Lost in Translation: Bibliotherapy and Evidence-based Medicine

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Abstract Evidence-based medicine's (EBM) quantitative methodologies reflect medical science's long-standing mistrust of the imprecision and subjectivity of ordinary descriptive language. However, EBM's attempts to replace subjectivity with precise empirical methods are problematic when clinicians must negotiate between scientific medicine and patients' experience. This problem is evident in the case of bibliotherapy (patient reading as treatment modality), a practice widespread despite its reliance on anecdotal evidence. While EBM purports to replace such flawed practice with reliable evidence-based methods, this essay argues that its aversion to subjective language prevents EBM from effectively evaluating bibliotherapy or making it amenable to clinical and research governance.

Keywords Bibliotherapy · Humanities · Evidence-based medicine

In his 1974 film, *The Enigma of Kaspar Hauser*, director Werner Herzog recounts the historically documented tale of a young man who appeared in Nuremburg in 1828, barely able to walk or talk and totally unfamiliar with social interaction. From the morning of his appearance to his mysterious murder five years later, Kaspar challenged the limits of prevailing paradigms in science, education and ethics, all of which proved incapable of addressing or even assessing his condition. In the closing scene, a government official is seen hurrying away from the camera, enthusiastically anticipating the thorough report he will complete from autopsy results revealing that Kaspar's brain possessed an unusually small cortex. Herzog leaves the viewer with a sense of despair at the official's failure of imagination and myopic trust in empiricism: the mysteries of Kaspar's life will not, cannot, be revealed in the measurement of his brain.

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Herzog's account serves as a cautionary tale concerning the limits of quantitative approaches and evidence-based ideology, which, to paraphrase Protagoras, appear to have become "the measure of all things that are, and of things that are not" in current medical research and practice. Following evidence-based medicine's (EBM) call for a greater role for empirical evidence in clinical decision-making in the early 1990s, the character of medical research changed rapidly and decisively. EBM's dominance has continued despite objections raised about its unsuitability for certain types of research questions. This raises the particular concern that such unsuitability may have a systemic effect on research and clinical practice as governance frameworks are employed in attempts to improve practice through audit and standardization.

This paper seeks to demonstrate the shortcomings of EBM methodology in relation to research in the field of bibliotherapy—the use of books by patients to address their emotional, psychological and other adjustment issues. In attempts to assess bibliotherapy's utility as a treatment modality within the EBM paradigm, researchers have refashioned and reframed the subject matter of bibliotherapy—books, stories, personal accounts—into objects that are amenable to quantitative measurement. The resulting focus has directed research away from the relationship between reader and text, ignored genres such as poetry and literature in favor of self-help manuals, and foreclosed on the knowledge that more appropriate approaches could potentially generate. To understand fully the issues involved here, it is necessary to first situate EBM in its philosophical-cultural milieu.

Language and quantification

One of the reasons that EBM has made such rapid inroads into medical practice is its resonance with values already long-held by biomedicine. In fact, one of the early criticisms about EBM was that "everyone already is doing it." There seems little problematic about EBM's project to find objective evidence for replacing unproven practices "with new ones that are more powerful, more accurate, more efficacious, and safer." This quest for objective evidence, it can be argued, makes EBM heir to the quest of logical positivism for a science free from the ambiguities of human subjectivity and bias. The very first step of evidence-based clinical practice, to "formulate a clear clinical question from a patient's problem," harkens back to the Vienna Circle's attempts to open the way to scientific inquiry though the use of unambiguous scientific language.

EBM's reliance on large-scale randomized clinical trials (RCTs) and meta-analyses of quantitative studies conspire to erase subjective, personal experiences. However, the dream of leaving the subjectivity of language behind is ultimately impossible in the clinical setting, where sickness (symptomatology and pathology) and illness (the social meaning of sickness) are distinct entities. As Segal points out, rhetoric, "a shorthand term for a system of discourse and values," in medicine negotiates the space between biomedicine and the patient's lifeworld. The attendant negotiation of values, encouragement, explanation and education are accomplished through ordinary language.

