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Building interventions when distress is under debate: a case study
from Appalachia

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Frances Feltner, DNP, MSN, RN, FAAN, is the Director of the Center of Excellence in Rural Health at the University of Kentucky and an Adjunct Assistant Professor in the University of Kentucky College of Medicine's Department of Family and Community Medicine and the College of Nursing. Dr. Feltner has worked for more than 30 years in rural health

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Abstract

Scholarship on idioms of distress has emphasized cross-cultural variation, but devoted less attention to intra-cultural variation—specifically how the legitimacy of distress may vary by context in which it is expressed, social position, and interaction with medical categories of distress. This variation can pose challenges for interventionists seeking to establish culturally acceptable ways of identifying distress and creating relevant resources for recovery. We describe efforts over 3 years (2014-2016) to identify and adapt a culturally appropriate evidence-based intervention for depressed rural Appalachian women. Though the prevalence of depression among rural women is high, limited services and social barriers restrict treatment access. Formative research revealed varied understandings of distress. Depression was (a) medicalized as a treatable condition, (b) stigmatized as mental illness, (c) accepted as a non-pathological reaction to regional poverty and gendered caregiving responsibilities, (d) rejected as worthy of individual care-seeking, and (e) diminished in comparison to other competing forms of distress (i.e., multiple morbidities, family members' distress). In a small pilot trial, we applied an implementation science perspective to identify and implement appropriate evidence-based programming for the context. We outline how we reached Appalachian women despite these diverse understandings of depression and established a flexible medicalization

of depression that enabled us to legitimize care-seeking, work with varied rural healthcare professionals, and engender culturally relevant support. Our adaptation and implementation of the concept of “mental health recovery” enabled programming that furthered non-pathological communicative distress while resisting the normalization that silences women in the context of deep health disparities.

Keywords: Depression, rural, women, recovery, intervention

Introduction

For nearly 40 years, medical and psychological anthropologists have urged sustained analysis of cross-cultural experiences of distress in order to understand variation in its expression and the contexts that provide it with meaning (Kirmayer, Gomez-Carrillo, & Veissière, 2017; Kleinman & Good, 1985; Nichter, 1981). Heeding this call, anthropological scholarship on distress describes the syndromes that appear in different cultural contexts, outlining the embodied experiences, links to deep cultural meaning, and indigenous treatments to alleviate such distress (Hinton & Lewis-Fernández, 2010; Kaiser et al., 2015; Nichter, 2010).

Reviewing this work decades in, Nichter reflected that, “anthropological studies have all too often emphasized one mode of expression” (2010, p. 399). He sought to draw attention to the socio-politics that privilege certain forms of distress while generating “alternative means of expressing distress,” revealing great diversity in

the interpretation of distress *intra*-culturally (2010, p. 403). At the center of this approach is a focus on transaction, to understand how meaning is negotiated between different parties responding to the environment, and how the response to distress—or absence of response—shapes the continued expression of distress (Nichter, 2010).

Social position—including gender, class, and age—shapes who is allowed to express distress, and in what way (Beauboeuf-Lafontant, 2007; Helms, 2014). When distress cannot be expressed in forms that are culturally valued, it is more likely to be repressed, unrecognized, or stigmatized (Hollan, 2004; Kirmayer, 1989). The norms of expressing and interpreting distress change in response to social shifts (Ng, 2009) and societal upheaval (Abramowitz, 2010). This literature demonstrates how debate is inherent to the expression and interpretation of distress—that who expresses distress matters, the form of expression matters to its interpretation, and that the meanings of distress shift over time.

We ask how these characteristics of distress under debate can be applied to improve care. We focus on the experience of depression among rural women living in Appalachia—a region where the meaning of distress has changed considerably in the recent generation yet where appropriate, quality care remains challenging to access.

Challenges of Intervention Cross-Culturally

Idioms of distress hold great significance for care management by revealing the social, economic, and relational contexts in which distress is expressed. In so doing, idioms of distress can illuminate what strategies would be adaptive or maladaptive for a given context (Nichter, 2010). Yet many researchers are skeptical of treating distress, warning of the cultural assumptions inherent within definitions of mental health pathology that underlie intervention. In particular, critics note the increasing medicalization of depression since the 1980s, in which biomedical definitions of depression and its treatment have expanded in popular consciousness, in healthcare settings, and through commercial products to treat depression. Such medicalization has transformed sorrow and sadness into illnesses to be treated with medication (Clarke, Shim, Mamo, Fosket, & Fishman, 2003; Horwitz & Wakefield, 2007). The process of biomedical intervention itself transforms whatever the patient experiences into a psychiatric entity that fits within its classificatory schemes (Abramowitz, 2010; Kirmayer et al., 2017). This process may potentially translating biomedical terms in ways that drastically misunderstand patients' experiences, such as changing the moral meaning of mental health experiences (Helms, 2014; Kohrt & Hruschka, 2010).

As a result of biomedicine's individualistic focus, many treatments have shifted the moral responsibility for maintaining mental health to the individual, "depoliticizing the problem and largely

ignoring the wider social and institutional context of individuals' physical and mental states and behavior and the deficiencies of the society in which they live" (Busfield, 2017, p. 13; see also Clarke et al., 2003). Ultimately, moral interpretations of distress that draw attention to broader social pathology may be best situated to reduce suffering, provided they are grounded in understanding how such ailments are also embodied by individuals (Kirmayer, 1989). To realize this shift, interventions must address the larger inequalities shaping mental distress, the contributions of culture, and the influence of organizational environments on provider care (Helms, 2014; Jackson, 2015; Kirmayer, Benneqadi, & Kastrup, 2016).

Still, with much of this literature placing the patient or person at the center, is there room for culturally grounded interventions that address how broader groups—not just individuals—may experience distress that is under debate? Further, how can interventions respond to varied expressions of distress not only in provider-consumer interactions, but through re-conceptualizing the types of providers offering care, the settings in which care is provided, and expanding the support provided?

