFS	Lancet (n=7)	Yes
	American Journal of Medicine (n=7)	Yes
NGB	JAMA (n=2)	Yes
	Journal of Palliative Medicine (n=2)	Yes
	<i>Death Studies</i> (n=2)	No
CGB	<i>Death Studies</i> (n=4)	No
IPV	Lancet (n=4)	Yes

Table 7: Most Commonly Cited Journals by UpToDate Main Entry

Types of Evidence Resources. The corpus of cited references (n=427) that make up the evidence base of the eight entries is dominated by studies. Sixty-three per cent of the cited references are sources located at the study level of the 6S hierarchy of evidence whereas only 15% are meta-analyses or systematic reviews from the synthesis level of research. Eighteen per cent of the references cited across the eight entries are not types of resources identified as evidence in the 6S hierarchy.

Table 8 describes the distribution of the references across the 6S hierarchy across the cases.

	AO	AGA	IBS	FIB	CFS	NGB	CBG	IPV	Tota
	M <i>n=82</i>	<i>n=41</i>	<i>n=89</i>	<i>n=91</i>	<i>n=46</i>	<i>n=20</i>	<i>n=30</i>	<i>n=28</i>	1 <i>n=42</i> 7
Not in 6S	3%	22%	12%	8%	15%	45%	13%	50%	18%
Hierarchy	(15)	(9)	(11)	(7)	(7)	(9)	(4)	(14)	(76)
System	-	-	-	-	-	-	-	-	-
Summary	6%	2.4%	3%	3%	-	-	-	7%	3%
	(5)	(1)	(3)	(3)				(2)	(14)
Synopsis/ Synthesis	-	-	-	2%	2%	10%	-	-	1%
				(2)	(1)	(2)			(5)
Synthesis	32%	2.4%	17%	21%	11%	15%	10%	18%	15%
	(14)	(1)	(15)	(19)	(5)	(3)	(3)	(5)	(65)
Synopsis/ Study	-	-	-	-	-	-	-	-	-
Study	59%	73.2	67%	66%	72%	30%	77%	25%	63%
	(48)*	% (30)	(60)*	(60)*	(33)*	(6)*	(23)†	(7)†	(267)
RCT	26%	59%	56%	35%	52%	20%	37%	7%	40%
	(21)	(24)	(50)	(32)	(24)	(4)	(11)	(2)	(168)

* All studies for AOM; IBS; AGA; FIB; CFS were quantitative studies

† One study in both CGB and IPV were qualitative studies

Table 8: Distribution of Resources across the 6S Hierarchy

The entries with the largest percentage of resources not considered to be evidence by the 6S hierarchy are in the *Normal Grief and Bereavement* (45%) and *Intimate Partner*

Violence (50%) cases. The *Androgenetic Alopecia* entry contained the highest percentage of RCTs and the lowest percentage of synthesis articles among its cited references.

While UpToDate does not explicitly provide formal inclusion and exclusion criteria for evidence in the entries, the UpToDate Editorial Policy does suggest that evidence higher on the evidence hierarchies is favoured for inclusion:

UpToDate follows a hierarchy of evidence consistent with most evidence-based resources. At the top of the hierarchy are meta-analyses of randomized trials of high methodological quality, followed by randomized trials with methodological limitations, observational studies and unsystematic clinical observations. (UpToDate, “Editorial Policy”, 2017)

Evidence hierarchies suggest that finding evidence higher in the hierarchy negates the need to evaluate lower level evidence. Across the eight entries analysed, 18.5% of the 351 references considered in the 6S evidence hierarchy were from the synthesis level. In contrast, over three quarters of the evidence cited was from the lowest level on the hierarchy, the Studies level.

In order to understand the availability of systematic reviews evaluating the clinical questions addressed within the UpToDate entries, systematic reviews that address the same or similar PICO elements (i.e. Patient, Intervention, Comparison, Outcomes) as cited clinical trials in UpToDate were identified through a portlet provided by PubMed (see Table 9). In the PubMed record for each trial, the portlet provides links to systematic reviews which cite that trial. Each individual clinical trial cited in each of the eight entries was evaluated for inclusion in a systematic review. The bibliographic information for the citing systematic reviews for each was recorded and compared to the reference list of the corresponding entry. Systematic reviews identified through the PubMed portlet that were deemed irrelevant to the topic were not counted (such as a clinical trial cited in the entry for Chronic Fatigue Syndrome that was cited by an article on post-stroke fatigue).

	AO							
	M	AGA	IBS	FIB	CFS	CGB	NGB	IPV
A. SRs cited in UpToDate	14	1	15	19	5	3	2	5
B. SRs identified in PubMed Portlet*	20	2	28	23	12	3	2	1
C. Highly relevant SRs from Portlet	8	0	12	14	3	0	0	1
D. Overlap between A and C	5	0	5	2	1	0	0	0
E. Potentially relevant SRs identified in Portlet not cited in UpToDate	3	0	7	12	2	0	0	1

*date restrictions applied to limit “Review Current” date

Table 9: Identification of Systematic Reviews (SRs) cited and not cited in UpToDate

The level of convergence between the SRs cited in UpToDate and the potentially relevant SRs identified by PubMed is quite interesting. In the entries for *Acute Otitis Media*, *Androgenetic Alopecia*, *Fibromyalgia*, *Chronic Fatigue Syndrome*, and *Intimate Partner Violence* there was at least one potentially relevant systematic review identified through the portlet that was not cited in UpToDate. For fibromyalgia, there were 12 systematic reviews identified by the PubMed portlet that were not cited in UpToDate. In contrast, only one systematic review for Androgenetic Alopecia was identified and it was cited by the authors. Generally, it appears that that systematic reviews addressing questions that were similar to those addressed in the entries were not always selected for inclusion. While there are many reasons that a systematic review may or may not be cited (e.g. perceived quality), UpToDate

does not provide an explicit statement of how evidence is selected for inclusion.

Across the eight entries, only two qualitative studies were cited, one each in the IPV and CGB cases. In order to gain an understanding of the availability of qualitative research that address the case topics, PubMed was searched using search strings targeted at identifying qualitative research studies and meta-analysis. (Table 3, Chapter 3 outlines the search strategies used.) All searches except AGA retrieved highly relevant and focused qualitative research on the treatment of the conditions. The qualitative research retrieved on male alopecia were related to hair loss as a symptom of another condition (e.g., cancer). Grief and bereavement (subject headings did not differentiate between complicated and normal grief) and IPV had the highest number of available qualitative studies. Meta-analyses of qualitative research were available for the topics of fibromyalgia, chronic fatigue syndrome, grief and bereavement and intimate partner violence, but not cited in the entries.

Case	MeSH Term	Qualitative Studies	Qual. Meta-Syntheses
AOM	"Otitis Media"[Majr]	3	0
AGA	"Alopecia"[Majr] AND "male"[MeSH Terms]	3*	0
IBS	"Irritable Bowel Syndrome"[Majr]	14	0
FIB	"Fibromyalgia"[Majr]	19	3
CFS	"fatigue syndrome, chronic"[Majr]	25	3
N/CGB	("Grief"[Majr]) OR "Bereavement"[Majr])	77	4
IPV	"Domestic Violence"[Majr]	167	6

Table 10: Qualitative Research Assigned with Topic Subject Headings as Major

Subject

Location of Study. There were 237 articles describing research studies cited across

the eight entries. The majority of studies (58%) were located in the United States. The breakdown of what continent each study was conducted in is presented in Table 11. Studies located in North American and Europe made up 96% of all studies cited across cases. The content of all eight entries in UpToDate was written by authors situated in the United States.

	<i>Author's Country</i>	North America	United States	Europe	Australia	Asia	Multi-national	Unknown
AOM <i>n</i> =48	<i>United States</i>	60% (29)	56% (27)	29% (14)	2% (1)	4% (1)	6% (3)	0% (0)
AGA <i>n</i> =30	<i>United States</i>	70% (21)	67% (20)	10% (3)	0% (0)	10% (3)	7% (2)	3% (1)
IBS <i>n</i> =60	<i>United States</i>	45% (27)	43% (26)	28% (17)	8% (5)	15% (9)	3% (2)	0% (0)
FIB <i>n</i> =60	<i>United States</i>	72% (43)	53% (32)	20% (12)	0% (0)	2% (1)	7% (4)	0% (0)
CFS <i>n</i> =33	<i>United States</i>	36% (12)	36% (12)	53% (19)	0% (0)	0% (0)	3% (1)	0% (0)
NGB <i>n</i> =6	<i>United States</i>	33% (2)	33% (2)	67% (4)	0% (0)	0% (0)	0% (0)	0% (0)
CGB <i>n</i> =23	<i>United States</i>	60% (14)	57% (13)	22% (5)	4% (1)	4% (1)	8% (2)	0% (0)
IPV <i>n</i> =7	<i>United States</i>	86% (6)	86% (6)	0% (0)	14% (1)	0% (0)	0% (0)	0% (0)
Total <i>n</i>=237		65% (154)	58% (138)	31% (74)	3% (8)	5% (12)	0% (0)	0% (0)

Table 11: Location of Study of Clinical Trials

Authorship. The 427 references cited across the eight entries were written by a total of 2230 authors. Among these, the highest known proportional representation (.39) of the authors were Medical Doctors (MDs) followed by Basic Scientists (.17) (see Table 12). The relative proportions of physicians across the eight entries are represented in Figure 23. The *Acute Otitis Media* entry had the highest relative proportion (0.56) of physician authors, while the *Normal Grief and Bereavement* had the lowest relative proportion (0.16).

