

# Practice to research: Integrating evidence-based practices with culture and context

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## Abstract

There are ways to integrate culturally competent services (CCS) and evidence-based practices (EBP) which can improve the experiences of patients and their families and communities when faced with health problems, as well as the effectiveness and positive experiences of practitioners. CCS and EBP evidence should be jointly deployed for helping patients and clinicians. Partnership research models are useful for achieving the integration of CCS and EBP, since they involve close observation of and participation by clinicians and practitioners in the research process, and often use integrated qualitative and quantitative mixed methods. We illustrate this with 3 examples of work that can help integrate CCS and EBP: ongoing collection of information from patients, clinicians and staff, or “evidence farming”; close study and continuous improvement of activities and accommodations; and use of evidence of tacit, implicit cultural scripts and norms, such as being “productive,” as well as explicit scripts. From a research practice point of view, collaborative partnerships will likely produce research with culture and context bracketed in, and will contribute stronger research models, methods, and units of analysis.

## Keywords

cultural competence, evidence-based practice, knowledge integration, partnership model, research design

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Few would disagree with the goal of developing better ways to integrate culturally competent services (CCS) and evidence-based practices (EBP) to improve the well-being of patients. The reason this goal matters, in addition to the intellectual project itself of understanding such an important topic, is to find ways to improve the experiences of patients, their families, and communities when faced with mental health problems. Culture matters in clinical interactions and affects health outcomes (Kleinman & Benson, 2006; Kleinman, Eisenberg, & Good, 1978) and cultural competence “aims to make health care services more accessible, acceptable, and effective for people from diverse ethnocultural communities” (Kirmayer, 2012, p. 151). In theory culturally competent health care services should benefit patients with diverse cultural assumptions, expectations, and life routines as well as address health disparities (Brach & Fraser, 2000; Smedley, Stith, & Nelson, 2005). Further, there is evidence that locally developed cultural competence training programs are successful in those particular local contexts (Kirmayer, 2013). Cultural competence on the part of practitioners should improve their ability to build rapport (Beach, Saha, & Cooper, 2006) and positive rapport is associated with better patient adherence to medication (Zolnierrek & Dimatteo, 2009). Even so, studies and reviews of cultural competence training intervention programs generally show no conclusive impact on provider behaviors and attitudes or patient health outcomes (Beach et al., 2005; Lie, Lee-Rey, Gomez, Bereknyci, & Braddock, 2011; Price et al., 2005; Thom, Tirado, Woon, & McBride, 2006) and may even exacerbate the structural inequities that contribute to health disparities (Shaw & Armin, 2011).

As for the usefulness of EBP, patients benefit from practitioners who make use of research evidence in diagnostic and treatment decisions. EBP is the current standard for patient care (Bassand, Priori, & Tendra, 2005; Clinton, McCormick, & Besteman, 1994), and physician use of EBP is increasingly mandated and monitored by hospital administrators, insurance companies, and ultimately, government oversight in the US and EU (Mathews, 2013). Yet EBP of course does not translate verbatim to all contexts or patients. Nonetheless those proposing to ignore EBP in treating patients in favor of CCS alone, are likely also proposing a reduction in overall patient benefit from treatments for most conditions. A mixed or blended practice combining EBP and CCS is far more likely to benefit the well-being of patients.

Can we find ways to improve the well-being of both patients and practitioners through mixed practice? Surely, culturally informed understanding and practice is one such way, just as effective implementation of EBP, whether using evidence from randomized trials or other kinds of research designs, is another. These two sources of evidence may be useful to distinguish analytically as well as to pursue in different ways for research purposes, but we suggest they should be integrated in practice in the service of helping patients. Both matter.

Another reason that integration of CCS and EBP approaches matters is to put to the test the very worthwhile and important goals of including cultural context and cultural competence, safety, compatibility, and awareness in mental health treatment and services. Do CCS goals, as implemented in specific situations, really matter

for patient outcomes and well-being? After all, the experiences of working with those from other cultural communities often is that neither the practitioner nor the researcher nor the client are feeling very “competent” in the sense of being comfortable and assured about what to say and how to treat! It is the experience of being more uncertain, being aware that our implicit knowledge may not be shared, and wanting to learn more about this and get it right, which very often is at the center of dealing with “culturally pluralistic” situations. Furthermore, “the evidence that [culturally competent] services actually result in improved effectiveness remains limited. In fact, in some instances, cultural adaptation may reduce the benefits of a program if essential elements are eliminated” (Kirmayer, 2012, p. 160). Yet Kirmayer also argues that locally developed programs increasing cultural competence can be successful at improving care (Kirmayer, 2013).