Shifting Meanings of Distress in Appalachia

In 2014, we began research on the experience of distress and depression among Appalachian women in order to understand epidemiological data that showed high prevalence of depression in

Appalachian Kentucky (BRFSS, 2013; Kentucky, 2015; Zhang et al., 2008) and rural women in U.S. more broadly (Hauenstein & Peddada, 2007; Price & Proctor, 2009). Historically, “nerves” has been a syndrome in the region characterized by feelings of nervousness, fear, anger, depression, and physical agitation understood to be caused by harsh social conditions and stressful social events (Keefe & Curtin, 2012; Van Schaik, 1988; Van Schaik, 1989). Yet contemporary research on rural women more broadly shows that more women identify their symptoms as depression (Simmons, Huddleston-Casas, & Berry, 2007) and, in Appalachia, use the expression “nerves” less often (Keefe & Curtin, 2015). Such a shift may indicate increased medicalization—that clinical categories of depression may be more widely embraced—or it may represent interaction between emic and etic categories of mental health (Kirmayer, 1989) as rural areas have become more exposed to direct-to-consumer advertising and treatment delivered through telemedicine and mobile technologies (Carpenter-Song & Snell-Rood, 2016).

Many initiatives have concentrated on increasing care for rural women with depression by expanding access to mental health specialty care in rural settings (Adams, Xu, Dong, Fortney, & Rost, 2006; Fortney et al., 2013). Yet research on rural settings demonstrates that considerable barriers remain, including expectations that women independently manage their distress,

persistent stigma (Hauenstein, 2003), and extensive shortages in mental health services (Mohatt, Bradley, Adams, & Morris, 2005).

Guided by the suggestion that culturally grounded interventions must “understand patients’ predicaments and devise solutions based on their individual, family and community resources” (Kirmayer, 2012, p. 252), we adopted an implementation science perspective to understand and address barriers and employ resources across systemic, organizational, provider, and individual levels. We initiated intervention planning through the Replicating Effective Programs Framework, a conceptual model that identifies local needs, applies these understandings to identify appropriate evidence-based practices, and examines the local context to understand how programs need to be effectively implemented in local organizational contexts through partnership with community partners (Kilbourne, Neumann, Pincus, Bauer, & Stall, 2007).

Methods

Intervention Adaptation. As shown in Table 1, from 2014-2016, we elicited the perspectives of Appalachian women with depression and the diverse healthcare providers who offer care to them in interviews and focus group discussions. Our team included research coordinators and collaborators based out of the Center of Excellence in Rural Health and their community health worker (CHW) program Kentucky Homeplace. Collectively, the team possessed extensive ties

in the community and vast experience in Appalachian health disparities work. We pursued our overall goal to adapt and implement a culturally grounded intervention for women in Appalachia through the course of five different stages: formative, exploration, adaptation, review, and intervention. In Table 1, we describe the multiple phases of this work by goal, participant type, and data collection method. In phases 1 and 3-4, we recruited women who felt “down” and evaluated depression with a standard scale (CES-D 10) but purposefully sought women with varied perspectives on depression as an illness category, including identification with, resistance to, and less familiarity (for more, see procedures in Snell-Rood et al. 2016). Participants with depression were predominantly white (97% white; 3% African American), reflecting the demographics of Appalachian Kentucky, with 95.4% people identifying as White, 1.7% identifying as Black, and 1.3 % identifying as Hispanic (Pollard & Jacobsen, 2011). We made efforts to over-sample African American participants, however, we found that depression stigma was an enormous barrier to follow-up. In phases 2-3, we sought the expertise of a range of healthcare practitioners who serve women in the region, some of whom identified as depressed and others who did not but still might engage in treatment. We reached out to primary care providers (physicians and nurses) the main providers of mental health services in this rural area (Wang et al., 2005), as well as mental health specialists who provide psychotherapy in integrated

care settings as well as community mental health centers. In addition, we relied on the perspectives of CHWs, lay health workers posted in the surrounding rural counties who provided care coordination for underserved rural residents and facilitated health programs. CHWs often had more sustained contact with their patients and were able to identify those who likely had depressive symptoms even if they did not identify with medicalized depression. All participants were briefed on study procedures and given the opportunity to ask questions as part of the process of informed consent. Throughout, we were in touch with WRAP developers and staff about our goals, receiving technical assistance during the implementation process to ensure the adapted program was delivered with fidelity. All phases of the study were approved by the University of Kentucky College of Medicine Institutional Review Board.

Intervention Outcomes. Primary outcomes collected at baseline and after the intervention included depression severity (Patient Health Questionnaire-9; Spitzer, Kroenke, & Williams, 1999) and rumination (Ruminative Responses Scale; Treynor, Gonzalez, & Nolen-Hoeksema, 2003), an outcome that can capture more subtle changes in mental health coping than depressive symptoms alone (Kinser, Bourguignon, Whaley, Hauenstein, & Taylor, 2013). Though we had employed the CES-D for the earlier study phases, we switched to the use of the PHQ-9 during the intervention because it is consistent with DSM-V

symptoms of depression and includes more accessible language. Secondary outcomes--all measures consistent with previous WRAP trials—included hopefulness (Hope Scale; Snyder, Harris, Anderson, et al., 1991); quality of life (WHO Quality of Life Brief Instrument; Skevington, Lotfy, & O’Connell, 2004); and self-perceived sense of recovery (Recovery Assessment Scale; Corrigan, Salzer, Ralph, Sangster, & Keck, 2004). On an exploratory basis, we measured social support (MOS 36-item scale; Ware & Sherbourne, 1992) and mental health service use and satisfaction (Experience of Care and Health Outcomes; AHRQ, 2015). At the conclusion of the intervention, we conducted individual phone interviews with intervention participants, asking about their perceptions of effectiveness (i.e., impact of the intervention on their mental health) and acceptability (i.e., relevance of content). Additional quantitative and qualitative data was collected on implementation and feasibility that is not presented here.

Qualitative Data Analysis. We used thematic analysis to guide our interpretation of the data across phases, building on themes derived from the literature on rural mental health, idioms of distress, and implementation science. Different codebooks were generated for each phase of the project to address separate research questions (see Table 1 for questions by phase). For each codebook, initial analysis was guided by broad review of the transcripts to identify initial themes. Code definitions were developed gradually through an iterative team

process of comparing themes across transcripts and differentiating between code boundaries. Once formally defined, the first and second authors applied codes line by line to the transcripts in the MAXQDA data analysis program. Coded data segments were compared across cases to identify patterns, differences by participant type, and to identify outliers which were resolved in follow-up team discussions. Analysis was presented to community-based team members for feedback and checking at the end of each study phase.