	# of Authors	Not Known	MD	Nurse	Basic Scientist	Pharm- acist	Public Health	Other	Prof Org
AOM (82)	376	0.25	0.56	0.01	0.08	0.01	0.00	0.02	0.06
AGA (41)	203	0.28	0.51	0.01	0.13	0.01	0.01	0.02	0.02
IBS (89)	534	0.54	0.33	0.00	0.08	0.00	0.00	0.03	0.02
FIB (91)	531	0.38	0.41	0.00	0.17	0.00	0.01	0.03	0.00
CFS (46)	259	0.38	0.32	0.01	0.25	0.01	0.01	0.02	0.00
NGB (20)	88	0.52	0.16	0.00	0.25	0.00	0.00	0.01	0.05
CGB (30)	127	0.60	0.18	0.00	0.22	0.00	0.00	0.00	0.00
IPV (28)	108	0.21	0.17	0.06	0.20	0.00	0.01	0.03	0.22
ALL (427)	2226	0.35	0.39	0.01	0.17	0.01	0.01	0.03	0.04

Table 12: Background of Authors Across the Eight Cases

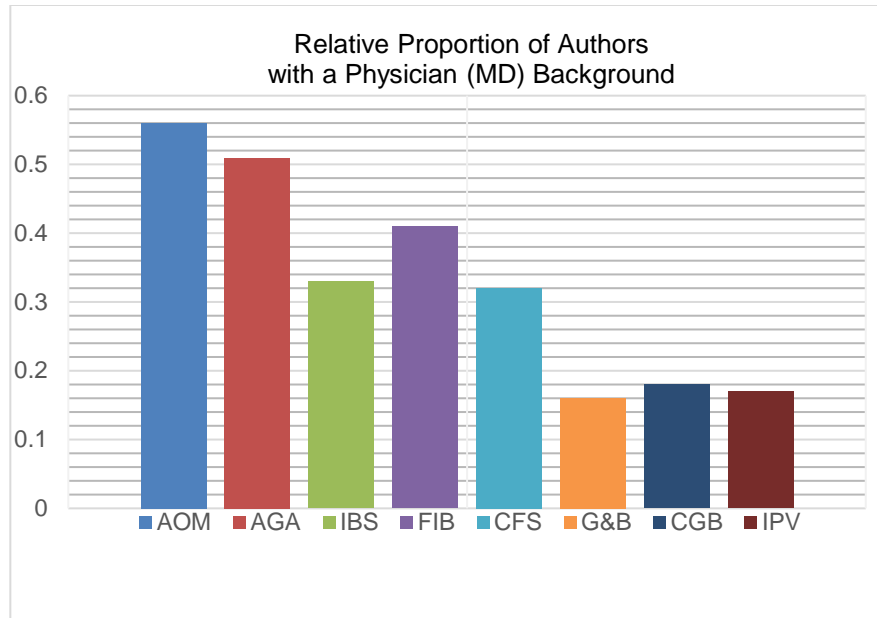


Figure 23: Relative Proportion of Authors with Physician Background

Because the publication in core journals and the presence of physician authors followed a similar pattern across the cases, a two-sample t-test was conducted to determine whether there is a relationship between the proportion of physician authors and the publication in a journal identified as a core by UpToDate. The t-test indicates that the mean relative proportion of authors with a physician background was higher in cited articles published in core journals ($M=.447$, $SD=.4$) than in non-core journals ($M=.2864$, $SD=.4$, $t(283)=3.87$, $p < .001$, $d = .16$). (Note that Levene's test indicated unequal variances ($F = 6.16$, $p = .433$), so degrees of freedom were adjusted from 425 to 283).

Cross-Case Textual Analysis

Situating the Authors. The degree to which the authors position themselves within the content varies greatly across the eight cases. As an indicator of this variance, the terms ‘we’ and ‘our’ were used 34 times in the *Fibromyalgia* entry, but never used in the UpToDate entry for *Intimate Partner Violence*.

The UpToDate authors position themselves in the content and share their expertise via the recommendations sections of the entries, although the frequency of explicit recommendations varied across the eight entries. Only the authors of the IPV entry chose not to make explicit recommendations using the phrases “we recommend” or “we suggest.” In the entries for *Androgenetic Alopecia* and *Chronic Fatigue Syndrome*, the authors only offered an explicit recommendation once. In contrast, recommendations were denoted with either the phrase “we recommend” or “we suggest” by the authors of the *Acute Otitis Media*, *Fibromyalgia*, and *Irritable Bowel Syndrome* cases 22, 16, and 15 times, respectively. The remaining three cases used the explicit phrases between three and 10 times.

When authors provided explicit recommendations they did so most often by addressing the tailoring of treatments to meet patient needs or by providing details as to how to best operationalize treatment regimens:

We suggest initiating therapy with a low dose of a tricyclic medication (eg, amitriptyline 10 mg) at night time, especially since these drugs are effective, widely available, and far less costly for most patients than some of the newer agents. (FIB)

This focus on details about how and to whom to deliver treatment regimens was common across the recommendations provided by authors. In the case of IBS, however, the details included in the recommendations focused overwhelmingly on the authors’ approach to the order of and execution of treatments following up from ineffective or incompatible treatments:

In patients with IBS with constipation (IBS-C) who have failed a trial of soluble fiber (eg, psyllium/ispaghula), we suggest polyethylene glycol (PEG). We treat patients with persistent constipation despite treatment with PEG with lubiprostone or linaclotide. (IBS)

Because of the differences among IBS patients, particularly in terms of their symptoms and their responses to treatments, these patients often undergo multiple attempts to find treatment success. The recommendations provided by the authors are intended to assist physicians to navigate treatment options over the course of multiple failed treatment attempts. Likewise, the entries for *Chronic Fatigue Syndrome* and *Fibromyalgia* refer to the need to try multiple treatment strategies, although the ordering of attempts was not explicit in these entries.

In addition to the explicit recommendations indicated by the phrases “we recommend” or “we suggest,” the authors also endorse treatment approaches implicitly by sharing their approaches to care used within their own practices. For example, the authors of the *Normal Grief and Bereavement* entry implicitly advise against using benzodiazepines for patients without mental disorders: “For bereaved individuals who do not have mental disorders, we generally do not use benzodiazepines” (NGB). Similar to explicit author recommendations, the accounts of the authors’ practices also include specific details about how the authors implement treatment. For example, in the *Fibromyalgia* entry, the authors provide details about the ways in which they introduce and increase the drug Milnacipran for the treatment of fibromyalgia:

Milnacipran is an alternative to duloxetine in patients with severe fatigue in addition to pain. We initiate therapy with 12.5 mg each morning, gradually titrating as tolerated to 50 mg twice daily. Some patients will require a higher dose; up to 100 mg twice daily may be needed ... In those patients with more severe problems with sleep, we use pregabalin taken at bedtime. (FIB)

The authors’ personal accounts of how they provide care for their patients convey an implied endorsement of those practices. This sharing of expertise was common in six of the eight entries: *Acute Otitis Media*, *Irritable Bowel Syndrome*, *Fibromyalgia*, *Chronic Fatigue*

Syndrome, Normal Grief and Bereavement, and Complicated Grief.

Though some recommendations were followed up with supporting evidence (discussed in detail below in the *Situating the Evidence* section), explicit recommendations were also provided in lieu of or in the absence of strong evidence in the entries for *Acute Otitis Media, Irritable Bowel Syndrome, and Fibromyalgia*. The *Acute Otitis Media* entry provides a good example of authors providing a recommendation in the absence of strong evidence:

There are no randomized trials to guide treatment of recurrent AOM in children. [...]
When recurrence occurs within 30 days of completion of antimicrobial treatment for the previous episode, we suggest [list of antibiotics]. (AOM)

Similarly, the authors of the entry for fibromyalgia concede that there is limited evidence for the drug gabapentin; however, they do acknowledge their own use of the drug as an alternative to pregabalin:

We use gabapentin, for which evidence is more limited, as an alternative to pregabalin in patients for whom cost of the medication or regulatory requirements limit the use of pregabalin. (FIB)

The entries for *Acute Otitis Media, Irritable Bowel Syndrome* and *Fibromyalgia* all contained authors' recommendations in spite of a lack of clear evidence. These recommendations are in line with the UpToDate editorial policy, which states: "When there is no published systematic evidence available (e.g., prednisone dosing regimen in pulmonary sarcoidosis), recommendations are based on the unsystematic clinical observations of our experts and reviewers, and on pathophysiologic rationale" (UpToDate, "Editorial Policy", 2017).

In the *Fibromyalgia* entry, the sharing of expertise extended beyond implicit and explicit recommendations. Here, the authors provided insight about what they have learned from their experiences and ultimately made comparisons between their own experiences and the outcomes of clinical trials. When the authors shared knowledge acquired from their

experiences, they framed that knowledge using the phrase “in our experience.” For example, the authors share elements of patient education that they have found to be helpful: “In our experience, a discussion of the role of muscle ‘spasm’ and deficient muscle blood flow is useful when prescribing exercise and physical therapy” (FIB). The use of the phrase “in our experience” makes it clear that this knowledge is coming from their patient encounters.

The authors of the *Fibromyalgia* entry are also forthcoming about disconnects between their own experiences with patient care and the results and conclusions garnered from clinical research. For example, they point out that: “In practice, it has been difficult to start and maintain fibromyalgia patients in a structured cardiovascular exercise program, because patients generally perceive that their pain and fatigue worsen as they begin to exercise” (FIB). Nevertheless, exercise remained a key recommendation for treatment based on clinical studies. The authors also refer to their own tacit knowledge: “Despite the clinical trial efficacy, in ‘real-world experience’ the majority of fibromyalgia patients do not achieve great benefit from any single medication” (FIB). Here it is not the clinical trial but the real-world experience of the authors that is used as evidence for ineffectiveness.