One example of the use of ordinary language in medical practice is bibliotherapy, reading as a means of treating illness. As advocates of bibliotherapy point out, the restorative and healing value of literature was known to Plato, the Romans and Benjamin Rush; spiritually and emotionally edifying literature has long provided readers with comfort and guidance. Bibliotherapy has been identified as an important area of medical research for several practical reasons as well: it is a form of alternative or traditional medicine; it has the potential to help patients who might not otherwise receive therapy; and it is a valuable



"practitioner extender" in patient education and treatment. Surveys reveal that a sizable majority of psychologists utilize some form of bibliotherapy, with experienced practitioners using bibliotherapy more frequently than their less seasoned colleagues. The growing number of relevant Medline articles suggests that the practice of bibliotherapy has increased substantially in past years, its scope extending to include self-help manuals, CDs, computer programs, videos and other media.

The wide range of bibliotherapeutic materials and the many contexts of their use make bibliotherapy a difficult subject for audit and implementation within clinical governance frameworks, but it presents an even greater problem for researchers. Despite its widespread use, assessment and evaluation of bibliotherapy as a treatment modality has presented unique problems for medical researchers because the subjective, aesthetic language of literature is incommensurate with that of scientific objectivity. Bibliotherapeutic texts frequently make use of subjective and experiential language in their educational and inspirational messages, readers use subjective language to describe their reactions to the texts they find moving, instructive or otherwise therapeutic, and therapists and clients use experiential and subjective language in the therapeutic interview. Indeed, bibliotherapeutic practice has historically relied on what Aristotle identified as the subjective forms of evidence used in literature: case studies (*logos*), anecdotes (*pathos*) and appeals to practitioner expertise (*ethos*).

It must be noted that many researchers prior to the introduction of EBM in 1992 were uncomfortable with the lack of evidence for bibliotherapy's effectiveness, and such subjective evidence was, of course, totally unacceptable to EBM researchers. However, a comparison of bibliotherapeutic research before and after 1992 reveals that EBM's quantitative methodology has not established bibliotherapy's effectiveness or provided tools for improving bibliotherapeutic practice. Rather, its Procrustean bed has constricted the ways in which the medical community can look at the healing and palliative effects of literature. To examine this claim, we will now turn to a history of bibliotherapeutic practice and criticism.

Bibliotherapy

Bibliotherapy was first identified as a medical modality in the early decades of the 20th century as librarians and hospital staff sought ways to treat WWI veterans and sanitarium patients facing long institutionalization and convalescence. Books were looked upon as a means to fill empty hours and to encourage patients along the road to recovery, providing diverting or calming reading material. Soon, however, books took on a wider clinical role. In the 1930s, William Menninger instituted an extensive experimental program of clinical bibliotherapy at the Menninger Clinic, a psychiatric facility in Topeka, Kansas, utilizing what came to be known as "mental hygiene literature," including *The Human Mind* and *Man against Himself*, written by his brother, Karl Menninger, a noted psychiatrist. Books were "prescribed" for patient education, encouragement, recreation, and as a means of integrating patient-readers into therapeutic reading groups.

The centrality of the physician is a prominent feature of these early approaches to bibliotherapy. Pomeroy emphasized that the bibliotherapeutic librarian's *raison d'etre* was to assist the physician; Menninger described the physician's control of the bibliotherapeutic process from book acquisition to assessment of therapeutic effect. Such assessment was made through case studies, the results of which were impressionistic rather than quantitative, in that "[t]he patient continued to improve symptomatically and she began to average three hours a day at reading, expressing an opinion about the soothing effect,



mentioning her ability to utilize spare time effectively and fruitfully in this way." ¹¹ The "prescription" of bibliotherapeutic reading materials rested exclusively with the physician who based his judgment upon clinical or pathophysiological considerations: ". . . we have found from experience that religious reading has been detrimental...religious reading of any kind has appeared to increase, rather than decrease, the mental illness" ¹² and "the highly exciting book as well as the depressing one must not be given to the tuberculous patient... he must not be overtired by reading." ¹³