Quantitative Data Analysis. Descriptive statistics of outcomes were determined. Paired t-tests were used to compare pre- and post-test scores and effect sizes were calculated using Cohen's *d*.

Results

Several broad themes appeared across the study's phases. First, we describe the varied debates about what depression was in the region. Second, participants discussed how "deep" needs and service disparities posed major limitations to creating an intervention within traditional clinical mental health services. Third, participant perspectives on the range of interpretations of distress in the region aligned well with recovery—a philosophy, social movement, and therapeutic orientation driven by consumers of mental health services (Amering & Schmolke, 2009). Fourth, participants recommended that we strategically engage with medicalization, employing its moral authority to encourage participation, while avoiding its hierarchical

relationships. By focusing on adapting a broad intervention that addressed recognized needs—without defining those needs specifically—we avoided the powerful consequences of the negotiation involved in interpreting distress. We briefly present results from the adapted intervention pilot trial. We found significant declines in depression severity (as measured by the PHQ-9), depressive rumination (RSS), and significant improvements in participant perceptions of their ability to deal with daily problems and accomplish goals (ECHO). Participants in the intervention commented on how the adapted group intervention helped them to de-individualize their distress as an individual pathology while enabling them to voice their own individual distress within their social worlds.

Part I: Program Adaptation

Varied Understandings of Depression

We found varied understandings of depression and distress as we talked to women and their healthcare providers. Many naturalized depression and feelings of being down as a reaction to the harsh social and economic conditions in the region, which made it extremely challenging to get by, much less imagine a future in the region. Many equated “depression” with a category of people who took part in specialty behavioral healthcare. Referring to patients with serious distress, one provider explained, “They do have bad nerves,” but “they don’t identify with” services offered in community mental health

centers. For others, “depression” was an illness for which they would take medication, but not *mental* illness, a term connoted people who were more different, who “need their treatment and their groups.”

Because of these mixed connotations of the severity implied by the label depression, some women who understood their feelings to indicate depression were careful to hide this from others, fearful they would be seen as crazy, incapable of performing their jobs or caring for their children. Older women described gradual generational shifts in the conceptualization of depressed feelings, with increased contemporary understanding of depression as an illness and more interest in pharmaco- and psychotherapy to treat depression. Some who attended church resisted medicalized depression, identifying their feelings as part of their own character to be resolved through prayer, while others insisted that psychiatric treatment was the only venue in which they could seek help for distress they attempted to conceal in church.

Providers and women with depression admitted that even when they identified their distress as depression, it did not feel as real or as urgent as the physical comorbidities common in the area. CHWs noted that their participants dismissed psychotherapeutic treatment, saying, “I don’t have time to go to town for 2 hours to just go over there to talk.” But CHWs questioned the deeper meaning in this evaluation, posing, “do they think they’re not worth it or that they can beat this on

their own?” As we describe in more detail elsewhere (Snell-Rood, Merkel, & Schoenberg, In Press), many women found it hard to differentiate their distress as depression when so many other family members expressed similar vulnerability. Many women struggled to find outlets in which they could voice their distress and have it validated. One provider, reflecting on the reticence of Appalachian women to seek care for depression, described, “I think sometimes women feel guilty for taking time for themselves and their own stuff because they have families.”

In this setting, people were willing to legitimize the distress of depression, but expressed ambivalence about how real it was, how exactly it should be dealt with, and whether it deserved to be dealt with. Even women who engaged with a more “medicalized” understanding of depression continued to debate the meaning of their distress, as we show elsewhere (Snell-Rood, Hauenstein, Leukefeld, Feltner, & Schoenberg, 2016).

Limitations of Adapting Traditional Mental Health Services

Both women with depression and diverse healthcare professionals remarked on the challenges of building sustainable interventions in a rural system with limited capacity. As one woman commented, “we have nothing here.” One social worker who described her own experience with depression admitted, “If someone were to call

me at work and say, ‘Look I need help,’ I wouldn’t know where to send them to.”

Still, many women managed to access care in primary care settings, and at times from mental health specialists. Yet with a few exceptions, women’s description of their clinical experiences resounded with frustration, which often resulted in fragmented treatment engagement. Healthcare providers emphasized the challenges in providing quality care due to time constraints and excessive needs. In traditional mental health services delivered in primary care and specialty settings, most women did not receive the intensity of care that they needed—in everything from the therapeutic encounter to the coordination required to access care.

Participants remarked that the hierarchical nature of interactions between patients and providers—whether primary care or mental health specialists—held multiple consequences. Providers’ professionalism alone could be aversive to women from considerably different social backgrounds, particularly those with negative experiences in overburdened rural service settings. Referring to the way in which providers’ position was embodied, one CHW explained the patient’s averse response: “when they walk in and I’m in heels and all that, they’re like, ‘she’s another one of them that ain’t going to help me.’” Providers were felt to not only have the capacity to apply stigmatizing labels and uncover sensitive situations undergirding

women's distress but also to have the power to reveal this information in ways that could threaten their employment or custody of family members. "It's scary because there's a doctor label behind their name," explained one woman, "you're like, 'okay, this doctor's going to find something and something's going to be taken from me.'"

At the same time, participants were skeptical that women in the region would participate in any intervention oriented explicitly around mental health because they felt that this distress was either less real or potentially dangerous. As one woman with depression said, "A lot of the places here put depression down as a disease...[But] a lot of people don't want to be put in the category of a mental illness; that scares them. If depression was put under a virus, they would be fine with it." In addition to stigma, mental health was felt to be too difficult to prioritize. In a region with such varied perspectives on distress, participants of all types agreed the greatest challenge would be "Getting people there: just getting people to decide that they'll sit in front of this group and say in front of a stranger that they're depressed." For women to attend the program, one community health worker insisted, our program must "look like just a group of women having snack instead of being a bunch of mental health people that needs their issues addressed."