In the entries addressing *Intimate Partner Violence* and *Normal Grief and Bereavement*, explicit recommendations or sharing of expertise by the authors are largely absent. However, within these entries there is also substantial content for which the origin of knowledge is unclear and not attributed to a source—neither published evidence nor the authors’ tacit knowledge. For example, the authors provide accounts of how people experience may react. Similarly, the authors of *Intimate Partner Violence* describe the complexities of providing care for the victim experiencing IPV. The authors here provide insight into what clinicians may witness from patients experiencing these challenges, in turn, tell the reader what the physician *should* do.

The entry for *Intimate Partner Violence* was different from all other entries in that the authors did not once refer to themselves as “we”. In all other entries, ‘we’ references were connected to an explicit or implicit recommendation. In the entry for *Chronic Fatigue Syndrome*, the authors apply the term “we” in a unique way not seen in any other entries. They twice describe the collective community of clinicians and researchers, in which they themselves and the reader belong, in this way. Specifically, the authors encourage clinicians to “... emphasize [to the patient] that we have considerable knowledge and experience with SEID/CFS” (CFS).

Situating the Evidence. The descriptive analysis of the eight entries demonstrates the dominance of sources of evidence from the Study level of the 6S hierarchy in the UpToDate content. While synthesized resources are encouraged, systematic reviews and meta-analyses are much less common in the entries than are individual studies, even when these are available. There was considerable variability in the extent to which authors provided details about and descriptions of the studies and systematic reviews cited in the entries. For some evidence, no description was provided, but rather only a parenthetical reference following a statement arising from the source conclusions; for others the authors provided extensive details about all four elements of the clinical question: the patient, the intervention, the comparators and the outcomes (PICO). The outcomes of the study sometimes appeared to affect the level of detail provided about it. For instance, in the entry for acute otitis media, a single meta-analysis that demonstrated benefit of antibiotic care was described in considerable detail while the description of five systematic reviews that do not support the use of antibiotics was captured in a single sentence.

A common attribute often included is the descriptions of a study’s design, particularly those using randomized controlled trials, the ‘gold standard’ in EBM hierarchies. The quality

and certainty of the results presented in the entries appear to rely heavily on this type of study, e.g.:

No randomized trials have demonstrated that antidepressants are efficacious for complicated grief, and these drugs are often not used. However, several small observational studies suggest that these drugs may be helpful. (CGB)

In this instance, randomized trials are presented to *demonstrate* effectiveness, while observational studies *suggest* effectiveness. The inclusion of study design emphasizes the importance placed on RCTs as a source of certainty. The authors also emphasized information that was based on conclusions from systematic reviews.

The authors' choice to highlight study attributes when citing RCTs contrasts sharply with their treatment of qualitative studies. Only two qualitative studies were cited across the cases, one in the *Intimate Partner Violence* entry and the other in the *Complicated Grief & Bereavement* entry. In neither instance was the qualitative nature of the study design acknowledged by the authors, nor was any information about the study provided other than a parenthetical reference. The authors also rarely acknowledged the type of resource used if they cited sources not included as evidence within 6S hierarchy. For example, the authors of the *Irritable Bowel Syndrome* entry note that "Patients with IBS should be advised to exclude foods that increase flatulence (e. g., beans, onions, celery, carrots, raisins, bananas, apricots, prunes, Brussels sprouts, wheat germ, pretzels, and bagels), alcohol, and caffeine" without acknowledging that the source of this information is the *Textbook of Gastroenterology*. While the UpToDate *Editorial Policy* acknowledges that in some instances "the type of study or the data are not stated explicitly," there does appear to be a pattern in what authors chose to highlight (or not).

In addition to underlining the PICO elements and study design of evidence, the authors' descriptions of the evidence often extended to include depictions of shortcomings

within individual research studies and deficiencies within the evidence base as a whole. The authors of the entries provided caveats on individual studies based on shortcomings or limitations of the research design:

However, the results of this study should be interpreted with caution due to methodological limitations and small sample size. (IBS)

However, many of the studies included in the meta-analyses had increased risk of bias (related to nonstringent diagnostic criteria, inclusion of children with mild disease, exclusion of patients <2 years of age, use of an inappropriate antibiotic or inappropriate dose, etc), making the results difficult to interpret. (AOM)

Across the seven cases authors also point out where more studies and attention are needed to create a stronger evidence base and advocate prudence when they consider evidence to be uncertain or inconclusive.

The authors' choice to use particular evidence is evident throughout the cases. At times, they are transparent about their selection of what they consider to be the *best* example from the evidence available to them. For example,

The efficacy of these agents was best described in a meta-analysis of five placebo-controlled randomized trials (four with pregabalin and one with gabapentin) consisting of 2918 patients with fibromyalgia. Compared with placebo, active therapy significantly reduced pain and improved sleep and quality of life. Evidence in support of the efficacy of each agent is described separately below. (FIB)

Likewise, when making recommendations, the authors follow a similar pattern, first providing their recommendation for treatment then following up with evidence that supports that recommendation. For example, the authors of the *Acute Otitis Media* entry recommend against the use of decongestants and antihistamines and then provide support for the recommendation with evidence:

We recommend not using decongestants and/or antihistamines in the symptomatic management of AOM in children. Studies of the efficacy of antihistamines and decongestants in treating AOM suggest a lack of benefit and a potential for delayed resolution of

middle ear fluid. A 2007 systematic review found that decongestants and antihistamines alone or in combination were associated with increased medication side effects and did not improve healing or prevent surgery or other complications in AOM [cited reference, systematic review]. In addition, treatment with antihistamines may prolong the duration of middle ear effusion [cited reference, study]. (AOM)

Here, the authors supported their recommendation against these two classes of drugs with descriptions of studies and systematic reviews that demonstrate a lack of benefit and the risk of side effects. The sequence of providing a recommendation and then supporting evidence is common in the entries for *Acute Otitis Media*, *Fibromyalgia*, and *Irritable Bowel Syndrome*, where recommendations lead the content. The authors of all eight entries acknowledge that multiple treatments have been evaluated unsuccessfully for effectiveness (particularly so in the entry for *Chronic Fatigue Syndrome*) and compare their approaches with clinical practice guidelines provided by key associations.

Situating the Physician-Patient Relationship.

The authors make overt reference to the physician-patient relationship in the entries for *Irritable Bowel Syndrome* and *Chronic Fatigue Syndrome*. The authors in the *Irritable Bowel Syndrome* entry advocate that physicians establish a “therapeutic clinician-patient relationship” as a key component of treatment. Details about the relationship include validation, patient education, and shared decision-making. Similarly, a supportive approach is identified as a treatment strategy in the *Chronic Fatigue Syndrome* entry, where the authors emphasize the importance of providing validation, being honest, addressing patients’ concerns without engaging in unhelpful debates and demonstrating a commitment to patients’ treatment process. The overt naming of the physician-patient relationship as a component of treatment and care occurs only in these two entries.

While not overtly named, the relationship between physician and patient is also a core component of the entries for *Intimate Partner Violence* and *Normal Grief and Bereavement*.

Intervention in both conditions focuses on interactions between patient and clinician. For normal grief, physicians are described not as a main source of bereavement support, but a rather natural and important one. Support “for acute grief typically includes empathic listening, information about the wide range of typical grief symptoms, reassurance, and monitoring.” (NGB). Similarly, the IPV entry emphasize key components of the physician-patient interaction:

The immediate expression of empathy, acknowledgement, and continued ability to support and assist the patient are the most important components of care after a patient has disclosed abuse. (IPV)

A feature unique to both of the *Intimate Partner Violence* and *Normal Grief and Bereavement* entries is the provision of authors’ guidance to the reader about how to deliver messages of support.

Validation of the condition as a real illness was a key theme in the entries for *Irritable Bowel Syndrome*, *Fibromyalgia*, *Chronic Fatigue Syndrome*, and *Complicated Grief and Bereavement*. In each of these entries, the physicians’ role in reassuring the patient that they have a real illness was underlined and emphasized. The authors suggest that patients experience a sense of relief when they have a diagnosis of a “treatable condition” (CGB). While not an illness, the importance of validation is also recognized in the entry for *Intimate Partner Violence*. Validation is a key element of care across five of the eight entries.

With respect to decision-making, two of the entries place responsibility with the patient. In the IBS entry, the authors call explicitly for the involvement of the patient in decision-making: “The clinician should establish realistic expectations with consistent limits and involve the patient in treatment decisions” (IBS). In the IPV entry, decision-making is situated overtly and solely as the responsibility and right of the victim. Here, the authors underline repeatedly that the patient’s autonomy and choice is paramount. They advocate

that: “Patients should be allowed to make autonomous decisions regarding health advice” (IPV). In contrast, in six of the eight entries, the primary responsibility for decision-making is implicitly or explicitly situated with the physician. Presenting decision-making as the sole responsibility of physicians conflicts with key clinical practice guidelines including those of the American Academy of Pediatrics and the American Academy of Family Physicians.

Throughout all eight entries, the authors develop content for physicians rather than a wide variety of health care providers. The majority of the care, including pharmaceutical treatments, described in the eight entries is treatment delivered by physicians, although the authors of the entries for *Irritable Bowel Syndrome*, *Fibromyalgia*, *Chronic Fatigue Syndrome*, and *Intimate Partner Violence* do acknowledge the need for care beyond that provided by physicians. For example, the authors of the *Irritable Bowel Syndrome* entry mention the need for professional dietitians to provide dietary education if patients are placed on a low FODMAP diet. Similarly, the authors of the *Chronic Fatigue Syndrome* entry call for an exercise therapist to supervise a graded exercise therapy program. The entries for FIB and IPV advocate for interdisciplinary care more broadly. For example:

“Ideally, treatment should include an integrated, multidisciplinary nonpharmacologic and pharmacologic approach, but there have been relatively few trials that have formally evaluated such a combined approach to therapy.” (FIB)

The authors of the IPV entry also advocate for care by multiple professionals asserting, “Care of the patient experiencing IPV requires a team approach involving medical, institutional, and community resources” (IPV). While the content does not address the delivery of treatment and care delivered by professionals across the health professions, there is recognition of need for interprofessional care.