By the 1950s, the role of the bibliotherapist no longer belonged exclusively to the physician.¹⁴ Bibliotherapy, defined as "a process of dynamic interaction between the personality of the reader and literature under the guidance of a trained helper,"¹⁵ opened the practice to teachers, social workers, librarians, nurses and parents with proper training. These new bibliotherapists described their method of action from a variety of different disciplinary perspectives: as an Aristotelian process of identification, catharsis and insight;¹⁶ "narcissistic gratification" either as emotional escape or as ego enhancement through learning;¹⁷ a source of models for problem solution;¹⁸ or of reassurance that the problems individual readers faced were not unique.¹⁹

Interest in bibliotherapy continued to grow through the introspective climate of the 1970s with the rise of "T-groups" and a general culture of self-improvement and selfactualization. Bibliotherapy was applied to children, seniors, the disabled, diabetics, for eating disorders, abuse, divorce, and a host of other ailments. However, lack of rigor in bibliotherapeutic research led to concerns about the effectiveness of the practice, e.g., "[t]oo little is known about the specific effects of reading on individuals in specific situations, the role of intuition in book selection, the importance of the therapist's knowledge and personality, and the interaction of those variables."²⁰ Further criticisms concerned the constraints on the types of materials that could be explored with the tools provided by objective scientific language: "fiction, poetry or inspirational sources for bibliotherapy remain essentially unvalidated...This may be the case in part because behaviorally oriented materials are more amenable to empirical scrutiny."²¹ Finally, concerns were raised about the quality of the research being conducted. Warner (1980) examined 28 doctoral dissertations on bibliotherapy completed between 1969 and 1979 and found disturbing inconsistencies in methodology and conceptualization of the subject matter. Most importantly, only two of the studies "claimed unqualified success for bibliotherapy" although Warner rejected these conclusions based on errors in methodology.²²

EBM and bibliotherapy

In the 1980s and early 1990s, bibliotherapy was a widely used, poorly researched therapeutic modality. Researchers and practitioners routinely conflated literature and self-help genres.²³ Books and articles on the subject consisted mainly of annotated bibliographies of available books,²⁴ accounts of "books that changed my life,"²⁵ or "how-to" guides on choosing appropriate books for clients. The field was dominated by anecdote, testimony of acknowledged experts, and impressionistic case studies. The research methods in use appeared unable to address the major question, "Does bibliotherapy work?"

In the same time period, the ideology of EBM emerged from the concern that medicine was held in place by unproved, unexamined traditions on one hand and propelled forward by equally unproved, inconclusive research on the other—a situation exemplified by the state of research in bibliotherapy. EBM sought a research-driven practice, in which both the



statements of experts and unsubstantiated researcher claims were replaced by rigorous empiricism. Evidence was ordered into a clearly defined hierarchy: the highest level of evidence came from strictly designed randomized, double-blind controlled trials (RCTs), with large-sized samples to assure that results were not unduly influenced by skewed samples or individual idiosyncrasies, and from meta-analyses, whose examination of a number of RCTs secured an even greater degree of generalizability. According to this hierarchy, the varieties of evidence available in bibliotherapeutic research—expert opinion, theoretically informed conjecture and practitioner consensus—were demoted to the lowest level of evidence. Clearly EBM methodology would demand a major restructuring of bibliotherapeutic research methods.

From a theoretical perspective, EBM seemed especially willing and able to resolve the questions plaguing unproven therapeutic modalities such as bibliotherapy. As stated by one of the earliest and most prominent EBM theorists, David Sackett:

It is when asking questions about therapy that we should try to avoid the non-experimental approaches, since these routinely lead to false positive conclusions about efficacy. Because the randomised trial, and especially the systematic review of several randomised trials, is so much more likely to inform us and so much less likely to mislead us, it has become the "gold standard" for judging whether a treatment does more good than harm. However, some questions about therapy do not require randomised trials (successful interventions for otherwise fatal conditions) or cannot wait for the trials to be conducted.²⁶

Widely used as a therapeutic adjunct or in patient education, not for fatal or urgent conditions, bibliotherapy was clearly positioned as a candidate for EBM scrutiny through randomized trials or other experimental approaches.

Bibliotherapy presented an interesting target for researchers eager to explore its potential as a low cost, self-administered therapy that could also reach patients who would not or could not seek professional treatment.²⁷ Indeed, bibliotherapy has been the subject of significant EBM study and meta-analysis and has attracted more interest from EBM researchers than other alternative or adjuvant therapies such as art therapy, prayer, therapeutic touch, mediation, or poetry therapy.