Mental Health Recovery Provides Room for Diversity

We chose an intervention based around the recovery philosophy that enabled us to make room for diverse understandings and experiences of depression but could be delivered outside of traditional mental health services. Emerging from a movement of mental health “consumers,” recovery is an approach to mental health that stresses overall wellbeing, consumers’ interpretations of their mental health and their own efforts to manage it—thus pushing away from clinical models of care that are hierarchical, emphasize pathology, and can impose unrealistic plans for progress (Amering & Schmolke, 2009).

Specifically, we chose the recovery intervention Wellness Recovery Action Planning (WRAP) that is oriented around wellness and self-management. An evidence-based intervention tested in randomized clinical trials (Cook et al., 2010; Cook et al., 2014; Cook et al., 2011; Starnino et al., 2010), WRAP serves as an augmentation to clinical mental health treatment. WRAP employs non-clinical terms to describe mental health and is delivered in a group format by peer providers--people who have experienced mental health challenges themselves who become certified to provide WRAP. Typically, trained peer facilitators lead 12-16 hours of content in group meetings that introduce participants to the concept of recovery and guide participants to create their own wellness toolkits and plans for crisis. In line with evidence-based guidelines requiring participants to be engaged in concurrent treatment, we recruited participants engaged in

treatment (either pharmacological or psychotherapeutic treatment; with pharmacological treatment predominant for rural populations).

Recovery's focus on wellness and absence of clinical mental health language would enable us to capture a broad group of women. The recovery intervention that we chose, however, was one that could respond to multiple interpretations of distress while straddling the category of depression as mental illness. Many felt that the group orientation of the intervention would enable women with varying interpretations of distress to see themselves within a shared experience rather than a singular label. With this in mind, women could consider their participation gradually: "they can be thinking about it, there is other people who feel the way I do and have the same problem and that might ease the door open for somebody."

Providers and women endorsed the "wellness" emphasis within the program. As one CHW reflected, "We have to present it in a way without saying, oh it's all about depression; it's a way to feel good...to maintain your everyday life...and not let it get you stressed out, overwhelmed." Further, diverse providers suggested building on the chronic disease self-management concepts of the intervention that might be familiar to women in a population with high rates of comorbid chronic disease. When people think of self-management, explained another CHW, "It's like initiative to help themselves but it allows them to be in control more" unlike the medication-focused treatment

typically received by most rural women in primary care. Participants recommended that we recruit for the program through language that focused predominantly on symptoms: “that will capture a whole range of folks who might say, ‘I don’t sleep good, my appetite’s not good, I’m really irritable a lot, but I don’t have depression.’” In addition, CHWs suggested that they could identify women whom they served through care coordination that experienced significant distress but likely would not seek care for depression outside pharmacotherapy. One CHW envisioned that she would explain the program to one of her existing clients by saying, “‘You know how you always say that that’s just the way it is and it ain’t going to change?’ I’d say, ‘but it could change though.’”

In this rural area with few people who publicly identified as “consumers” of mental health services and no peer provider workforce, we opted to deliver WRAP through CHWs, lay health workers with extensive knowledge of and ties to the community. Our participants suggested that CHWs’ relational style of care could help address some of the limitations of existing services. CHWs explained that the women with whom they worked needed reassurance, particularly because many of them had multiple negative experiences in healthcare and some felt unable to rely on others. Sustaining contact was vital—if an entire week passed and “they don’t hear from you, ‘Then they’re thinking, well they don’t care; they just want me up there in that

session you know but have they called to check on me?’” Providers noted that the relationship itself was meaningful, arguing that she must let women know that “I do care that they come, that that does matter to me.” In this sense, participants recommended that the relationship with CHWs would be more “high touch”—characterized by more intensive communication. Because most women had struggled to find receptive family and community support, positive, non-hierarchical communication would be crucial to any intervention: “You just have to make them feel like you’re on their level; that you’re not above them at all.” Unlike providers with advanced medical training, community health workers would avoid the clinical mental health language that reinforced hierarchies during treatment encounters.

Even as we had CHWs serve as peer facilitators, we implemented WRAP in fidelity with core principles (Federici, 2013) by ensuring that they were a) recently trained in WRAP facilitation, b) described their practice of WRAP in their own lives, c) received technical assistance from WRAP mentors as needed through the course of the intervention, and d) conducted groups in accordance with the WRAP curriculum.

Flexible Medicalization

Based on the input of women with depression and healthcare providers, we adapted the program through flexible medicalization—using medicalization strategically to legitimize participation, but avoiding psychiatric terminology and differentiating the program from

traditional treatment. Women found it hard to prioritize care for their depression because it was less “real” and because gendered obligations for caregiving subsumed their individual needs. For women with “too many other people depending on them...admitting that there’s an issue,” reflected one provider, “[well] they just don’t have time for it.” Yet providers and women alike explained that a doctor’s referral would help them to realize that seeking care was important. In rural healthcare settings where patients see primary care providers for physical and mental health, “most people will trust recommendations from their provider,” explained one practitioner.

Some recommended that the program be implemented as part of care planning within appointments rather than presenting WRAP as a casual choice that women would opt in to. Holding the program at a medical site would enable women to identify the program in a more culturally acceptable way, rather than likening it to mental health services that bore stigma: “Women wouldn’t have to call it anything, it could just be ‘going to the doctor.’” Because we opted to locate our WRAP trial in the same building as a federally qualified health center and the offices for CHWs, the program benefited from the legitimacy of existing care. Participants would think, explained one CHW, that “I go to the doctor there; I go visit the community health worker there; everything is confidential you know so they’re having it there so this has to be legit.”

Even as we wanted to encourage women to seriously consider care for their distress, we took steps to ensure participation was voluntary. Participants had to voluntarily reach out to the study coordinator to learn about our WRAP study. While we encouraged providers to refer their patients to the program, we neither informed providers of participants' decisions to take part nor did providers follow-up with potential participants about their decisions to participate. We described study procedures to participants during a formal consent process, enabling participants to ask any questions or decline participation, clarifying that their decisions would have no influence on any other services they would receive at the health center with which we were affiliated.