The analysis of the patient information provided in the entries for *Acute Otitis Media*,

*Fibromyalgia*⁷, *Chronic Fatigue Syndrome*, and *Irritable Bowel Syndrome* further provides insight into the positioning of the patient within UpToDate. The patient information for these four conditions both diverges from and converges with the clinician information (interestingly, no patient information is provided for the entries for *Normal Grief and Bereavement*, *Complicated Grief*, or *Intimate Partner Violence*).

Like the clinician information, the patient information for *Fibromyalgia*, *Chronic Fatigue Syndrome* and *Irritable Bowel Syndrome* acknowledge that there are treatments to alleviate symptoms, but physicians are not currently able to cure these conditions. Similarly, the lack of understanding and knowledge about these conditions is highlighted. For example, the *Beyond the Basics* patient information for FIB states that “despite ongoing research, the cause, diagnosis, and optimal treatment of fibromyalgia are not clear” (*Beyond FIB*). CFS advice repeatedly highlights the authenticity of the condition and validates the patient experience. The long-term trial and error nature of treatment for IBS is acknowledged in the patient information. Patients with IBS are encouraged to be open to treatment options, but recognize the need for long-term management.

Compared to the clinician entries, decision-making is presented as a more collaborative process in the patient information for FIB, CFS, and the *Basics* patient information for AOM. Patients are encouraged explicitly to communicate with their health professionals and to work together as a team. In contrast, the responsibility for decision making in the clinician entry and the AOM *Beyond the Basics* is assigned primarily to physicians.

The central role of patients in non-pharmacological approaches to treatment is

⁷ Because the content of the *Beyond the Basics* was directed towards clinicians and written at a very high level of sophistication, the cross-case analysis focuses on *The Basics* patient information for Fibromyalgia included in UpToDate

emphasized in the patient information for AOM (i.e., monitoring, follow-up), IBS (i.e., exercise, symptom monitoring, dietary modifications), FIB (i.e., maintaining a positive attitude, exercising), and CFS (i.e., exercise). For example, patients are encouraged to understand, monitor, and alter their fibre intake: “By reading the product information panel on the side of the package, you can determine the number of grams of fiber per serving” (IBS, Beyond). While patients are rarely recognized as decision-makers, the patients are encouraged to take an active role in their care through non-pharmacological treatments. These patient activities and roles are similarly emphasized in the main clinical entries.

Although largely absent in the clinician entries, psychological elements and factors are overtly acknowledged in the patient information for AGA, IBS, FIB and CFS. There were also other examples of divergences between the clinicians’ entry and patient information provided by UpToDate. For instance, in the AOM *Beyond the Basics* patient information, the authors included the side effects and risks of antibiotic use, although this was absent in the information for clinician. Similarly, only in the *Beyond the Basics* entry is the preference to try non-pharmacological approaches for treating IBS prior to medications recommended. It is possible that such discrepancies between the information directed toward clinicians and patients may contribute to misunderstandings during the clinical encounter.

Circuit of Culture

In order to bring insight to the position and meaning of UpToDate in medical and information fields, Hall’s Circuit of Culture was applied to the cross case analysis. Specifically, an increased understanding of UpToDate emerges using the five elements of the Circuit of Culture: representation; production; consumption; identity; and regulation (du Gay et al., 1997).

UpToDate is a commercial product that evolved from an identified need and

opportunity within medical practice (*production*). Specifically, the producers and publishers of UpToDate responded to the observation that medical doctors were confronted with countless clinical questions that require nuanced approaches. Concurrently, physicians were faced with an overabundance of research-based evidence, and the emerging imperatives of evidence-based practice, that required intense translation to be deemed applicable for clinical practice. In response, UpToDate was developed to sell evidence packaged by physicians, for physicians. UpToDate recognized the value that physicians place on consultations with other physicians as a source of information and expertise; as such, the product is closely associated with physician-experts as content producers. UpToDate represents clinicians' desire for certainty in clinical decision-making (*representation*). Physicians' certainty is increased by invoking the available evidence as part of recommendations made by fellow physicians, themselves recognized as topic experts.

While the creators do not publish a systematic and explicit framework or policies for the development of content in UpToDate, the content is organized and regulated by the norms and conventions of EBM, including evidence hierarchies (*regulation*). For example, as noted above, the principles of EBM most value systematic reviews and randomized controlled trials, and therefore privilege such sources for inclusion in the point-of-care tool. UpToDate is used by students and clinicians faced with clinical uncertainty (*consumption*), and, laterally, by patients (directly or via their physicians). Physicians and medical students (largely unquestioningly) accept and use UpToDate as its creators intended it, as an evidence-based clinical tool. This use aligns with Hall's concept of the 'preferred reading,' meaning that the audience (i.e. the users of UpToDate) use the product the way the producers intended (Hall, 1980). UpToDate closely identifies itself with the author-experts. UpToDate is thus marketed as "an evidence-based, physician-authored clinical decision support

resource which clinicians trust to make the right point-of-care decisions” (UpToDate, “About Us,” 2017). While UpToDate is marketed and consumed as an evidence-based tool, the notion that it is produced and consumed by trustworthy and responsible physician-experts is central to the identity of UpToDate (*identification*). The experience and status of the authors is underlined by UpToDate: “Although these physicians serve on the faculty of prestigious medical schools, practice medicine, and in some cases conduct groundbreaking research, they repeatedly carve time from their demanding schedules to contribute to UpToDate” (UpToDate, “Physician Authors and Editors,” 2017). For UpToDate, the authors’ identity as trusted and prestigious experts is key to bringing together evidence and practice for practicing physicians.

Summary of Results

Evidence Selection

In the absence of transparent, clear, and systematic guidelines for the production of content for UpToDate, the selection of evidence is loosely aligned with the commonly accepted guidelines of evidence-based medicine. For example, systematic reviews and clinical trials highly valued within evidence hierarchies were commonly privileged for selection by UpToDate authors. In contrast, evidence sources often overlooked in evidence hierarchies (such as qualitative research) were very rarely included.

Authors selected evidence for their entries from a large corpus of research. In order to better understand what is overlooked or omitted as evidence for UpToDate, searches aimed at understanding the body of literature from which evidence was selected were completed. For each topic two targeted searches were performed: one to identify systematic reviews addressing clinical questions similar or the same as those addressed in the entry, and one to identify qualitative research on the topics of the cases. The availability of systematic reviews

and qualitative research varied across the topics. For example, the UpToDate entry for fibromyalgia cited the most systematic reviews, yet the targeted search still identified the highest number of potentially relevant systematic reviews that had not been cited. In contrast, while the fewest systematic reviews and the greatest number of clinical trials were cited in the entry for androgenetic alopecia, no additional systematic reviews were identified in the targeted search. Despite a robust body of clinical trials there appeared to be a dearth of systematic reviews available on the topic. For androgenetic alopecia, this lack of systematic reviews may reflect the commercial investment in trials of treatment, but not the synthesis of the trials. This analysis demonstrated that additional systematic reviews addressing clinical questions similar to those addressed in the entry were available. However, in the absence of clear guidelines by UpToDate, the reasons reviews were or were not cited are not known.

The targeted searches indicated that availability of qualitative research varied for each topic. Not surprisingly, searches identified the largest bodies of qualitative research for the topics of grief and bereavement and intimate partner violence, both of which have prominent social, emotional, and psychological features. Qualitative meta-analyses, which aims to synthesize a large body of qualitative studies, were also identified for the topics of fibromyalgia, chronic fatigue syndrome, grief and bereavement, and intimate partner violence. Although qualitative research was often available, across the eight topics, only two qualitative studies were cited (neither of which were syntheses). Qualitative research helps to provide increased understanding of the patient experience of illness from the patient perspective, and this knowledge is largely absent from the content of UpToDate.

In addition to methodological approaches to research, other commonalities also existed across the evidence selected for inclusion. For example, although the authorship of the evidence cited was made of up many professional backgrounds, the voice of the

physician was dominant. . Only in the cases of *Grief and Bereavement* and *Intimate Partner Violence* did non-physician authors equal or slightly exceed the numbers of physician-authors. The journals that UpToDate identified as key journals for evidence selection (core journals) were heavily called upon and also further favoured the physician voice. Not surprisingly, the physician-authors favoured the expert voice of fellow physicians. The favouring of like-voices also transferred to the location of the studies cited. The content of all eight entries was written by physicians situated within the United States. Similarly, research that was located with the context of the United States was more commonly cited than research undertaken in other countries. While research is often transferrable across sites, it is reasonable to expect that the availability of drug and treatment options and coverage may vary across nations. This is noteworthy because UpToDate is widely marketed for use around the world. UpToDate is used by physicians in more than 187 countries across the globe (UpToDate, “Around the Globe”, 2017). While the content of UpToDate is only available in English, the search is available in nine languages. The emphasis on American authorship and research seems a divergence from the international marketing focus.