These conclusions have been confirmed in a recent review of evidence-based treatments and their effectiveness with ethnic communities primarily in the United States (Huey, Tilley, Jones, & Smith, 2014). Cultural competence is typically considered at the provider or treatment levels (skills; adaptation of treatment; or client–therapist processes, interactions, and meaning systems), rather than at the institutional or systemic or sociocultural levels. Summarizing over 300 randomized trials, the review finds that EBP generally are effective with all groups. Cultural tailoring can be efficacious in addition, but “support for cultural competence as a useful supplement to standard treatment remains equivocal at best” (Huey et al., 2014, p. 305). One conclusion from the review is that cultural competence protocols and tailoring that actually are effective and that can be made relatively easy to adopt and adapt, are needed in order to overcome barriers to dissemination in real-world treatment contexts (Huey et al., 2014, p. 331).

There indeed are features of culture and context that are essential to consider and use in patient interactions and treatment that can increase our awareness. These essential constructs include attending to the shared narratives of practitioners and patients, and understanding the “local social world” of the patients and healers/providers of care and what is at stake for all sides within that community (Lakes, López, & Garro, 2006). These all are important for CCS. The features of the cultural learning environment (CLE), are also essential to consider. These include features of the context including the values and goals, scripts and norms, resources available, people and relationships present, emotions and motives that engage actors, and the stability and predictability of the contexts of care and treatment (Edwards & Bloch, 2010; Worthman, 2010). Hence the shared goals of providing strong descriptions and evidence mean that CCS and EBP need to work together to reduce uncertainties inherent in pluralistic situations, and maximize benefits of care.

As these features of culture and context show, cultures are not fixed categories or social identities with trait lists of attributes—at least not in hybrid, interconnected multiracial and ethnic communities in the world today. It is expectable that there will be within-group heterogeneity across these features, even within a defined cultural-ethnic group (Weisner, 2009). Language, race, ethnicity, SES, religion, and

family patterns commonly cross-cut and complicate cultural group categories. “Hyperdiversity” can become the norm in some situations (Good, 2011; Hannah, 2011). Our emphasis in this paper is on culture as enacted in daily routines within local situational contexts more than as a social address category. Nonetheless there are *essential* features of culture and context, and their identification and use are not to be confused with *essentialism*. Essential features of culture and context that are part of a conceptual framework for research and treatment remain crucial, and are not the same as static, stereotyped, ahistorical typologies described negatively as essentialism.

### The practice to research or partnership model

Research in EBP and evidence-based medicine usually follows a research to practice model in which the researcher directs the study, expecting that the disseminated results or practices will be taken up by practitioners, whether the purpose of the study is to contribute to scientific evidence or interventions to change behavior (Figure 1). While in many ways useful for driving scientific knowledge forward, it is less useful for acquiring knowledge that can be readily and with contextual appropriateness, translated into policy or practice.

The common phrases “research to policy” or “research to practice” can be fruitfully turned around to suggest another model: “practice to research” (Tseng, 2013). In the practice to research model, scientists collaborate with practitioners and clients in a clinic, school, or community program from the beginning, thereby increasing the relevance of the study to practitioners from the outset (Figure 2). Practice to research partnership models offer promising ways to connect evidence-based practice and culturally competent services.

Our more general point is that few interventions, no matter how well assessed through research studies, will do well unless that intervention can find a place in the daily routines and activities of practitioners and policy makers in a wide range of settings. In order for that process of translation and implementation to progress,

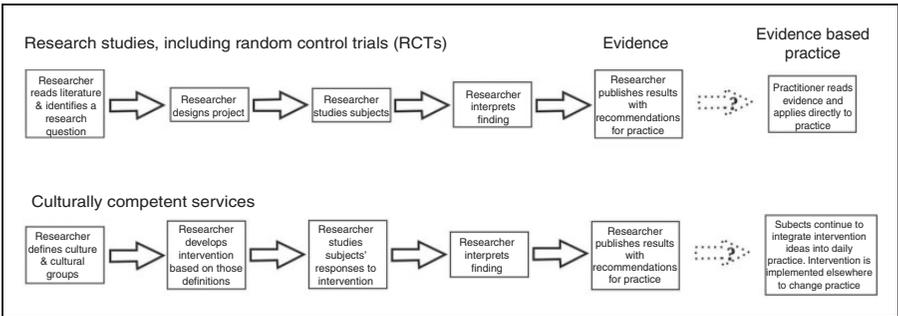


Figure 1. Research to practice models.

the practice and community setting has to be well understood. It is also a process that so often can foil scaling up an intervention: strong evidence for effectiveness in the test sites does not necessarily mean the intervention will transfer unaltered into other settings.

Davies and Nutley (2008, p. 14) argue for a situated model of research–practice collaboration and transfer in educational research, suggesting that:

Terms such as knowledge exchange, knowledge interaction, and knowledge integration more appropriately capture the complex, social, and interactive processes through which new and contextualized understandings are created . . . we need to move beyond individualized framings of the research use process (i.e., how do individuals access, make sense of, and apply research thinking and research findings?) to a focus on research use within organizations and systems. This means asking not just how practitioner organizational arrangements can best support individual uses of research-based knowledge, but also how research-based knowledge can become properly embedded in organizational systems, practices, and cultures.