With WRAP designed as an augmentation to clinical treatment, only women currently engaged in treatment were eligible for our study. However, formative themes on debate about treatment led us to anticipate that participants' treatment experiences would be varied. Some would likely adhere fully to treatment regimens and formulate wellness plans including deeper treatment engagement; others might engage more sporadically in treatment and reject clinical care in their recovery plans. Still, providers and CHWs expressed concern that adaptations to WRAP included implementation strategies that would enable CHW facilitators to draw on the support of mental health clinicians if WRAP participants expressed severe distress during

sessions. Conversely, women expressed fear of being perceived as “crazy” or “out-of-control,” citing the fear of psychiatric institutionalization if their words were misconstrued. To address the sometimes problematic procedures applied in crisis and the need for additional support for severe aspects of depressive illness, we consulted with WRAP developers and mental health specialists, evaluated on-site resources, and assessed CHW facilitators’ own comfort. Drawing on these perspectives, we designed flexible procedures to address the emergence of extreme distress that drew on women’s understanding of their distress, social supports, and existing services.ⁱ

Even as we linked the program to primary care through referrals and site, we avoided full embrace of medicalized depression. Stakeholders warned us to differentiate the program from traditional pharmaco- or psycho-therapy treatment due to the past negative treatment experiences of many women. “If they have some issue with mental health care or they haven’t been treated well,” commented one provider, “it might be good to emphasize that this [program] would be different.” It must be clarified, suggested one woman with depression, that “we’re not here to give you any kind of medication, we’re not here to judge you on anything, we’re just here to talk and listen and try to help you.” In this way, participants suggested that medicalization could

increase the priority of depression care, while acknowledging the negative experiences many had already faced in treatment settings.

Part II: Adapted Intervention Results

Quantitative Findings: Pre- and Post-Intervention Outcomes

Paired-sample t-tests of survey responses before and after the WRAP intervention showed significant improvement in four areas related to participant symptom burden and recovery strategies. Participants reported decreased overall depression severity as measured by PHQ-9 ($D = 2.7$, $p = .04$), decreased rumination on depression as measured by RRS ($D = 3.1$, $p = .02$), improved ability to deal with daily problems as measured by ECHO ($D = 0.8$, $p = .04$), and improved ability to accomplish goals as measured by ECHO ($D = 0.4$, $p = .02$). Due to our small sample size, we also report effect sizes. The intervention resulted in large effect size for the improved ability to deal with daily problems as measured by ECHO (0.72) and medium effect sizes for depression severity as measured by PHQ-9 (0.60), decreased rumination on depression as measured by RRS (0.53), improved ability to accomplish goals as measured by ECHO (0.51), decreased symptoms as measured by ECHO (0.45), and decreased overall rumination on the RRS (0.42). A small effect size was seen for the ability to deal with social situations as measured by ECHO (0.36) and decreased brooding as measured by RRS (0.36). Other subscales did not show significant improvements and some measures showed little

impact of the intervention (e.g., HOPE, WHO). See Table 3 for the full listing of responses.

Qualitative Findings: Individualizing Distress as a Voice and De-Individualizing Distress as Problem

Anthropologists have pointed out how the philosophy of recovery is generally oriented around the individual, potentially conflicting with collectivist orientations toward wellbeing (Adeponle, Whitley, & Kirmayer, 2012). We were surprised to hear how many participants voiced an appreciation of the individualistic focus that enabled them to navigate their immense social demands differently. Though we had initially focused our research on women because of the gendered patterns of depression's presentation, the gendered focus resonated with consumer and healthcare provider stakeholders advising us on intervention adaptation. The need was for "something like where women can come and meet and they can discuss what they need." Repeatedly, providers pointed to the weight of social demands on women they felt were at the root of their depression: "It trickles back down to some strong woman somewhere has to be the one; whether she's strong or not, she has to be the one [to do it]."

In line with this emphasis, women noted that the largest impacts of the intervention on their mental health were related to the ways that they negotiated their family relationships. "It's like the weight of the world went off our shoulders," reported one woman. Before, her adult

son would stay with her and “take over. Now he can’t do that because WRAP has taught me to stand up for myself and to be alright with telling people no and to reach out to other people.” Instead of accepting others’ demands felt to be social obligations, numerous women voiced how they now felt it was acceptable to voice their own desires, to say “no” when they did want to oblige others’ requests.

Other women stressed how participation in the program affirmed their individual needs amid ever-present obligations to care for family members. CHWs had warned us that with the women we hoped to reach, “That’s one thing you run into with women, that nurture thing—I take care of my family and I’m last. The kids, the family, the husband, and the house, the chickens all come before mom or the wife or the woman does, she’s last.” In contrast, commenting on her experience in our trial, one participant explained, “One thing in the program stood out with me was something about I deserve this. Like, I deserve a day to myself or a day to do something I haven’t done before and I think I needed.” Though women faced considerable pressure to handle their family challenges independently, some indicated the relief of feeling that “now I can reach out and ask people. It’s just awesome. It’s a totally different feeling.”

Participants voiced how the group delivery of the program enabled them to see people with “similar problems.” Many women reported being reassured by the familiarity of the challenges that their

fellow group members shared. “At the time, you think, I’m the only one going through this,” shared one participant, “but then you learn that, no, you’re not the only one.” Having women decide their level of participation in the group freed women from having to create group consensus about experiences. Strikingly, participants did not frame their similarity in terms of their mental health, but instead their experience of similarly challenging social conditions. “You meet people who have the same problems you have but in a different form.” In the group, “there were women who were working and kind of struggling. Some who were going to school, trying to get a job. There were some other women that we made these judgments that they were better off financially but still we have some of the same things. I think it was good for me to see the group of people coming together and sharing on that basis.” Removing hierarchy in the group setting not only removed judgment, but also the perception of different life experiences.