Situating the author, the evidence, and the patient-physician relationship

Authors situated themselves as experts sharing their knowledge and guidance within the entries. Suggestions and professional guidance, made explicitly or implicitly, by the authors often focused on operationalizing treatment regimes in practice to meet the needs of individual patients. Author recommendations for treatment were also provided when the literature base lacked strong evidence to address a clinical question. How the authors position themselves in the content varied across the eight cases. For example, much of the content of the entry for *Acute Otitis Media* was situated as emerging from the authors’ expertise. In contrast, the authors of the entry for *Intimate Partner Violence* referred explicitly to

themselves as a source of expertise only once. While some authors appear to be cautious about positioning themselves explicitly, their experiences, expertise, and tacit knowledge are present within all eight entries.

The evidence selected by the authors for inclusion in the entries was generally situated within the entry as support for the authors' implicit and explicit recommendations. For selected evidence, the authors' provided detailed descriptions of the study design, patient population, and outcomes of the research. Robust descriptions often were included for clinical trials and systematic reviews which clearly supported authors' recommendations. Authors sometimes provided commentary on the quality and quantity of evidence available on the topics. In the absence of a clear and consistent framework for the topics, the authors selected, presented, and used the evidence in ways that supported their approach and their recommendations.

The patient-physician relationship was not situated prominently across the entries. The patient's role in decision-making was nearly absent across the entries, with the exception of the entries for *Intimate Partner Violence* and *Irritable Bowel Syndrome*. The importance of the physicians' role in validating the condition as 'real' was a key element for entries for the more contested conditions: *Irritable Bowel Syndrome*, *Fibromyalgia*, *Chronic Fatigue Syndrome*, and *Complicated Grief*. Where included, the patient information provided additional insight as to how the patient is situated in UpToDate, but key elements of the patient-physician relationship, such as decision-making responsibilities, sometimes appeared to contradict content in the expert entry.

The Circuit of Culture and the Emergence of Expertise

Applying the Circuit of Culture provides additional understanding of the position and meaning of UpToDate within the health and information environments. UpToDate is

represented and consumed as an evidence-based clinical tool; however, concurrently, expertise emerges prominently across the five elements of the Circuit of Culture: representation, production, consumption, identity, and regulation. UpToDate is produced for physicians, by physicians and the analysis using Circuit of Culture suggests that expertise is an important facet in securing the meaning and position of UpToDate in the health information environment. The content producers of UpToDate do not follow a rigid framework as often associated with evidence based medicine resources. Instead, they interpose their experience and expertise with the evidence in order to increase the applicability of evidence to clinical practice. The emergence of expertise across the five elements of the Circuit of Culture points to ways in which UpToDate may bridge evidence with the realities of clinical practice.

Chapter 4: Discussion and Conclusion

Discussion

Findings from this study illustrate what evidence and whose voices are privileged in the process of creating clinical guidance for the widely used information tool, UpToDate. The analysis of the seven cases reveals that physician-authors are situated not only as writers and creators, but also as sources of expertise. While the ways in which the authors enact or position their expertise varies, the authors incorporated their own recommendations, suggestions, and clinical experiences, as well as their tacit knowledge into each of the entries studied. In the absence of explicit guidelines, the authors chose evidence to support their recommendation, loosely adhering to the principles of evidence-based medicine. The permeation of expertise across the five components of Hall's Circuit of Culture reinforces the importance of expertise in UpToDate. From the overall analysis, UpToDate emerges as a potential surrogate for consultation and knowledge-sharing between physicians, traditionally performed through face-to-face interactions. Specifically, those engaged in the production of UpToDate are not simply intermediaries who replicate information, but rather are mediaries who transform, translate, and modify information for consumption (Latour, 2005). Through the mediary functions of the producers, UpToDate becomes a technological surrogate and performs the roles of 'Curbside Consultant' and 'Mentor'.

UpToDate within the EBM Landscape

Although evidence-based medicine was conceived by David Sackett as an approach to practice that promoted the application of evidence within the context of clinical judgement and patient needs and preferences, it quickly evolved into a structured set of rules and guidelines that privileged and excluded certain types of information and knowledge. While the focus on evidence was intended to move clinical practices away from anecdotes, habits,

and traditions, the first decade of the evidence based medicine movement created an overabundance of evidence that had limited application to clinical settings. Clinical trials, synthesized bodies of trials, algorithms, and rules have not been able to adequately address the complex realities facing individual patients. As such, in recent years, the value of applying a broader range of knowledge to clinical questions, beyond the data provided by studies, is increasingly being integrated into the practices of evidence-based medicine. Likewise, there is an increased recognition of the uncertainty inherent in evidence, as well as appreciation of the importance of psychosocial elements of care, patient experiences, and the physicians' expertise. In the last decade, new models are evolving in order to integrate expertise and uncertainty into evidence tools in a systematic way. One such example is GRADE, the Grading of Recommendations Assessment, Development and Evaluation approach, which produces a rating of the quality of a recommendation based on transparent criteria of the evidence including study design, risk of bias, imprecision, inconsistency, inconsistency, indirectness, and magnitude of effort (Guyatt, Oxman, Vist, Kunz, Falck-Ytter, Alonso-Coello, et al., 2008), while also considering issues such as acceptability (to providers and patients), feasibility and equity. The systematic and transparent process leads to the classification of recommendations along a continuum, from conditional to strong, which also leaves room for the emergence of new, potentially different, evidence and knowledge.

In seven of the eight entries analysed in this study, the UpToDate authors applied a final assessment of the evidence with a GRADE ranking, but the structured process was not applied or shared. Similar to the ways that evidence is selected following overarching EBM principles in the absence of an explicit and systematic process, the comprehensive and transparent steps of the GRADE process were not followed. Instead, the authors loosely

applied these principles, choosing to address and expand the evidence through their own narratives, tacit knowledge and expertise. This expertise appears to emerge as a critical component of UpToDate's capacity to bridge evidence and practice.

The Emergence of Mediary Roles

Examining how physician expertise permeates the five components of the Circuit of Culture is useful for understanding the techno-social aspects of clinical practice tools, such as UpToDate, which can act as surrogates for traditional physician interactions and knowledge sharing in face-to-face contexts. As Champ and Brooks (2010) explain:

those promoting the circuit of culture argue that, even more than recognizing these separate locations of meaning-making activity, we must attempt to account for the interrelation of the five processes of representation, identity, production, consumption, and regulation... It is the researcher's task to identify and describe how particular meanings result from the overlap of these processes. (pp. 576-577)

A key role of UpToDate authors, the content producers, is to provide expertise to the consumers of the UpToDate product. Expertise, in turn, becomes an important element of the representation, identity, and regulation of the tool. Through the provision of expertise, the authors of UpToDate are not simply intermediaries who reproduce information without modification, but rather, are mediators who transform, distort, translate and modify the meaning of the information they convey (Latour, 2005). Content producers are mediators positioned "between the information sources [the evidence] and the information seekers [physicians]" (Wyatt, Harris & Wathen, 2008). In 2008, Wyatt, Harris, and Wathen used this framework to construct the concept of info(r)mediation wherein health information (or in this case, evidence) is translated and transformed to effect changes in thinking, behaviour, or attitude. In this case, the physician-authors of UpToDate attempt to effect change in, or at least guide, others' clinical practice.

The overt recognition of the mediator function of the content producers is critical

because the hierarchies, rules, and guidelines of EBM can “become a form of collective forgetting, or naturalization, of the contingent, messy work that they replace” (Bowker & Star, p. 299). Providing evidence to guide physicians in answering multifaceted clinical question is “messy work” and can often be concealed by the presentation of EBM’s somewhat facile rules and frameworks (Wieringa, Engebretsen, Heggen & Greenhalgh, 2017). To recognize content producers and the subsequent technologies/tools that collect and share medical evidence not as intermediaries, but as mediators, ensures that the social elements and the complexity of the process of creating ‘practice-ready’ advice are acknowledged.

Through their sharing of clinical experiences, expertise, and judgement, UpToDate’s authors are key mediators who exist between the evidence and the information users and are integral to creating a technological surrogate for key physician interactions, specifically, as a Curbside Consultant (Findling, Shaker, Brickner, Riordan & Aron, 1996; Kuo, Gifford & Stein, 1998) and as a Mentor (Balmer, D’Alessandro, Risko, Gusic, 2011; Taylor, Taylor & Stoller, 2009).

UpToDate as Curbside Consultant

In much of the content analyzed in the cases included in this study, authors are prominent not only as the selectors and interpreters of evidence and content, but as *sources* of clinical expertise. The UpToDate *Editorial Policy* highlights that evidence is not enough to make decisions, but rather clinical expertise “is required to move from evidence to recommendations” (UpToDate, “Editorial Policy,” 2017). Further, the *Editorial Policy* defines expertise as the ability to address what evidence cannot. Specifically, the *Policy* points to Guyatt and colleagues’ observation that evidence cannot address “the benefits and risks, inconvenience, and costs associated with alternative management strategies, and ... the

patient's values” (Guyatt, Rennie, Meade & Cook, 2002). This type of knowledge is often attained through experience, a key contributor to the attainment of expertise (Haynes, 2002). The sharing of clinical expertise is reflected in the authors’ provision of recommendations, suggestions, and experiences, and is a key component of building a resource “which clinicians trust to make the right point-of-care decisions” (UpToDate, “About Us,” 2017). As reflected in this statement, UpToDate is situated as a trusted colleague upon whom physicians would call for advice. Positioning UpToDate as a trusted colleague aligns with longstanding research recognizing the value of colleagues in physician information seeking and decision-making (Dawes & Sampson, 2003; Leckie, 1996; Verhoeven et al., 1995).