From its inception, research that seeks to improve the well-being of a person, family, or community as its goal should involve a partnership with the people, programs, or communities that it hopes to benefit (Nutley, Walter, & Davies, 2007). In a partnership model, a research team establishes a long-term relationship with a clinic, school district, state mental health agency, or other organization. The team members meet on an ongoing basis. The practitioners (teachers, clinicians, therapists, policy staff) describe their concerns, what they believe they would like to know to improve their services. They describe the constraints and opportunities they see ahead for their organization and for their clients. The staff “lives in the world of the research team” in the sense that they understand the research goals and their significance, what the researchers hope to learn from the project, and what matters for researchers in their own jobs and careers. At the same time, the research team “lives in the world of the clinic” or the school, or the family service agency, or therapist’s practice, understanding the practitioners’ motivations for engaging in the research, what the practitioners hope to learn from the project,

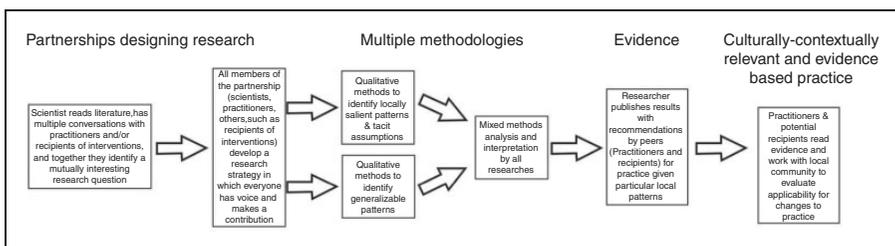


Figure 2. Practice to research or partnership models.

and what matters for the practitioners in terms of their own jobs and careers. Through this mutual understanding, the research team crafts research programs and works with the practitioners to design the relevant conceptual framework and predictive logic model for research. The researcher team changes and adapts what practitioners describe they want, based on what a strong design should be, what methods would work best, and what outcomes can be assessed. Partnership research teams often develop a series of research studies, in stages that integrate all the team hopes to accomplish.

Partnership models are not easy to establish and sustain, obviously. The relative success of partnership models in developing new evidence that in turn can be implemented and clearly improve the desired outcomes (relative that is, to research to practice approaches, randomized controlled trial [RCT] only, or staff learning and continuous improvement models) has yet to be proven, and itself should be assessed.

There is research underway on partnership models themselves to identify the elements that are needed for effective collaboration, and improve the desired outcomes for patients and staff (Coburn & Stein, 2010). Continuous improvement or learning organization models also attempt to blend the active research and data collection efforts with the experiences and feedback from the clinicians, staff, and research participants. The explicit understanding of these approaches is that all team members (researchers and staff) share the goal of improving the organization, or clinical practices, and so improving the well-being of the clients. These kinds of partnership models are especially relevant for the topic of this special issue—the creative tension between EBP and CCS and how to take advantage of both to improve the well-being of those suffering from mental illness through research.

The explicit intent of a partnership research team is to incorporate the cultural and contextual evidence necessary for stronger research and increase the likelihood of effective implementation. Thus from inception, “cultural competence” and institutional knowledge are represented by the community members or practitioners at the table. Compare this with a straight research to practice dissemination model, in which a research project recruits subjects for a designed RCT, completes the results and then turns to a “dissemination phase” where the people, clinics, and communities are informed of the results and then expected to take steps to implement those results, perhaps using a manualized series of procedures. Partnership research models are in place in the fields of education, public health interventions, and other settings (Coburn & Stein, 2010). In many international and community circumstances, such evaluation and improvement research programs can’t necessarily meet every criterion for a full-on RCT, but can nonetheless be successfully adapted for local contexts and conditions in the “real world” (Bamberger, Rugh, & Mabry, 2012).

For many in the ethnographic research tradition and community based health and healing traditions, partnership models for practice to research might seem self-evident. Qualitative and ethnographic evidence that is contextual, meaning and experience-informed, and concerned with intentions, goals, and values

surely matters. But studies using such evidence, however much they have important things to say, may not be believable by EBP or RCT standards. Further, some studies in this tradition consider biomedicine an adversary at best, and immoral and/or presumed to be detrimental to the patient, at worst. Collaborative and partnership models, in contrast, invite a conversation focused on measurable improvements in well-being for those suffering from mental illness. Biomedical science, is “an essential though unfinished project” of unique value, and should not be stereotyped as “scientism” which can have rigid barriers and could be used to divide and close off debate and research (Kirmayer, 2012, p. 156). Science, its research methods, and evidence generating standards, offer skills and epistemologies deserving of support and respect, that are essential to incorporate in partnerships if research findings are to be useful to practitioners and gain wide acceptance.