Philosophical limitations to evidence-based bibliotherapeutic research

However, serious barriers have obstructed the application of EBM methods to bibliotherapy. In order to obtain the highest levels of evidence, such as, that obtained from RCTs and systematic meta-analyses, EBM relies on methods designed to reduce the effect of individual idiosyncrasies that skew results and compromise generalizability. These methods have forced researchers in bibliotherapy—identified as cognitive or psychological therapy that employ books or other material, either as a self-administered or therapist-initiated intervention—to focus solely upon those factors amenable to quantification and measurement (e.g., performance on standardized instruments, reported compliance or abatement of symptoms), to compare largest possible numbers of subjects, and to avoid individualistic and subjective factors. As a consequence, EBM-based bibliotherapy researchers could consider only the outcomes of standardized measures pre- and post intervention—the *therapy*—while being forced to ignore the personal, emotional engagement of an individual reader with a particular text—the *biblios*.

Ultimately, although the scientific, objective language of EBM enabled researchers to compare the results of standardized quantitative instruments, it was poorly equipped to



investigate those aspects of bibliotherapy that emerge when it is approached from a literary perspective:

Bibliotherapy focuses on one central process which occurs in the most significant acts of reading: a book enters the life of an individual, a deep relation is formed, and the person changes in some significant way as a result of this engagement. Bibliotherapy deals with how and why this happens.²⁸

Conceptualizing bibliotherapy in such subjective language suggests a number of interesting and relevant questions, such as, the process by which a book makes an impression on a reader or changes behavior. However, such questions are not translatable into the language of EBM, and thus are lost from any analysis of the mechanism or effectiveness of the therapy.

Randomized studies

One of the ways EBM-based bibliotherapy researchers resolved the problem of subjective reader reactions to a text when constructing RCTs was to regard the text not as the object of reader's interpretation and engagement but as a constant about which quantifiable statements can be made. An example of this approach is presented by Ackerson and colleagues in their study of adolescent depression. The researchers assessed a control and treatment group using a number of standardized psychological instruments. The treatment condition consisted of the reading of Feeling Good, a book that is described only as having "a 6th-grade reading level" and "rated as highly interesting." The study assessed both groups with the psychological instruments three times over a period of two months. The study concluded "bibliotherapy may be an effective treatment for adolescents experiencing depressive symptoms."30 This claim was based upon statistical analysis of the subjects' scores on the standardized tests. The readers' responses to the book were ignored, except as they could be refigured along quantifiable parameters: "[c]ompliance was measured by participants' self-report of the number of pages read in the book. Participation was assessed by recording the number of written exercises completed in the workbook."31 Nowhere in the study were the readers' reactions to the book or its content described.

Similarly, a study of the effectiveness of bibliotherapy in enhancing the life skills of older adults focused on the assessment of frail elders before and after receiving a five-part bibliotherapy called "GRIP on life," described as "[c]omposed of 11–19 pages, which were printed one-sided in black and white." The argument for the therapy's moderate effectiveness was supported by statistical comparisons of the control and therapeutic groups. Several qualitative statements were offered about the readers' response to the entire course: "a course that gives you food for thought;" "the intellectual standard of this course is not particularly high," but the actual texts and their content were not further described.³³

Meta-analyses

The central problem facing RCTs that follow EBM methodology in the evaluation of bibliotherapy is that the focus on quantifiable factors restricts researchers to taking standardized physiological measurements before and after a therapy and prevents them from looking directly at the texts—the presumed therapeutic agent of bibliotherapy. This creates a strange set of data, a situation that becomes particularly evident in meta-analyses, which "combine the findings of individual studies to estimate the true relationships between the exposures or interventions and outcomes of interest" in order to describe the patterns these relationships form.³⁴ This is apparent in Marrs' seminal and widely cited meta-