Toward this end, the content producers provide recommendations for treatment, made explicitly or implicitly, across all cases examined. While, “[i]t is the policy of UpToDate to make specific recommendations for patient care whenever possible” (UpToDate, “Editorial Policy,” 2017), explicit recommendations were most prevalent in the entries for *Acute Otitis Media*, *Fibromyalgia*, and *Irritable Bowel Syndrome*. Further, in alignment with the UpToDate *Editorial Policy*, recommendations were often denoted with the phrase ‘we recommend’ or ‘we suggest’. The use of the collective first person pronoun implicitly denotes that the recommendation is emerging from the individual (albeit collective) experience and expertise, rather than directly from the evidence. Explicit recommendations most often provided details about how to implement or tailor treatments to best meet the needs of specific patients.

Because there are recognized challenges in effectively applying the results of structured research studies to the complexities of practice (Greenhalgh, 2002; Greenhalgh & Weiringa, 2011; May et al., 2006; Tonelli, 1998), recommendations are rarely a reiteration or intermediation of research conclusions. EBM requires clinicians to translate the results of

RCTs or systematic reviews into a treatment plan for an individual (May et al., 2006). For example, unavoidably, the patients who comprise the subject base of a given study, often those most likely to be responsive, do not necessarily or precisely reflect the population seen by physicians in their clinics (Daly, 2005). The authors of UpToDate attempt to address this limitation of evidence by sharing their expertise and experience as a means to provide recommendations for tailoring treatment for an array of patients. Such recommendations, shared by the expert authors in UpToDate, reflect the “experiential know-how” of tacit knowledge (Abidi, Cheah & Curran, 2005, p. 193). Abidi et al. provide a simple differentiation between explicit and tacit knowledge in health care: Explicit knowledge is documented and articulated knowledge presented in the published medical literature and presents “how things should work”; while tacit knowledge focuses on “what really works and how to make it work” and embodies experiential know-how, personal skills, and intuitive judgment (p. 194). At times, the tacit knowledge shared by the authors in the analysed entries seems to be in conflict with the explicit knowledge presented in the published literature. For example, the authors of the entry for *Fibromyalgia* are very direct about their perception of the lack of effectiveness of a single medication in the “real-world”, despite promising study outcomes:

Despite the clinical trial efficacy, in “real-world experience” the majority of fibromyalgia patients do not achieve great benefit from any single medication. (FIB)

Because tacit knowledge relies heavily on personal experiences (anecdotes), individuals with familiarity and expertise often share their tacit knowledge through personal exchanges (Panahi, Watson & Partridge, 2015). In health care, informal interactions during which physicians share their expertise and guidance as it relates to patient care are referred to as curbside (or hallway) consultations. Curbside consultations are informal physician-to-

physician information exchanges regarding the management of a particular patient, without the consultant seeing the patient or keeping any written record (Findling, Shaker, Brickner, Riordan & Aron, 1996; Kuo, Gifford & Stein, 1998). Information studies scholars have long recognized interpersonal resources as a key information source of physicians (Dawes & Sampson, 2003; Elayyan, 1988; Haug, 1997; Leckie, 1996; Verhoeven et al., 1995), and such interpersonal sources continue to be central avenues—primarily due to ease of accessibility and time efficiency—through which physicians seek answers to clinical questions (Andrews, Pearce, Ireson & Love, 2005; Clarke et al., 2013; Gonzalez-Gonzalez et al., 2007). Increasing workloads and pressure to see more patients may “squeeze out the time that previously allowed them to provide curbside consultations” (Cook, Sorensen, & Wilkinson, 2014, p. 606). Clinicians may feel uncomfortable imposing on the busy schedules of their colleagues to ask for guidance and advice. Additional challenges in curbside consultations identified by Cook et al. include incomplete or misinformation, trouble accessing an expert, and communication barriers. It may be challenging in the context of a fragmented and busy health care system to conduct meaningful curbside consultations and so the popularity of UpToDate may indicate a shift from interpersonal to new digital resources as a source of tacit knowledge.

UpToDate as Mentor

In addition to providing tacit knowledge about how to implement treatment regimes in ‘the real world’, UpToDate authors also share their tacit knowledge in relation to what to expect from the patient encounter. Specifically, most of the entries analyzed for this study include authors’ perceptions of the patient experience, advice on how to navigate the patient-physician relationship, and descriptions of the challenges in providing care, especially to those with contested and uncertain diagnoses, treatment and outcomes. The sharing of this

type of tacit knowledge aligns with the mentorship that occurs in the clinical setting. The role of senior physicians in providing socialization, guidance, and modeling for younger colleagues is a long-standing and important tradition in medicine (Boudreau, Macdonald & Steinert, 2014; Cruess, Cruess, Boudreau, Snell & Steinert, 2015; Kenny, Mann & McLeod, 2002). The information shared about the patient-physician encounter is akin to the tacit knowledge shared from mentor to mentee.

The authors provide detailed guidance to the reader about how to navigate the patient-physician encounter. For example, they suggest that those experiencing normal grief and bereavement will appreciate “condolence letters, telephone calls, attending the funeral or memorial service, and home visits” (NGB). In the entries for *Intimate Partner Violence* and *Grief & Bereavement*, the authors provide talking points and scripts to help physicians speak with patients. The authors also detail what information physicians should provide to patients to ensure proper follow-up and self-care.

In addition to providing guidance about navigating the patient-physician relationship, UpToDate also brings readers’ attention to features of certain conditions that physicians may find challenging. For example, authors warn readers that doctors “will not be able to satisfy all patients with [chronic fatigue syndrome]” (CFS), patients will “take up a great deal of time” (CFS), and doctors “may be surprised or frustrated” (IPV). The authors emphasize that these conditions are not simple or easy to treat. While the evidence establishes that no treatment can cure these conditions, the authors’ sharing of professional challenges helps prepare the reader for interactions with patients. The authors’ experiences and tacit knowledge of the difficulties faced in practice is also validating to the reader—and is a form of emotional and psychological support—one of the key components of the mentorship relationship (Balmer, D’Alessandro, Risko, Gusic, 2011; Taylor, Taylor & Stoller, 2009).

While UpToDate entries may help to prepare physicians for patient encounters, especially potentially difficult ones, the authors in these cases place little emphasis on the role and experience of the patient. For example, the patient's role in decision-making was largely ignored in most of the entries directed at clinicians. In the majority of cases examined, authors position the physician as the primary decision-maker, either by explicitly stating so or by not mentioning the patient when discussing treatment options in the professional entries. The physician is, explicitly or implicitly, the individual given primary responsibility for decision-making in all professional entries except *Intimate Partner Violence*. The focus on the physician in decision-making can be contrasted against the patient information entries which were more likely to suggest a greater decision-making role for the patient. By placing the responsibility for decisions solely with the physician in the professional entries, UpToDate may in fact reinforce the patriarchal doctor-centred model of medicine and, simultaneously, through the patient education material that appears to contradict this message, set up potential conflicts as a result of competing expectations in the physician-patient encounter.

The emphasis on physicians' roles in decision-making found in these case entries aligns with the literature addressing the socialization of medical students. Specifically, the teachings of patient-centred care and the role of patients in their own care, which are often provided early in the medical curriculum and often delivered in the preclinical classroom sessions with medical students, may be overshadowed by the informal "hidden curriculum" represented in the experiences and socialization to which students are exposed during their clinical education (Hafferty, 1998; Haidet et al., 2002). Medical students have demonstrated an increase in doctor-centred attitudes and a decrease in patient-centredness as they moved from their pre-clerkship (classroom) training to clinical training (Haidet et al., 2002; Hur,

Kim, Park, Cho & Choi, 2014). This may be a result of the students' observations of the "dissonance between didactic concepts from the curriculum and observed medical practices" (Gallentine, Salinas-Miranda, Bradley-Klug, Shaffer-Hudkins, Hinojosa & Monroe, 2014, p. 95). Because UpToDate is used heavily by medical students, medical residents and new medical professionals, the mentorship role of UpToDate has the potential to reinforce the hidden curriculum of medicine by de-emphasizing the patient in clinical decision-making. Additionally, the authors' description of the patient experience via imparting their personal perceptions, rather than calling upon research, may further reinforce the potential for doctor-centred approaches over patient-centred approaches, as well as re-affirm the position of UpToDate as mentor.

As noted above, qualitative research was almost entirely absent in the content analysed. Despite the availability of qualitative research for all but one topic, only two qualitative studies were cited across all eight entries. As such, patient experience was presented through the eyes and experiences of the physician, not of the patient. For example, the authors of the *Chronic Fatigue Syndrome* entry explain that "[b]ecause of the lack of laboratory abnormalities, most patients struggle with the validity of their disease (as do many of their clinicians) and may experience feelings of guilt" (CFS). While the authors describe what they commonly see in their practice, this information is not situated in the documented lived experiences that would evolve from a qualitative study. For example, participants in Winger et al.'s (2014) phenomenological study describe adolescents with CFS observing their teachers' doubt and skepticism of their condition through body language and disbelieving glances. The study emphasized the participants' feelings of disrespect and isolation (Winger, Elstedt, Wyller & Helseth, 2014). Qualitative research attempts to capture patients' complex and multifaceted lived reality. The lack of inclusion of qualitative evidence

that captures the illness experience through the lens of the patient may re-enforce the dominance of the physician perspective.

The authors of UpToDate entries attempt to assist physicians through the patient encounter, providing guidance and advice, disclosing their practices, and sharing experiences. This type of information sharing is an essential element of the apprenticeship model of medical education. In the cases examined in this study, the authors seem (consciously or unconsciously) to replicate these practices and roles that they have experienced as trainees and enacted as mentors.