EBP designs typically include a comparison sample or randomized trial design, and cultural-contextual evidence often requires qualitative and ethnographic evidence. Though far too seldom used together, more research should integrate randomized designs with strong qualitative and ethnographic studies of how experiments and interventions are experienced by those in them—including a study of both the treatment and control groups (Duncan, Huston, & Weisner, 2007; Palinkas et al., 2011; Yoshikawa, Weisner, & Lowe, 2006). The use of strong research designs that combine EBP with the use of qualitative and other methods for deep contextual study of cultural processes should happen more often. RCT studies, particularly social experiments in which family or community interventions are tested, should include nested subsets of participants who also are part of qualitative research embedded in the intervention or experimental study. How are these interventions experienced and taken up by participants in them? At which points do the logic models and active elements of the intervention work or do not work (and what are the active ingredients of the intervention or treatment)? Valuable information will be discovered about how a standardized treatment or manualized intervention actually works for individual clients, and which factors might be shared across clients grouped by variables of social address (ethnic group, SES levels, genders, ages) or local setting. These kinds of findings should then routinely inform how EBP can be more effectively implemented.

The exclusive focus in RCT or EBP research on the outcome measure alone (or impact in randomized experiments) misses the chance to ask about subgroups and individual differences in responses, and the mechanisms or active ingredients that may or may not have produced or prevented a treatment outcome. The goal should be to analyze the treatment and outcome contrasts in detail so as to learn about the contextual influences on the intervention or trial. These kinds of integrated, mixed designs and methods should become the gold standard for such research in our view. The world certainly is not linear, additive, and decontextualized and so our methods should always include qualitative, ethnographic, and experience-based evidence (Weisner & Duncan, 2013). At the same time, for perfectly valid analytic reasons, we can model interventions, clinical practices, and other features as if they were linear, additive, and context-free, as long as we know more about the settings

and cultural and institutional context, and recognize the analytical pretense that goes along with such a research design, modeling and methodology.

We now turn to three examples of work that can help to integrate CCS and EBP, within the practice to research framework using mixed methods. The first example, *evidence farming*, provides an illustration of how clinical services could use their own local evidence, combined with EBP evidence, to improve care. Physicians in our studies supported this goal. In a second example, family *accommodations* to children with disability and mental health problems are shown to be useful units of analysis to help understand family practices in the context of dealing with their children and integrating services and treatment advice into family routines. Finally, integrating practice and EBP research will require understanding that there are cultural assumptions that are sufficiently *tacit* and deeply implicit, that they are not even recognized as “culture” yet which nonetheless fundamentally affect interactions in the clinic and well-being of patients.

### **Evidence farming: Legitimizing the rich knowledge available from local practice**

Research partnerships at their best incorporate the intentions and goals of staff themselves in order to design research and develop measures that can better capture local context. We will illustrate this process with a study of “evidence farming,” a term developed by Naihua Duan (2007) to conceptualize ways to cultivate and harvest the rich contextual knowledge in the minds, experiences, and local practices of clinicians, staff, social workers, teachers, and others. Evidence-based medicine (EBM; or evidence-based practices, EBP) based on randomized controlled trials (RCTs) is readily accessible and rapidly available knowledge which is distributed systematically through publications, as well as through subscription to compilation services such as UpToDate, Epocrates, or Cochrane Reviews. Practitioners can obtain such evidence on handheld devices. But they have no such ease of access to systematic knowledge of local practice experiences and the evidence of what works best for local clinical populations. We explored ways to make more accessible, useful, and systematic what local practitioners do in their local practices and know about their patients (Hay et al., 2008).

RCT evidence, although the gold standard for medical practice, is gained from research based on generalized, averaged knowledge about homogeneous, single-morbidity populations that usually do not match local clinical populations. The question for physicians is how best to apply, revise, and monitor EBM standards of care to best serve their own local population. The evidence farming (EF) concept focuses on the local population and their clinical situation and sociocultural context. We had one question driving our study: Can local, contextual, embedded practice evidence and experience be utilized more effectively, so that it becomes somewhat more systematized and available for practitioners and patients as EBM information is now? If so, we could marry the two kinds of knowledge (EBP and culturally contextual) more easily, with better fidelity and better outcomes for patients.

There certainly is evidence that medical practices rely on institutional contexts and on their own networks of professional knowledge for gathering and interpreting research evidence. For example, Gabbay and le May (2004) describe a version of this that they call “mind lines” in their ethnographic study of English primary care practices. They did not find much evidence of a linear process of reviewing RCT evidence and applying it. Rather, clinicians relied on their colleagues’ experiences, some reading, and reliance on key influential practitioners. They relied on communities of practice in their social and professional world to find, vet, and decide if and how to use, evidence and information. For example, a quote from one of the psychiatrists in our evidence farming study describes the balancing of EBM data, her network of colleagues, local practices, and her own clinical experience and judgment with children:

I have to have a specific question to go to the evidence-based lit—just trolling Pub Med doesn’t work very well. But if for example, I’ve been to one of the Grand Rounds presentations and they talked about a certain medication, then I’ll look at how else it’s been used and see whether that something would be applicable. Has it actually been tested in this age group. Almost nothing has been tested on children... If somebody is really suffering and it looks like this could be safe, I get as much evidence as possible and present it to whoever the decision maker is so that they’re really making an informed decision with me about what seems reasonable... With medically complicated kids and PTSD [for example], last time I looked—there were about 15 small studies each with different medications. But that’s about as good as the evidence is right now anyway.