Discussion

Though research on idioms of distress has brought great attention to the debate inherent within the presentation of distress, the few scholars who have engaged with this dynamism in therapeutic application of idioms of distress have done so outside of the U.S. (Hagaman et al., 2013; Kohrt & Hruschka, 2010). Here, we have examined how appropriate treatments can be identified and

implemented when distress is under debate in a U.S. setting, using the example of depression and distress among women in rural Appalachia. We focus our discussion on three key areas: 1) the dangers and possibilities engendered by expanding the categories of mental health intervention; 2) how flexible medicalization can be productive to address distress under debate; and 3) the potential of recovery-based interventions to offer therapeutic spaces for individualized and social distress.

In contrast to intervention strategies that respond to particular distress idioms or syndromes, we have shown that it can be productive to engage with diverse expressions of distress and the shared conditions understood to be at its root *rather* than responding to one specific distress idiom. Such a strategy attempts to avoid the power-laden transactions highlighted in research on the idioms of distress in which only certain types and voices of distress are legitimized (Beauboeuf-Lafontant, 2007; Helms, 2014; Hollan, 2004; Nichter, 1981; Nichter, 2010). But in intervening upon broader experiences of distress, does our approach further what medical anthropologists critique as “bracket creep” (Nichter, 2010)? Such a critique draws attention to how psychiatric diagnostic criteria have expanded to include more behavior as pathological (Clarke et al., 2003; Horwitz & Wakefield, 2007) and the enlargement of intervention goals to address increasingly more social problems (Abramowitz, 2010). Bracket creep

can transform the original meanings of distress (Abramowitz, 2010; Nichter, 2010), and ultimately obscure the social causes at its root, instead placing the onus of change upon individuals (Busfield, 2017; Clarke et al., 2003).

In the case of our intervention, expanding the brackets of distress to include women who had significant symptoms of depression (as measured by the PHQ-9) but who identified as “down,” “stressed,” or “overwhelmed,” and only in some cases “depressed,” enabled us to explore a variety of meanings around distress. It also allowed us to reach women who described significant isolation and shared similar problems generated by difficult social conditions, but engaged with services and clinical diagnoses in very different ways. Like most others, our intervention did not focus on changing the structural causes of the inequality that played a large role in many of our participants’ distress. However, overwhelmingly, our participants noted that the peer-focused nature of the group intervention and content on self-management enabled them to see that their distress was not their fault nor were they alone in experiencing it. Participants indicated the critical intervention effect of learning to voice their distress about their social demands, predominantly in terms of their gendered burden to care for family members. While we do not know how such distress was received, we do know the relief that women reported in stating their own needs and also reaching out for help in new ways. Future

intervention work in the region could amplify the impact of this recovery intervention through broader strategies that address the harsh economic conditions furthering women's suffering. Further, future research must address the needs of rural women of color whom we were challenged to reach---women who often face even deeper, intersectional stigma and spatial and social-economic isolation (Burton, Garrett-Peters, & Eason, 2011).

Diverse stakeholders recommended that we strategically medicalize distress and intervention strategies—legitimizing distress by describing our mental health intervention as a medical necessity while avoiding the hierarchical, clinically circumscribed nature typical of rural mental health services in this region. Our participants drew attention to the multivalent meanings of medicalization in this rural setting—the trust that can be invested in primary care providers even when they are felt to be at times overwhelmed or insufficient, and the deep hesitation toward engaging with mental health providers due to the fear of being labeled as mentally ill. Making the case for distress and depression a “medical necessity” through doctors’ recommendation enabled women to allow themselves such care despite their considerable social demands, while the location of the intervention at a medical establishment allowed women to gloss their participation in WRAP as merely “going to the doctor.” We resisted clinical categories and treatment when describing the intervention

itself, which though identified as evidence-based, is not classified as mental health treatment. We suspect that for some participants, as shown in the broader literature, participation in our program may have been a means to express distress (e.g., Nichter, 2010; Nichter & Nordstrom, 1989), whether participation in the program communicates that distress socially to others or resists dismissal by other providers (Nichter & Thompson, 2006; Snell-Rood et al., In Press). In this way, selective medicalization can enable the communicative ends of idioms of distress particularly in settings where social expectations limit the expression of distress.

The adaptations that we made to WRAP based on our preliminary included delivery of WRAP through CHWs serving as peers employing WRAP in their own lives, additional outreach between CHW facilitators and participants, the option for participants to be referred to WRAP through their primary care provider, and holding the program in a medical setting. However, our primary innovation was to employ an intervention based on recovery philosophy for a population that did not consider themselves to be “mental health consumers,” and for whom standard clinical care (predominantly in primary care settings) is the only available treatment option. Yet in so doing, we crossed an often unnamed boundary between intervention strategies most often applied for those with serious mental illness and those with common mental disorders. However, the fact that we tested WRAP among a different

population—one that was not only rural, but also not strictly consumers with SMI—may account for the fact that we found no impact of the intervention with several measures traditionally used to assess the impacts of WRAP, like the Hope Scale and Recovery Assessment Scale. Previous trials of WRAP have included participants with more extensive involvement in community mental health centers that include recovery-focused programming (Cook, et al, 2012).

Questions remain as to the longitudinal impacts of flexible medicalization for WRAP participants also engaged in mental health services: what is resolved in debates about distress? Findings from our study here do not show a resolution of debates about the terminology and labels of distress. However, our study does show that participants find relief in the recognition of their distress—what is agreed is that their distress *exists* and deserves the attention of participants and others to attenuate such distress. Nor do we illuminate participants' decisions post-intervention to pursue further care in traditional clinical care or in recovery spaces. However, we suspect that the flexibility enabled in WRAP self-care planning—which can include biomedical treatment alongside other treatment systems—might not pose a contradiction for patients. Indeed, research on medical pluralism in Appalachia (Cavender & Beck, 1995; Hill & Fraser, 1995) and elsewhere (Wade, Chao, Kronenberg, Cushman, & Kalmuss, 2008) has demonstrated how frequently patients simultaneously engage in health

services grounded in entirely different orientations toward wellness. Future research could clarify how patients and providers reconcile the potential contradictions between recovery-based interventions' flexibility and the rigidity and hierarchy embedded in clinical psychiatric care.