analysis of bibliotherapy addressing a variety of psychological problems. Marrs noted that his meta-analysis "did not attempt to address the relative efficacy of different books within problem types," but allows that "it is probable there are differences in quality of bibliotherapies within problem types." Similarly, Apodaca and Miller's meta-analysis included an alcoholism treatment study that compared three groups who received bibliotherapy, physician advice only and assessment only. While all three groups showed a modest reduction in drinking, the authors urge caution because "only 17 of the 29 participants in the bibliotherapy condition actually received the book." Presumably, if only 17 of 29 subjects in a drug trial actually received the drug, the study's results would warrant rejection, not caution. If one posits that it is the bibliotherapeutic material that differentiates "bibliotherapy" from other types of "therapy," the resulting meta-analysis is analogous to one of drug trials that ignores information about the drugs administered.

Such disinterest in the evaluation of bibliotherapeutic material is characteristic of other meta-analyses. For example, Gould and Clum privileged medical and methodological criteria over discussion of text and reader in their evaluation of over one hundred studies. These studies were compared on the amount of therapist interaction, duration of treatment and method of outcome evaluation, as well as methodological features such as type of control group used and internal measures of validity. Bibliotherapeutic material was only considered as to modality: print, video, audio or combination.³⁷ Similarly, Marrs emphasized research design (e.g., sample size, control group, methods of statistical analysis) and psychological approaches (e.g., theoretical approaches, therapist interactions, problem addressed) in his examination of two hundred seventy bibliotherapeutic studies, paying little attention to the nature of bibliotherapeutic materials (bibliotherapeutic material was discussed solely in terms of its length, modality, or provenance of publication).³⁸

Despite neglecting the nature and content of bibliotherapeutic texts, the meta-analyses suggested a greater awareness of the role of literature as a bibliotherapeutic agent than was generally evident in the RCTs. In his inclusion criteria, Marrs coded bibliotherapeutic material as either "direct or indirect instruction; indirect instruction includes readings of a fictional, poetic, or metaphorical nature,"³⁹ although no further mention was made of this distinction in the analysis. Scogin observed a shortcoming in the treatment of bibliotherapeutic materials by most RCTs, which did not evaluate literature and popularly read books but focused rather on proprietary manuals specifically written by therapists for use in their own practice and "not likely to be found at the bookstore. This creates the ironic situation that the most validated materials are the least available."40 McKendree-Smith expanded upon this methodological "blind-spot," noting that it "is useful to distinguish bibliotherapy from books that are inspirational but are not intended to be a selfadministered treatment...These books may be therapeutic, in that readers may experience insight, gain knowledge, and evidence symptom relief. However, these works are not within our definition of bibliotherapy."⁴¹ Although the meta-analyses appear to take a wider view of the nature of therapeutic literature than do the RCTs, the language of EBM prevents these researchers from formulating a definition of bibliotherapy that could accommodate not only the didactic materials of formal therapy but also the inspirational literature and popular books familiar to the majority of readers.⁴²

Perhaps the most global shortcoming of EBM is that the restrictions imposed by EBM methodology do not clearly result in improved knowledge about the effectiveness of bibliotherapy. Marrs, for example, while analyzing the effectiveness of bibliotherapy for different types of psychological diagnoses, lamented the inconsistency of subjective researchers who "could not agree as to which problems were amenable to bibliotherapeutic change." However, after statistical analysis of properly conducted RCTs, Marrs



nevertheless could not clearly establish significant effects for bibliotherapy and therefore urged caution in interpreting data suggestive of the effectiveness of bibliotherapy for specific psychological conditions. While he suggested that such analysis is superior to "affective approaches" which are "based on simple case studies and other qualitative evaluations, not quantified evidence," he was criticized by other meta-analysts for his failure to identify appropriate, systematic approaches in place of those examined by subjective measures. 45

Humanities and bibliotherapeutic research

The above examination of RCTs and meta-analyses is representative, not comprehensive, and is descriptive of the methodological resources available to EBM researchers in the field of bibliotherapy. While EBM methodology is appropriate for determining the effectiveness of pharmaceutical or physiology-based therapies such as coronary embolism treatments or angioplasty protocols, bibliotherapy is not captured in the language of science and quantification. EBM researchers are limited by their methods from undertaking analysis of the content of the books and other media that are used in bibliotherapeutic interventions. This inattention to the bibliotherapeutic materials that form the core of the interventions seems negligent or at least peculiar in light of the assertion by EBM researchers that bibliotherapy, like any other therapy, may be ineffective or even harmful to patients. ⁴⁶