In our study, we explored how physicians might collect and utilize local knowledge in more systematic ways and how they might then use it. We asked physicians about their resources for clinical decisions and about the potential usefulness of evidence farming data, and then we developed professional-quality trigger films consisting of four different scenarios of clinical decision-making, each film about 2–3 minutes long. In one, an African American mother comes in with her ill child and wants antibiotics; the pediatrician shows the mother data from her practice (evidence farming data) that 98 of 100 children in her own practice get better without using them. “Other mothers and children just like you, do not need antibiotics—and if your child does not get better in a couple more days, you can call me.” In another, an elderly phenotypically Asian man comes in following a heart attack and the doctor wants to prescribe medication; the man is wary; the doctor describes how in his practice the medications he wants to prescribe have helped his patients. We showed these four films to 14 focus groups consisting of clusters of physicians and one interviewed physician, 72 in total, from the Los Angeles area.

Four findings consistently emerged. First, physicians liked the idea of being able to use their own local data to improve their treatment strategies by seeing trends in local infection rates, emergent resistance patterns, and treatment strategies that are

successful for patients with comorbidities and for those who come from different economic, racial, cultural, or ethnic groups in their own clinics and practice groups. Some, it turned out, were already doing so and gave us examples.

Second, physicians found the idea of “evidence farming” a compelling way to inform patient decision-making. As one physician put it,

I think for the mom who wanted the antibiotics [for her child] . . . it makes her feel okay about [not taking antibiotics] versus like, ‘Oh, I’m a bad mom if I don’t give him the antibiotic—‘you should give me the good stuff,’ she says—because all these patients (who are ‘just like me’) did well without it.’ And so it puts her at ease saying, ‘I can sit back and don’t have to give him medication and he’ll still get better most likely.

Of course there are other reasons that parents might want antibiotics, or a similar “quicker” treatment offering symptomatic relief for their child, including: the need to get back to work, worry about siblings becoming infected, beliefs (tacit or explicit) that only ingesting medication or having a shot is going to be powerful enough to treat the child, and that only prescribed medications justify the doctor visit. These complexities are all possibilities to be considered in culturally aware practice, rather than defining CCS as a single list of criteria to be applied to a single class, ethnic, or other socially defined group. This also means that locally tailored questions specific to the practice and the person (not only EBM or disease-specific topics) can be asked.

Third, physicians emphasized that their clinical experience—the accumulated knowledge of applying EBM to patients—enables them to “treat the patient at hand.” The emphasis on the patient as the person for whom treatment must be specific emerged repeatedly:

[E]verybody’s patients are different. That’s the whole reason that you’re a physician; you’re not there just to give verbatim—‘Okay, these are the prescriptions you need because you just had an MI [myocardial infarction]’—You’re there to look at the patient and make your own assessment.

But fourth, practitioners worried about implementation, costs, and ownership of these local knowledge data. Would their employers or drug companies have access to it? Who would be responsible for collecting evidence and making it easily accessible in usable form? Doctors and their key staff definitely should *not* be asked to do so, in their view—they are too busy already and are not compensated for that. How would these data be integrated into existing paper or electronic medical records systems that they are required to follow?

The literature on medical decision making has long shown that experienced specialists make more accurate diagnoses and have better treatment outcomes than novices (Hay, 2012). In the evidence farming study, we found that experienced physicians did not report that they treat patients based on EBM or on perceived

patient demographic categories (age, race, ethnicity, SES, or origin). Rather they described how they treat *individuals*. Since the physicians are embedded in their local practice context, and clearly recognize this and its importance, they then want to apply and think critically about the best EBM that in their experience could be adapted to effectively treat the person at hand. In other words, if we look at the clinical decision making of top-notch, experienced physicians, their practice draws on EBM, their clinical experience, their patient population, local clinic rules regarding drug availability and other issues, and person-centered approaches all combined together in a blend.

The practice of combining EBM in a culturally informed and contextual way, is already happening in the USA, EU, Canada, and other places as well—though no doubt this kind of awareness and CCS should be greater than it is at present. However, although EBM research knowledge is already synthesized, summarized and made available to practitioners and local communities, *local, contextual knowledge is not*. It could and should be made more readily available in our view, and such information is desired by practitioners. Better synthesis, summary, and easy availability of local, culturally informed and contextualized evidence would balance out and complement EBM evidence. There are clearly opportunities in this inevitable mix of clinical practices and judgment to infuse better organized local knowledge data to improve care. It could be done if any level of reasonable comparable investment to what goes into EBM/RCT evidence were made available for the study of CCS, and if confidentiality and ownership and use issues were addressed.

### **Accommodations: Studying the decisions and intentions of parents in everyday routines and practices affecting patients and families**

Our second illustration of blending EBP and CCS has to do with the units of analysis for research and practice improvements. Setting-level change (midway between individual change on the one hand, and institutional, organizational, policy, or structural change on the other) seems so often to be where culturally meaningful practice and EBM evidence come together. The setting or context is a very important unit for analysis and important target for intervention. No family or community intervention or better treatment for a person will have an impact if it cannot find a place in the settings, the daily routines and activities of an organization, a family, or an individual. Setting-level change thus almost always needs to be a key part of the process of integrating EBP and CCS.