Anthropologists have been skeptical of recovery philosophy because of its emphasis on Euro-American forms of individualistic personhood, which potentially excludes collectivist models of personhood valuing relatedness and restoring social personhood through the healing process (Adeponle et al., 2012). Our experience with this recovery-based intervention shows its potential to offer therapeutic spaces for individualized and social distress, even for a group whose gendered care-giving obligations are vital to sustaining kinship (Buer, 2016; Snell-Rood et al., In Press). Women's strong affirmation of their newfound ability to say "no" to family members—indicating a more "individualistic" notion of personhood—indicates the need to think beyond personhood as either individualistic or collectivistic. Instead, our findings support other work demonstrating that recovery interventions must include careful consideration of how participants navigate the stresses and harness the support of their close social relationships (Aldersey & Whitley, 2015). Our experience suggests the flexibility of this program to address the ways that, cross-culturally, the disproportionate burden of domestic and relational labor

is connected to women absorbing their own emotional challenges (e.g., Weaver, 2016).

One limitation of the material presented here is our lack of focus on implementation of the adapted intervention. Due to the scope of the study, we have not described, for instance, the experience of primary care providers referring participants to the program or the experience of the CHW facilitators or how WRAP could be delivered long-term alongside clinical care. In addition, though primary care providers expressed great interest in the study, their busy schedules severely restricted their participation, limiting our ability to fully describe implementation strategies for primary care referral. Our future work will concentrate on the critical implementation factors needed to support practitioners and organizations (Jackson, 2015) to address distress under debate in group interventions that may limit the person-centered care that has been the emphasis of previous work (Kirmayer et al., 2016). In addition, in future work we will delve more deeply into measuring different aspects of recovery in order to understand what is salient in this cultural context (Whitley & Drake, 2010). Future large scale trials that include an equal emphasis on effectiveness and implementation (Curran, Bauer, Mittman, Pyne, & Stetler, 2012) will be critical to evaluate whether recovery programs like WRAP may be appropriate to address distress in wider populations. Such research must interrogate not only the impacts of WRAP as an

intervention on distress and mental health outcomes, but also test how well implementation strategies (including delivery through intensive contact with CHWs and limited medicalization) can be feasible, acceptable, and appropriate for rural women in distress.

Conclusion

As much as research on the idioms of distress urges attention to cross-cultural variability, equal emphasis is placed on variation within particular cultural contexts—and the ways that social position, social changes, and medicalization can shape multiple experiences of voicing and interpreting distress. Even as distress may be under debate, people seek resolution for their suffering, sometimes exhausting multiple options when systems for care have not adapted to the changing meanings of distress (Abramowitz, 2010). In this case study, we have shown how recovery-based interventions enabling flexible interpretations of mental health can be combined with strategic engagement with healthcare institutions in order to provide options for care even when distress is under debate.

Table 1: Overview of Study Phases, Goals, and Participants

Phase and Goal	Participants	Eligibility Criteria	Data Collected
<u>1. Formative:</u> understand how Appalachian women with depression understand their experience and make treatment-seeking decisions	Low income women with depression ⁱ (N=28)	Screened for depression with the CES-D, diagnosis of depression or identification with term not necessary, up to 200% of poverty line, resident of Appalachian Kentucky.	Semi-structured interviews of 45 min-1.5 hours conducted by the first author.
<u>2. Exploration:</u> identify diverse care provider perspectives on needs of Appalachian women, barriers to seeking care, opportunities for task-shifting, provider needs	Care providers (N=11) who work with Appalachian women with depression: primary care, mental health specialists, and community health workers	Inclusion criteria consisted of working in a healthcare role in eastern Kentucky for at least 2 years and experience working with Appalachian women with depression.	Semi-structured interviews of 45 min-1 hour conducted by the first author.
<u>3. Adaptation:</u> identify care provider and consumer perspectives on selected intervention WRAP and how it should be adapted to be feasible for Appalachian women and providers	Care Providers (N=10) who work with Appalachian women with depression (primary care, mental health specialists, and community health workers) and Appalachian women with depression (N=9)	Inclusion criteria for care providers consisted of working in a healthcare role in Appalachian Kentucky for at least 2 years and experience working with Appalachian women with depression. Inclusion criteria for consumers include female gender, depressive symptoms (as measured by the 10-question brief	Focus groups (n=4) were conducted with groups of similar backgrounds (PCP and mental health specialists; CHWs; women with depression). Logistical challenges led us to conduct remaining data

		CES-D).	collection through semi-structured interviews.
<u>4. Review:</u> present adaptated intervention to provider and consumer stakeholders for final review	CHWs (N=3), Providers who would be in referral role (N=3), CHW adminstrator (N=1), Women with depression (N=3)	Same as previous. Administrator had same healthcare role inclusion criteria in addition to experience in overseeing rural CHW program.	Structured interviews conducted by phone by first and second authors.
<u>5. Intervention:</u> evaluate the experiences of participants who took part in adapted WRAP program	Appalachian women with depression (N=11) who took part in adapted WRAP. <i>[Though N=15 completed the intervention, only 11 were reachable by phone for follow-up interview.]</i>	Screening for depression completed with the PHQ-9 ⁱⁱ , and, in accordance with WRAP evidence-based guidelines, currently engaged in treatment (defined as either pharmacological or psychotherapeutic treatment in the last year).	Semi-structured interviews conducted by phone by first and second authors.
<p>Acronyms: WRAP = Wellness Recovery Action Plan; CES-D = Center for Epidemiological Study Depression Scale; PHQ-9 = Patient Health Survey 9-item; PCP = Primary Care Provider (physicians, nurse practitioners); CHW = Community Health Worker</p> <p>ⁱ We define depression here as measured by the CES-D, knowing that this category was not meaningful to all participants.</p> <p>ⁱⁱ Later in our project, based on the advice from a new collaborator we switched to the use of the PHQ-9, because it is consistent with DSM-V symptoms of depression but more friendly for community-based settings due to its accessible language.</p>			