Summary

This analysis, which situates authors, evidence and the patient-physician relationship within UpToDate, reveals how the function of UpToDate extends beyond that of merely providing a quick summary of evidence. Through the lens of the Circuit of Culture, expertise emerges as an important element in the role and meaning of UpToDate in the information landscape. UpToDate represents an attempt to address documented gaps between evidence and practice. In particular, the evidence contained within hierarchies such as 6S that are called upon to inform summary resources appear to be a poor fit when it comes to addressing the complex needs of individual patients, the need for tailored care, and the challenges of the patient-physician interaction. Within this research, UpToDate is revealed to be a mediator, rather than an intermediary, between evidence and clinicians. Specifically, the function of UpToDate extends to include the roles of mentor and curbside consultant. In these roles, UpToDate emerges as not only a supplement to, but a technological surrogate for human interaction and expert consultation. The challenges embedded within these surrogate roles also mirror those of the human interaction. This dominance of the author in describing the patient experience, alongside the tendency to place decision-making responsibility with the

physician, may lead UpToDate to reinforce doctor-centered care, as well as perpetuate the much criticized ‘art of medicine.’

Limitations and Future Research

Two potential limitations of the current study that may limit the applications of the findings are: 1) the selection of entries to represent specific phenomena, rather than, for example, a random selection; and 2) the selection of a single summary resource. While the selection of eight entries, representing seven topic cases, aligned with the principles of qualitative research and case study methodology (Cresswell, 2007; Stake, 2006; Yin, 2009), the extent to which these findings are generalizable across all entries is unknown. These eight entries were chosen from more than 9,500 topics across 24 specialties. Case study research allows the researcher to purposefully select cases that represent different contexts for phenomenon of interest to exist (Stake, 2006). The criteria used to select the eight entries were to represent varying levels of medicalization, certainty, and contestation within the cases. These eight entries are not, and are not intended to be, representative of all 9,500 topics. Many of the topics addressed in UpToDate are conditions with recognized organic causes and have a widely accepted level of certainty in their aetiology, treatment and outcomes. Additional research is required to evaluate the generalizability of the themes and analyses from in this study across the numerous topics of UpToDate. For example, future research may explore how the authors, evidence, and patient-physician relationship is situated in acute conditions, rare diseases, or conditions that are not considered to be contested or medicalized.

UpToDate is one example of point of care resources occupying the Summary level from the 6S Model. Across the literature, UpToDate is consistently reported to be the most useful product for answering clinical questions (Ahmadi et al., 2011; Campbell & Ash, 2006;

Thiele, 2010) and is cited to change the way physicians manage patients (Isaac, Xheng & Jha, 2012). Other resources situated on the Summary level of evidence include DynaMed, FirstConsult, BMJ's Best Practice and, generally, clinical practice guidelines from a wide range of authors (Ahmadi et al., 2011; Campbell & Ash, 2006). Each point of care resource will apply a different set of editorial policies and make use of different authors. As evident in this study, editorial policies and author approaches are likely to influence greatly the final product, especially if standardized criteria are lacking. In order to gain an understanding of how the findings from this analysis of UpToDate compares to other Summary resources, repeating such analysis in comparable products would be beneficial. Using the same methods to analyze the same cases would not only advance understanding of how the author, evidence, and patient-physician relationship are situated, but should also reveal the overlap and divergences of what evidence is included and excluded and, in turn, inform a greater understanding of resource creation and utility. Comparing the same topics in another summary evidence resource (e.g. DynaMed) would not only expose differences in processes between two summary resources but would also reveal whether it is possible that two sets of authors, using the same evidence, arrive at similar or different recommendations and guidance. Further, exploring differences in the knowledge contained across the resources (e.g., presence or absence of tacit knowledge) may be useful in understanding the reported application, utility, and influence of UpToDate (Ahmadi et al., 2011; Campbell & Ash, 2006; Thiele, 2011; Isaac, Xheng & Jha, 2012).

This study points to additional opportunities for future research for library and information studies scholars. For example, while research-derived evidence is one part of evidence-based practice, this analysis accentuates the key roles of expertise and tacit knowledge in the information practices of physicians (Dawes & Sampson, 2003; Elayyan,

1988; Haug, 1997; Leckie, 1996; Nasir, Nicholson, Vandermeer, Kumar & Robinson, 2014; Verhoeven et al., 1995). Building on the results of the current study, future research should address the consequences of documented shortcomings of evidence-based practice through the sharing of observations, experiences and acquired expertise. In a resource like UpToDate, such tacit information guides readers through the clinical encounter, possibly at the cost of returning to a model of care that is more doctor-centered and that relies on the ‘art of medicine.’ Further investigation into this dynamic would be valuable.

Future research should also focus on the information seeking behaviours within UpToDate. This research has identified potential new functions for UpToDate as a technological surrogate for mentors and curbside consultants. The importance and influence of the tacit knowledge that contributes to these functions is not known. Are these surrogate roles a driver for UpToDate’s popularity? If so, what conditions lead to the need for physicians to seek out this information through technology? Further, what information is most memorable and most used in UpToDate? How does the importance and application of the tacit knowledge presented in UpToDate compare to the application of evidence from clinical studies? Further investigation is needed to understand how the need for UpToDate to fulfill the role of mentor and consultant developed and to understand the importance and influence of sharing tacit information alongside clinical evidence.

Conclusion

Prior to the evidence-based medicine movement, clinicians relied heavily on a knowledge base made up their own experience and the collective experiences of the profession learned through apprenticeship and modeling (the so-called ‘art’ of medicine) to navigate decision-making. While evidence based medicine is a widely accepted feature of contemporary medical practice, the applicability of clinical trials to clinical practice is often

questioned. Within this context, UpToDate emerges as one of the most popular and heavily used Summary level, point-of-care evidence resources. While studies have been done previously to evaluate the utility and features of UpToDate, no critical analysis of the content has yet been undertaken. This study is an attempt to understand the context, process, and underlying meaning of how lower order evidence (i.e., studies and synthesis) evolves into highly applicable evidence in Summary resources.

While it was expected that patterns would emerge based on the level of certainty and medicalization of the topic, the results of the study indicate that the variability across the cases did not appear to follow a systematic pattern based on attributes of the cases. In contrast to the loose adherence to principles of EBM found in UpToDate, structure and hierarchy are a fundamental features of evidence-based medicine. UpToDate's lack of explicit structure calls into question the truth of its primary claim that it is "an evidence-based, physician-authored clinical decision support resource which clinicians trust to make the right point-of-care decisions" (UpToDate, "About Us," 2017).

By applying the lens of Science and Technology Studies in this research, the value of investigating the development of evidence (and evidence tools) as 'social' rather than merely 'technological' acts has been underlined. Library and information practitioners and scholars often view the production as an act of intermediation, whereby information is transported without transformation (Latour, 2005). The present results support Latour's observation that individuals who create, develop and package evidence for clinical care "translate, transform, and modify" research in order to create meaning and initiate change in practitioners (Latour, p. 39). Authors who contribute to UpToDate not only provide and translate evidence, but also interpose their own expertise and tacit knowledge. Analysing the results through the lens of Hall's Circuit of Culture suggests that expertise is an integral element of the role and

meaning of UpToDate within the health information environment.

This research broadens what is known about the content and functions of UpToDate and offers insights that may help to explain the immense popularity of this clinical tool. UpToDate attempts to address a very real gap between evidence and practice, but this research sheds light on a ‘hidden curriculum’ that is embedded in the tool. UpToDate attempts to bridge evidence with practice by incorporating clinical judgment, clinical expertise, and the incorporation of ways to tailor care for patients with selected evidence; however, the results of this study raise important questions about the nature of this content and the potential risk in entrenching physician-centred care and the ‘art of medicine’ —the very things that evidence-based medicine was intended to attenuate - within a tool marketed as ‘evidence-based’.

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Appendix A: Descriptive Data Extraction Form

Resource and Review Information

Completed

- Yes
- No

Clinical Question

Clinical Question in PICO Format that the resource addresses, if applicable.

[Text]

UpToDate Entry:

Title of UpToDate Entry

[Text]

Study Reference ID #

Study Code i.e: AOM-1

[XXX-#]

Reference ID # from UpToDate

Reference number from ref list.

[#]

Bibliographic Information from UpToDate

Bibliographic Information from UpToDate

[Text]

Published in

Journal title, if applicable

[Text]

From UpToDate Core Title List

[Text]

Has this article been cited in a systematic review (identified through PubMed SR portlet?)

- Yes
- No

Bibliographic Information from citing SRs

[Text]

Professional Background of Authors

Indicate number of authors from each of the professional backgrounds.

	<i>Response</i>
<i>Unknown</i>	#
<i>Medical Doctor</i>	#
<i>Nurse</i>	#
<i>Basic Scientist (PhD)</i>	#
<i>Librarian</i>	#
<i>Pharmacist</i>	#
<i>Public Health</i>	#
<i>Other</i>	#
<i>Professional Organization</i>	#

Location of Study

- United States
- Canada
- Australia
- United Kingdom
- Other, specify:
- Not applicable (ie: review)

Publication Date

Month and Year

Reviewed by:

SB

Date of Review

Full date

Abstract

[Text][

Other Notes on General Information

[Text]

Resource Type

Level of Evidence (Haynes 6S Model)

- System
- Summary
- Synopsis of Synonym
- Synthesis
- Synopsis of Synthesis
- Study
- Not in the 6D Hierarchy of Evidence

Type of Resource

- UpToDate Entry
- Practice Guideline
- Systematic Review
- Research, quantitative
- Research, qualitative
- Research, mixed method
- Other, specify

Quantitative Research Design

If quantitative research design

Quantitative Research Design

- Randomized Controlled Trial
- Non-Randomized Controlled Trial
- Cohort/Prospective/Longitudinal
- Before-After/Time Series
- Other quantitative design, specify
- Not Applicable

Qualitative Research Design

If Qualitative Research Design

Qualitative Research Design

- Ethnography
- Phenomenology
- Case Study
- Grounded Theory
- Other qualitative design, specify:
- Not Applicable

Review Article Design

If Review Article

Type of Reviews

- Systematic Review
- Meta-Analysis
- Meta-Synthesis
- Scoping Review
- Narrative Review
- Other, specify:
- Not applicable

Type of review clearly identified in paper?