A theory or conceptual framework for understanding settings and activities—the cultural learning environment or CLE—begins with social relationships in that setting, available resources, and how those are allocated. It includes the key features of the activities and practices that make up the daily routines in those settings (Weisner, 2002). Everyday activities—such as bedtime, meals, visiting, hanging out with friends, clinic visits, “taking your meds,” soccer practice—are

rich with cultural meaning. They are what we experience—the scripts that we follow—and therefore, we believe are an important locus for what can be changed to bring CCS and EBP closer. Those features include resources needed for each activity; the people and relationships among them; the scripts, norms, and customary ways of acting in that activity; the goals and values of the participants and customs; the emotions and engagement in the activity; and the stability and predictability of that activity. Accommodations are changes made in behaviors and normative scripts in the family or institutional setting that are due to perceived problems or successes. Settings and activities can change through our *accommodations* within them. Our research has focused on family accommodations to children with disabilities with associated mental health problems. Accommodations in families are functional responses and adjustments to the demands of daily life with a child with delays. As a unit of analysis, accommodations are a part of cultural practice as instantiated at a local and family level within which interventions can be slotted into the daily routines of patients and families (Bernheimer & Weisner, 2007; Skinner & Weisner, 2007).

Settings and activities can change through accommodations that alter one or more of those setting features. Accommodations in families, for instance, are the actions taken, or actions not taken that would otherwise have been taken, in the family that are due at least in part to the child or adult with disabilities. They are functional responses and adjustments to the demands of daily life with a child with delays and/or mental health problems. The accommodation is an important unit of analysis for understanding change in settings. Accommodations are practices or activities, embedded in a daily routine of family life, that are intended to improve the relationship with the child with disabilities and/or the family circumstances, and are due at least in part, to the child. Accommodations can be done by and include all family members involved with the child. Accommodations are setting- or context-level changes, which alter the allocation of resources, or people and relationships, emotional engagement, and/or the beliefs, scripts, and norms for conduct of those in those settings.

“Context-examined, EBP-informed best practice” is a short-hand phrase for the ideal of what we have in mind as a useful unit for study: Accommodations informed by EBP evidence. The concept of accommodation is more general than its specific application to disability and mental health research. It is a unit of analysis blending everyday routines and practices that look specifically at a person within his or her cultural world—and then applying the best EBM/RCT evidence to what is practicable and applicable for that person in that local context. The application of this unit for study from the setting to the individual level, no doubt is complex and is an important part of the art of clinical practice, whether in mental health treatment, teaching in classrooms, social welfare, or any other service field. Kravitz et al. (2008) suggest one interesting example in their work on “n of 1” designs for adapting EBM right down to the individual patient, including prescribing medication, and the cultural and setting features that matter for that patient (see also Kravitz et al., 2009). At another level of blending, providers may

recognize that patients with a particular social address (e.g., country of origin, gender, age) have similarities of worldviews or routines that can be usefully taken into account in considering treatment strategies, as Hinton and Good show in exploring both the universal feature of anxiety disorders (primarily consisting of catastrophic cognitions) and the culturally variable ideologies and symptoms that must be considered in designing successful treatment (2009).

We followed 102 Los Angeles area Euro-American families with children with a wide range of disabilities for 15 years, from age 3–4 through late adolescence, and asked them about their daily routines and activities and their accommodations across several waves of data collection (Bernheimer & Weisner, 2007; Gallimore, Coots, Weisner, Garnier, & Guthrie, 1996). We also assessed the developmental status of the children and asked parents to complete questionnaires and surveys asking about their satisfaction with and use of services, overall family life, their aspirations and expectations for their child, and basic demographic information (Keogh, Bernheimer, Gallimore, Weisner, & Vaughn, 1998). We identified domains of family life and activities where most accommodations were focused: these included family subsistence; services for the child; home and neighborhood safety; domestic workload; childcare tasks and workload; peers/playgroups for child; marital roles and relationships; social support from community and extended family; gender roles, including role of father; available information about disability, services, and other resources. The Ecocultural Family Interview (EFI), a conversational interview focused on walking the parents through their daily routines of life with their child, is used to understand the everyday family activities and accommodations made (Weisner, 2011).

We identified hundreds of distinct family accommodations described by parents, and then summarized them within 10 domains of family life. Examples of accommodations from the range of families in our study include (Gallimore, Bernheimer, & Weisner, 1999; Gallimore et al., 1996; Weisner, Beizer, & Stolze, 1991):

A father stays with his job because it provides health insurance for the child even though he would otherwise want to change.

A mother stays home to care for the child, deferring her educational plans. Father then takes over on weekends.

A mother turns down a job since it interferes with the therapy session schedule for her child. Mother later goes back to work since family can't afford new therapies otherwise.

Mother cuts back on housework, cooking and other tasks since time with her child is higher priority.

Father increases domestic tasks and childcare; mother and siblings do too.