<i>Table 2: Participant Demographics</i>		
<i>I. Consumers (N=37): Phases 1, 3, 4</i>		
	N	SD
Age	41.38	12.42
Years lived in Appalachia	32.90	15.66
Number of people in household	2.87	1.37
Years of education completed	13.70	2.38
	N	%
Currently in treatment for depression	17	46
Female	37	100
<u>Race</u> ¹		
White (not Hispanic)	36	97
Black	1	3
<u>Marital status</u>		
Married/partnered	22	59
Divorced	7	19
Widowed	1	3
Never married	7	19
Currently employed	24	65
<u>Household income</u>		
<\$10,000	7	19
\$10,000-20,000	11	30
\$20,000-30,000	8	22
\$30,000-40,000	4	10
\$40,000 and above	7	19
<u>Insurance coverage</u>		
Private insurance	8	22
Company insurance	11	30
Medicaid	6	16
Medicare	10	27
Veterans' insurance	1	3
No insurance	2	5
<i>II. Providers (N=21): Phases 2, 3, 4</i>		
	N	SD
Age	43.85	9.18
Years lived in Appalachia	34.71	16.56
Years worked with consumer population	12.97	9.33
	N	%
Female	17	81
<u>Race</u>	20	95

White (not Hispanic)		
Black	1	5
<u>Job title</u>		
Community health worker	11	
Social worker, Counselor (LCSW, LPCC)	5	
Healthcare administration (RN)	2	
Psychologist	1	
Primary care provider (MD, NP)	2	
<u>Current location of practice²</u>		
Community outreach	11	
Public clinic	5	
Community Mental Health Center	2	
Administration	2	
Hospital	1	

note: “insurance coverage” allowed more than one count.

¹ Participant racial backgrounds reflect the demographics of Appalachian Kentucky, which is a predominantly non-Hispanic White population: 95.4% people identifying as White, 1.7% identifying as Black, and 1.3 % identifying as Hispanic (Pollard & Jacobsen, 2011).

² The vast majority of providers had served in different healthcare locations during the course of their careers, many with experience across community mental health centers, public clinics, hospitals, and outreach.

Table 3: Pre- and Post-Intervention Results

Measure	Assessm ent	Range	Pre- Intervention		Post-Intervention		Paired t-test		Effect Size (Cohen's <i>d</i>)
			Mean	SD	Mean	SD	<i>t</i> (df)	P-value	
Depression severity	PHQ-9	0-27	18.00	6.28	14.13	6.61	2.3(13)	0.04	0.600
Overall mental health	ECHO	1-5	3.25	1.16	3.23	0.80	0.6(10)	0.59	0.020
Deal with daily problems	ECHO	1-5	2.83	1.21	2.00	1.11	2.3(10)	0.04	0.716
Deal with social situations	ECHO	1-5	2.42	1.11	2.00	1.24	1.4(10)	0.19	0.357
Accomplish goals	ECHO	1-5	2.83	1.83	2.08	1.11	2.9(9)	0.02	0.510
Symptoms	ECHO	1-5	2.67	1.37	2.08	1.27	1.8(10)	0.10	0.447
Overall rumination	RRS	22-88	55.07	15.54	48.33	16.22	2.0(13)	0.07	0.424
Reflection	RRS	5-20	10.73	3.86	10.20	3.45	0.4(13)	0.69	0.145
Brooding	RRS	5-20	13.00	4.20	11.47	4.35	1.3(13)	0.22	0.358
Depression rumination	RRS	12-48	31.33	8.47	26.67	9.29	2.5(13)	0.02	0.525
Hope	HOPE	12-96*	65.47	7.88	65.53	10.39	-0.3(13)	0.79	-0.007
Agency	HOPE	4-32*	19.33	5.45	20.27	6.30	-1.0(13)	0.34	-0.160
Pathways	HOPE	4-32*	22.00	4.83	22.13	4.77	0.1(13)	0.94	-0.027
Physical health	WHO	7-35*	20.27	4.55	21.67	4.32	-0.9(13)	0.38	-0.316
Psychological	WHO	6-30*	17.73	4.27	18.87	4.35	-1.1(13)	0.29	-0.265

health									
Social relationships	WHO	3-15*	9.00	3.58	10.00	2.94	-1.5(13)	0.17	-0.307
Environment	WHO	8-40*	25.27	4.65	27.00	5.42	-1.6(13)	0.14	-0.344
Quality of life	WHO	1-5*	3.40	0.80	3.47	0.81	-0.4(13)	0.67	-0.087
Health satisfaction	WHO	1-5*	2.87	1.02	3.13	0.72	-1.1(13)	0.39	-0.299
Recovery	RAS	41-205*	147.67	17.89	156.53	17.52	-2.0(13)	0.07	-0.500
Confidence	RAS	9-45*	32.20	4.66	33.93	3.70	-1.7(13)	0.12	-0.414
Willingness to ask for help	RAS	3-15*	10.93	2.02	11.20	1.97	-0.2(13)	0.86	-0.135
Goal- and success-oriented	RAS	5-25*	17.13	3.18	19.07	2.84	-1.7(13)	0.12	-0.645
Reliance on others	RAS	4-20*	14.80	2.51	14.80	2.83	-0.2(13)	0.85	0.000
Not dominated by symptoms	RAS	3-15*	9.73	2.02	10.27	2.35	-0.9(13)	0.38	-0.247
Social support	MOS	19-95*	63.93	15.49	70.73	20.58	-1.9(13)	0.08	-0.377

Acronyms: PHQ-9 = Patient Health Survey 9-item; ECHO = Experience of Care & Health Outcomes survey; RRS = Rumination Response Scale; HOPE = Adult Hope Scale; WHO = World Health Organization Quality of Life-BREF survey; RAS = Recovery Assessment Scale; MOS = Medical Outcomes Study Social Support Survey

*: denotes that the scale has reversed values, i.e. an increase in the measured value indicates clinical improvement

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ⁱ We include the text of our procedures here: In the case of participants expressing extreme distress, one facilitator would bring the participant outside of the room, and she would talk to the participant. They would ask her, "What can we do to support you?" If she needs a prompt, the facilitator would ask her to identify a support person (friend, family, etc.) that she can call. If she wants medical help, the facilitator could offer to set up an appointment for her in the on-site clinic immediately (when sessions occur during day) *or* if when sessions are after regular business hours, the facilitator could accompany her to the psychiatric hospital or emergency room facilities immediately adjacent to the intervention site. Note: We never needed to use these procedures during the course of our small trial.