Other disciplines, although decried by EBM as subjective and unscientific, have proved themselves better able to shed light on bibliotherapy's effectiveness and use. Qualitative studies in psychology and social work journals report on clients' subjective responses to actual texts. ⁴⁷ Holistic nursing research, with its disciplinary focus on the unity of physical, spiritual and psychological concerns, is likewise equipped to examine the role of the aesthetic and inspirational in therapeutic interventions. ⁴⁸

Such work draws upon the tools of humanities research. Science and humanities are popularly thought of as disparate fields, but humanities methodologies, such as structural criticism, familiar from high school literature classes, offers medical researchers discrete parameters for comparing bibliotherapeutic texts (plot, character, scene, metaphor, themes). Although structural criticism is rejected by postmodernists on charges of gratuitous and unwarranted imposition of form, these structures represent theoretical tools for thinking about these texts' impact on readers. For example, the work of Northrop Frye examines the effects of plot structures; for instance, the structure of comedy chronicles the triumph of the individual, while tragedy depicts the survival of the group. ⁴⁹ Considering these differences may open researchers' thinking about the structure of bibliotherapy used in bereavement and other areas of intervention. ⁵⁰

For its part, postmodernism sheds light on the role of the reader and the multiple meanings that can be drawn from any text. The polysemy of texts is of central concern for bibliotherapy, as it underscores the fact that a reader's interpretation of a text is a function of subjective factors such as past and present experiences, worldview, and perhaps even existing psychopathology.⁵¹ The works and on-going criticism of Freud, Fromm and Bettelheim on interpretation of fairy tales offer many focus points for research into the potential dangers and benefits of bibliotherapy.⁵²

The role of the reader has been given a different emphasis by cultural critics, whose work sheds light on the material, socio-political conditions that help or hinder a patient's ability to modify his or her experiences. Research has shown that children, an important target of bibliotherapeutic interventions, are more keenly aware of the disturbing political,



economic and ecological problems of the day than adults acknowledge.⁵³ Beyond its therapeutic intentions, children's literature serves as a major vehicle for socialization, modeling behavior ranging from good citizenship to uncritical consumerism.⁵⁴ An understanding of the effect of reading is essential in assessing the effectiveness of materials used in bibliotherapy for adults, children and all demographic subgroups.

The humanities, in short, possess the full panoply of tools for textual analysis that can provide researchers with alternatives to quantitative methods for evaluating the effectiveness of bibliotherapeutic texts. Alternative approaches permit new types of research questions as well as fresh analyses of existing ones.

Conclusion

Disciplines such as medical humanities, nursing, literary criticism and health communication maintain a vigorous sector of research that does not employ, or even stands in conscious opposition to, EBM methodologies. Because such forms of research can make broad use of interdisciplinary methods, they are capable of examining the relationship between reader and text ignored by RCT and meta-analysis of bibliotherapeutic interventions. The insights gained by such interdisciplinary methods could be applied to other uses of literature in medicine, such as in the pedagogy of medical ethics, professionalism and decision-making. Nevertheless, given the dominance of EBM methodology, such alternative research retains second-class status. EBM methodology, for its part, is ill suited to the study of the therapeutic use of fiction, literature, inspirational works as well as popular self-help books. As a result, the effectiveness of these texts in bibliotherapeutic interventions is inadequately understood and excluded from consideration within the framework of clinical and research governance.

As depicted in the cinematic example of *The Enigma of Kasper Hauser*, quantification is capable of speaking in an authoritative voice, although it is not always capable of asking useful or even relevant questions. The humanities offer the theoretical and conceptual tools to ask questions about bibliotherapeutic texts in popular use and to discuss their therapeutic effect. Indeed, it is interesting to speculate that the introduction of humanities' methodologies into bibliotherapy research could familiarize educators, creative writers and other stakeholders with the legitimate concerns and questions inherent in EBM research, leading to new research paradigms in both bibliotherapy and the literary arts in general.

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