The family does not eat together at the same time because the child with disabilities is too disruptive and unpredictable.

Family moves to another school district for what they believe are better services.

Family moves to another state so that extended kin can help with care; "I don't trust anyone else other than my family."

Father stops attending church because they do not include their child in Sunday School; "...and how could a God have done this?"

A mother describes the situation regarding her child as an opportunity, not a burden, given to her by God.

An older sister brings her friends and boyfriends over to the house; "it's a test; if they don't get along with my younger brother—I probably won't be so close to them."

The parents organize play groups with mixed typical developing and handicapped children so as to include their child.

"I struggle to protect my daughter from stigma or people who might take advantage of her; it's up to the school to try and help her with learning."

"We try hard not to change our morning and bedtime routines; if we do, our son just can't understand. We don't really go anywhere much."

This sample shows the variety of ways parents adapt their lives to their children. Accommodations are a very useful unit for blending culturally and situation-adapted behaviors and beliefs with EBP evidence about the likely outcomes of those accommodations. Accommodations are very much a part of cultural practice as instantiated at a local and family level (Skinner, 2005). Of course clinics and other care settings are also places for understanding and improving accommodations using CCS and EBP combined.

Just as members of a cultural or ethnic group differ, so do family and kin. Accommodations are always done in the context of the family resources available (financial, information, and social or relational) and the competencies and abilities of the individuals in those settings. Family members have somewhat different goals and core values orientations and beliefs about the causes and likely effects of their and others' efforts to accommodate. They often appraise the situation differently. They share some goals and yet may differ as to whether they believe that these accommodations can be sustained over time.

Accommodations were associated with what parents described to us as the "hassles" they faced as parents. Hassle was an everyday, nonpejorative term that many parents used to describe not simply child symptoms or problems, but rather behaviors that had an impact on the family daily routine. A child might have difficulty with verbal communication, for example, but that might have little impact on the family routine as parents experienced this, and so not be a hassle (it's a concern certainly, but not a hassle for sustaining the activities in their daily routine of activities). Parents reported on six different kinds of hassles: behavioral (e.g., frequent tantrums); medical (e.g., unusual care demands); communicative (e.g., nonverbal); social appropriateness (e.g., tiresome overtures); activity rate (e.g., extremely active); responsiveness (e.g., ignores, does not respond to others). The degree each hassle impacted family routine shaped the intensity and variety of accommodations families implemented.

Accommodations vary in the amount of effort and attention families put into them (intensity), as well as in the number of types of different accommodations made with the various domains of their daily routine (services;

subsistence/resources; domestic workload; etc.). We followed families when their child was 3, 7, and 11 years old. Intensity of accommodations remained stable from age 3 to 7, and then started to decrease somewhat as kids reach 11 and older. However, the number and types of accommodations increase as children get older, reflecting the greater impacts of the child on more domains of family life. The child's disabilities were the focus of most accommodations, and reported hassle levels were associated with accommodation type and intensity (Gallimore et al., 1996).

Parents reporting higher hassles also tried more accommodations and changed them more often. Accommodations were not associated with a child's test scores (motor, cognitive, and developmental assessments) nearly as strongly as they were associated with hassle. Accommodations are in response to (seemingly) mundane circumstances of everyday life and the daily routine, more so than they were to levels of parent-reported "stress." Accommodations were influenced by parents' values regarding what they thought of as normal, their views on career or work, their religious convictions, and beliefs about education and achievement.

Barring parent practices that might be dangerous or pathological, accommodations are not themselves positive or negative except as understood in the *context* of how they fit into the overall family routine and values and goals. What fits for one family would not for another: every accommodation has to be understood for how it affects all family members, not only the child with disabilities or the primary caretaker. Did these accommodations help the family sustain a meaningful routine? The father who did not change his job for instance: was that a "good" accommodation or not? Only understanding this decision and its consequences in the context of the family routine, beliefs, values, and so forth, could such an assessment be made.

Accommodations were not related to conventional child outcome measures for this disability population. Rather, accommodations were related to higher reports of *family* life satisfaction, family well-being, and sustainability of the family daily routine. Accommodations can enhance family-level changes and success, even though specific accommodations themselves may not change individual-level child outcome assessments such as cognitive developmental change, socioemotional measures, and so forth (Weisner, Matheson, Coots, & Bernheimer, 2005). Accommodations certainly provide learning opportunities for children. Yet these opportunities are not best understood only by the criteria of whether they are cognitively stimulative for the child for example, or whether or not they improve developmental assessment scores for a child with disabilities. Accommodations matter for sustaining the overall family daily routine.