- Yes
- No

Clear Criteria for inclusion of literature

- Yes
- No

If yes, indicate criteria:

[Text]

References Used**Response***Number of references that met inclusion criteria* #**Review Conclusions**

[Text]

(P) Population/Patient Details

Applicable

- Yes
- No

Who is the population of interest?

[Text]

What was sample size?

Please indicate N/A if not appropriate

#

Information extracted from Abstract only

- Yes
- No

(I) Intervention Details

Applicable

- Yes
- No

What was the intervention that was delivered?

[Text]

Information extracted from Abstract only

- Yes
- No

(C) Comparison Details

Applicable Yes No**Was there a comparison included in the study?** Yes No**If yes, what type of comparison was included?** Patient Intervention**Describe the Comparison?**

[Text]

Information extracted from Abstract only Yes No**(O) Outcome Details**

Applicable Yes No**What are measured outcome(s) of the Intervention?**

[Text]

[Text]

[Text]

Were any adverse outcomes reported? Yes No**If so, what adverse outcomes were reported?**

[Text]

Information extracted from Abstract only

- Yes
- No

Conclusions

What conclusions did the author come to?

[Text]

Information extracted from Abstract only

- Yes
- No

UpToDate Summary

How is the study represented in the UpToDate summary?

Cut and paste text of UpToDate Statement that references this evidence.

[Text]

Curriculum Vitae
Selinda Adelle Berg

Education

PhD. Candidate, Faculty of Information and Media Studies
 “Expertise, Mediation, and Technological Surrogacy: A Mixed Method Critical Analysis of a Point of Care Evidence Resource”
 Western University, London Ontario
 2008- 2017

Masters of Library and Information Studies
 University of Alberta, Edmonton
 May 2004

Bachelor of Science Nutrition, with Distinction
 College of Pharmacy and Nutrition
 University of Saskatchewan, Saskatoon
 May 1998

Professional Practice

2017- 2018	Associate University Librarian <i>Interim</i>	University of Windsor Leddy Library Library Administration
2016- 2017	Department Head	University of Windsor Leddy Library Information Services
2015-2016	Researcher-in-Residence (July-June sabbatical position)	University of Saskatchewan’s Centre for EBLIP
2008-present	Medical Librarian	University of Windsor Schulich School of Medicine- Windsor Leddy Library.
2013-present	Adjunct Appointment	Schulich School of Medicine & Dentistry Dept. of Biostats and Epidemiology
2014-2015	Limited Duties Instructor	University of Western Ontario Fac of Information and Media Studies
2004-2008	Research and Instruction Librarian	University of Western Ontario Western Libraries

Publications

- Hoffmann, K., Berg, S., & Koufogiannakis, D. (2017). Understanding factors that encourage research productivity for academic librarians. *Evidence Based Library and Information Practice*, 12(4), 102-128.
- Berg, S. A., & Jacobs, H. L. M. (Editors). (2016). Special Issue Valuing Librarianship: Core Values in Theory and Practice. *Library Trends*, 64(3).
- Berg, S. A. & Jacobs, H. L. M. (2016). Introduction: Valuing librarianship: Core values in theory and practice. *Library Trends*, 64(3), 459-467.
- Berg, S. A., & Banks, M. (2016). Beyond Competencies: Naming Librarians' Capacity for Research. *The Journal of Academic Librarianship*, 42(4), 469-471.
- Wilson, V, & Berg S. A. (2016). Reciprocal benefits of Researcher-in-Residence program. *Evidence Based Library and Information Practice*, 11(2).
- Johnston, D. J., Berg, S. A., Pillon, K., & Williams, M. (2015). Ease of use and usefulness as measures of student experience in a multi-platform e-textbook pilot. *Library Hi Tech*, 33(1), 65-82.
- Hoffmann, K., Berg, S. A., & Koufogiannakis, D. (2014). Examining success: Identifying factors that contribute to research productivity across librarianship and other disciplines. *Library and Information Research*, 38(119), 13-28.
- Hoffmann, K., & Berg, S. A. (2014). "You can't learn it in school": Field experiences and their contributions to education and professional identity. *Canadian Journal of Information and Library Science*, 38(3), 220-238.
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- Berg, S. A. & Jacobs, H. L. M. (2013). By librarians, for librarians: Building a strengths-based institute to develop librarians' research culture in Canadian academic libraries. *Journal of Academic Librarianship*, 39(3), 227-231.
- Berg, S. A., Jacobs, H. L. M., & Cornwall, D. (2013). Academic librarians and research: A study of Canadian library administrator perspectives. *College & Research Libraries*, 74(6), 560-572.
- Jacobs, H. L. M., Berg, S. A. (2011). Reconnecting information literacy with the core values of librarianship. *Library Trends*, 60(2). Special Issue on Information Literacy Policy, 383-394.
- Berg, S. A. Harris, R. (2011). "Everyone's dressed the same": Pre-clerkship medical students learn who's who on the health care team. *Health and Education*, 24(1).
- Jacobs, H. L. M., Berg, S. A., & Cornwall, D. (2010). Something to talk about: Rethinking conversations on research culture in Canadian academic libraries, *Partnership: The Canadian Journal of Library and Information Practice and Research*, 5(2).
- Berg, S. A., Hoffmann, K., Dawson, D. (2010). Not on the same page: Undergraduates information retrieval in electronic and print books, *Journal of Academic Librarianship*, 36(6), 518-525.
- Berg, S. A., Hoffmann, K., Dawson, D. (2009). Integrating research into LIS field experiences in academic libraries, *Journal of Academic Librarianship*, 25(6), 591-598.

Selected Conference Presentations 2013-17

- Berg, S. A., Hoffmann, K. M., & Koufogiannakis, D. A. (2017). Understanding Research Productivity: Fresh New Evidence for Librarians. Evidence-Based Library and Information Practice 9. Philadelphia, Pennsylvania.
- Berg, S. A., Hoffmann, K. M., & Koufogiannakis, D. A. (2017). Understanding Ourselves as Researchers; Critical Reflections on National Survey. Canadian Association of Professional Academic Librarians. Toronto, Ontario.
- Berg, S. A., Hoffmann, K. M., & Koufogiannakis, D. A. (2017). Focus on what matters: Factors that improve the research productivity of academic librarians. Ontario Library Association, Toronto, Ontario.
- "Success in research: Factors that contribute to research productivity in LIS" May 2014. Canadian Association of Information Science. St. Catharines, Ontario. (Peer reviewed)
- Invited Keynote:* Making it our own: Research culture in Canadian academic libraries. April 2014. Concordia Libraries' 12th Annual Research Forum. Montreal, Quebec. (Closing Plenary)
- "I felt like a real librarian': Field experiences as an opportunity for professional identity development" January 2013. Association of Library and Information Sciences Education. Seattle, Washington. with Kristin Hoffmann (Peer reviewed)
- "Perceptions of current and ideal research environments: Feedback from the inaugural Librarians' Research Institute in Canada" July 2013. Evidence Based Library and Information Practice. Saskatoon, Saskatchewan. With Cathy Maskell (Peer reviewed)

Research Grants and Awards

Canadian Association of Research Libraries Research Grant: Co-Principal-Investigator
Co-op Placements in Academic Libraries: Their Role in the Formation of Professional Identity
- Award Date: November 2009

Research Grant for Women (University of Windsor): Principal Investigator
Early Medical Students Perceptions of Information Application & Exchange in Clinical Settings
- Award Date: April 2009

Courses Taught

W2014 & W2015	LIS 9320: Consumer Health Faculty of Information and Media Studies, Western University
2009- 2015	Patient Centered Context: Integration & Application Year 1 Schulich School of Medicine, Windsor Program
2010- 2015	Patient Centered Context: Integration & Application Year 2 Schulich School of Medicine, Windsor Program

Related Teaching Experiences

Research Workshops

- May 2016 Delving Deeper: Building a Meaningful Program of Research
CAPAL 2016 Pre-conference Workshop (workshop design only)
- October 2015 Transforming Ideas into Well-Designed Research Questions
C-EBLIP 2015 Pre-symposium Workshop
- March 2015 Questions, Methods, and Habits: Preconference Workshop
Association of College and Research Libraries Conference, Seattle
Presented with Heidi LM Jacobs and Kristin Hoffmann
- Nov 2014 Librarians as Researchers
Grant McEwan Library, Edmonton
Workshop presented with Heidi LM Jacobs and Denise Koufogiannakis
- May 2014 Questions, Methods, & Habits: A Research Workshop
University of Toronto Libraries
Workshop presented with Heidi LM Jacobs and Kristin Hoffmann

Selected Service to Library and Academic Community

- 2015- present Reviewer: Canadian Journal of Academic Librarianship
Canadian Association of Professional Academic Librarians
- 2014- present Reviewer: Partnership Journal
Partnership: The Provincial and Territorial Library Assocs of Canada
- 2012- present Reviewer: Journal of Academic Librarianship
Elsevier
- 2015- 2016 Researcher-in-Residence
Centre for Evidence-Based Library and Information Practice
- 2013 and 2014 University of Saskatchewan
Librarians' Research Institute, Program Chair
Canadian Association of Research Libraries
- 2010 – 2012 2012 Librarians' Research Institute, Creator, and Program Chair
Canadian Association of Research Libraries