Accommodations can connect EBP evidence to culturally competent services. Any clinical service or community-based program depends on links to accommodations, since

no intervention [or treatment], no matter how well designed or implemented, will have an impact if it cannot find a slot in the daily routines of an organization, family, or

individual. The intervention (the information and practices and resources that make it up) must fit into the existing beliefs and practices already in place in the family or clinic or other context. The accommodations that parents make in their daily routines show that family routines and practices can and do change—that interventions can indeed find their places. The practitioner participates in this “conversation” between the social structural constraints and opportunities of families and communities, the beliefs and values of parents, and the valuable contributions of the intervention. (Bernheimer & Weisner, 2007, p. 8)

## Tacit cultural assumptions and clinical care

CCS requires a focus not only on explicit cultural beliefs and practices, but also the tacit expectations of clinical institutions, providers, patients, and families. Cultural assumptions that are sufficiently tacit that they are not even recognized as “culture” nonetheless affect interactions in the clinic (Strathmann & Hay, 2008, 2009) and patient well-being (Hay, 2010). When people’s everyday concerns, routines, resources, and abilities are not taken into account in developing explicit or tacit expectations (of treatment compliance, of behavioral changes, of improved functioning), outcomes may not be optimal. Tacit scripts and expectations drive everyday routines for families and for clinics alike (Kirmayer, 2013), as well as the well-being of people struggling with life’s challenges such as poverty, disabilities, mental illness, infectious diseases, or chronic diseases. During a 3-year mixed methods research project with rheumatology and neurology physicians and their patients, these kinds of implicit cultural issues emerged as important to patient experience both inside and outside of the clinic.

For example, in America, there is a pervasive expectation of productivity. One should always be doing something, accomplishing a task, or overcoming a challenge (see Polanyi, 1989)—and it is this productivity that is associated with personal value. If the challenge is visible, so much the better, for working to overcome a visible challenge is seen as heroic. However, among some of the people with chronic disease that we worked with, particularly those with invisible diseases (invisible at least to lay people) like lupus, rheumatoid arthritis, fibromyalgia, scleroderma, and multiple sclerosis, some of these patients could not work or even accomplish everyday tasks like self-dressing. People with these chronic but largely invisible diseases are known in the medical literature to have low rates (50%) of adherence to medications that have strong clinical evidence of effectiveness (Harrold & Andrade, 2009; Sabat e, 2003; Treadaway et al., 2009). These people are also known to have high rates of learned helplessness, fatigue, and depression (Nicassio, Schuman, Radojevic, & Weisman, 1999; Nicassio, Wallston, Callahan, Herbert, & Pincus, 1985; Thombs et al., 2010; Zautra, Fasman, Parish, & Davis, 2007). But little work has attempted to explain *why* some people with chronic diseases have higher levels of well-being and resilience than others.

In our research in clinics, listening to patients talk about their experiences and listening to clinical interactions, being able to “do” things and to be productive in everyday life emerged as a salient difference between those who were coping well with their disease and those who were not (Hay, 2010). The people who were suffering the most were often seen by friends, family members, and occasionally even physicians as not trying hard enough—to use patients’ own words, they were seen as “lazy” and “couch potatoes.” Indeed, the patients saw themselves this way. They were seen and saw themselves as morally culpable for not being up to tackling the challenge of their illness. And they voiced greater psychological suffering because of this failure to live up to the pervasive cultural expectation in the US for being productive, busy, and active (Hay, 2010), a finding that may be of relevance to research identifying demographic and psychosocial factors associated with work disability in people with chronic rheumatological disease (Nicassio et al., 2011).

The CCS or EBP literature typically does not hold up pervasive yet tacit American cultural assumptions to critical analysis. Thus even if physicians are sensitive to the patient’s presumed “culture” defined by a social category or ethnic label, physicians and others may still unwittingly project their own tacit cultural expectations, such as being active and productive, onto the patient, thereby contributing to negative patient affect and health outcomes. Research partnerships that bring together clinical, mental health, and social science expertise are inherently innovative, merging the methodologies that can examine disease activity, psychological well-being, and cultural and contextual factors, including those that are tacit, to develop holistic explanations for why some patients do better than others; this kind of partnership research then could lead to interventions to fill those gaps.

## Conclusion

A practice-to-research partnership model may often be the best choice to integrate CCS and EBP. Increased availability, integration, and synthesis of local, culturally and contextually informed knowledge through evidence farming is needed and desired by practitioners. Accommodations are pervasive, socioculturally defined, and critical to understand in order to make EBM and interventions have an impact. Finally, awareness of tacit expectations is essential to include for the goals of integrated EBP and CCS. Cultural-contextual understanding enhances the impact of EBP. Our examples come from the United States, so the blending of EBP (which is developed mostly from Western contexts and medical models) and local partners is easier. Partnerships when working outside the West of course require much more adaptation both of EBP research and to local practices. Nonetheless, we argue that mixed qualitative and quantitative methods, interdisciplinary as well as patient–practitioner collaborations, and a pluralistic epistemology are valuable in this kind of work. This partnership model, reproduced across many sites, can identify structural features, mechanisms of effect and characteristics of activity settings (relationships; goals; resources; meaning and value

systems; scripts and normative and tacit practice; etc.) that are found across countries, cultures, and contexts and lead to general understanding. Recognizing that bridging is not always easy or even possible, we nonetheless see the integration of practice-to-research, culturally contextual social science as among the most promising ways to develop findings that matter in improving the lives of those with mental illness.

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