Peer Support, Self-Determination, and Treatment Engagement: A Qualitative Investigation
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Peer Support, Self-Determination, and Treatment Engagement: A Qualitative Investigation

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Objective: To address gaps in the literature concerning the relationships among participation in peer-led mental health programs, the development of self-determination in service use, and medication use and engagement with medication prescribers and other traditional providers, we conducted focus groups with individuals involved in Wellness Recovery Action Plan (WRAP) programs. Method: We carried out five focus groups with 54 WRAP participants and/or facilitators, and analyzed transcripts using a grounded theory approach. Results: Emergent themes revealed differences of opinion regarding the role and value of medication adherence, broad agreement on the benefits of WRAP in increasing self-determination and self-awareness, and positive effects of participation on patient self-advocacy, medication-related decision-making and meaningful engagement with traditional providers. Conclusions and Implications for Practice: Findings emphasize the importance of examining the influence of stand-alone peer-led program involvement on relationships with traditional providers and decisions regarding medication use, as well as the heterogeneity of consumer treatment values, choices, and associated outcomes.

Keywords: peer-led services, medication use, treatment engagement, self-determination, recovery

Adherence to mental health treatment is a complex issue with significant implications for policy and services. Recently Corrigan et al. (2012) proposed that self-determination replace treatment “adherence” as a core goal of recovery-based mental health services. Investigations of how involvement in self-determination-focused peer-led interventions affects medication use and service engagement with traditional providers are largely absent from the empirical literature. To explore these relationships, we undertook a qualitative study of mental health consumers involved in the peer-led Wellness Recovery Action Plan (WRAP) initiative.

Since the introduction of psychotropic medications, evidence has suggested that these drugs (a) may be effective in treating positive psychosocial symptoms (Leucht, Hierl, Kissling, Dold, & Davis, 2012); (b) have limited effects on the negative and cognitive symptoms that often predict long-term disability (Bowie et al., 2010; Milev, Ho, Arndt, & Andreasen, 2005); and (c) induce significant side effects in almost every organ system (Shirzadi & Ghaemi, 2006). Because of side effects and other concerns, some people opt not to take medications, though decisions like these may lead to relapse and increased functional disability (Kreyenbuhl, Nossel, & Dixon, 2009; Velligan et al., 2009). Although the earlier concept of “compliance” has generally been used to index passive acquiescence with a professionally prescribed treatment regimen, the more recent term adherence suggests a greater level of active involvement on the part of the consumer (Corrigan, Liberman, & Engel, 1990). Even adherence, however, implies that encouraging consumers to follow a professionally recommended medication protocol remains a primary goal for service providers (Corrigan et al., 2012).

In this context, potential pragmatic and ethical trade-offs between shared decision-making and robust self-determination raise important questions. Self-determination typically refers to the extent to which choices are autonomously motivated and self-directed, and has been identified as a strong predictor of mental health and well-being (Ryan & Deci, 2000). By extension, self-determination regarding medications and treatments implies that individuals have the freedom to choose the activities they believe will be helpful, regardless of professional recommendations (Corrigan et al., 2012). Resulting tensions between self-determination and adherence are intriguing. Should clinicians encourage consumers to make their own choices even if this freedom leads them to refuse recommended medications? Is a goal of full self-determination only viable for consumers who possess some requisite level of clinical “insight”? Mixed attitudes on the part of consumers complicate these questions. In a qualitative study focusing on medication and recovery, Piat, Sabetti, and Bloom (2009) identified both “complying with medication” and “having a say about medication” (including choosing to ignore professional recommendations) as core themes identified by participants. This seeming contradiction parallels other studies of consumer views about the impact of involuntary treatment, with one subgroup describing such experiences as profoundly damaging, while another viewed them as justified.
necessary, and sometimes helpful (Katsakou et al., 2012; Sibitz et al., 2011). Clinical and sociopolitical goals of the consumer or survivor movement raise additional questions. Although some peer-led initiatives promote explicitly medical approaches and rehabilitation, others oppose traditional treatment approaches, while still others emphasize the integration of traditional and alternative treatments (Anthony, 1993; Morrison, 2006). In more anti-traditional settings, consumers might be influenced by peers to refuse medications and disengage from providers in order to make their own autonomous choices. Although research on peer providers operating within traditional mental health settings (e.g., as part of an assertive community treatment team) has demonstrated positive effects on overall treatment engagement (Sells, Davidson, Jewell, Falzer, & Rowe, 2006; Sells, Black, Davidson, & Rowe, 2008), to our knowledge, only one study has explored the effects of participation in nonintegrated peer-led programs on medication adherence (Magura, Lauden, Mahmood, Rosenblum, & Knight, 2002). Theoretically, both increasing and decreasing engagement with traditional providers and treatments seem plausible outcomes. In addition, although the active ingredients of peer support with respect to improved well-being and recovery have received careful attention (Davidson, Bellamy, Guy, & Miller, 2012), the question of how peer-led interventions may affect the domains of medication use and provider relationships remains underexplored.

To investigate these questions, we conducted focus groups with peer facilitators and participants involved in peer-led WRAP programs. WRAP, typically involving 8- to 12-week classes geared towards developing individualized recovery and symptom self-management “plans,” was selected because of its emphasis on self-determination and positive reception among both consumer and survivor groups. Our goal was to better understand how WRAP might influence opinions about adherence and self-determination, medication use, and relationships with traditional providers and medication prescribers.

Method

A group of researchers and the steering committee of a statewide WRAP initiative constructed a focus group protocol examining “self-determination” and “adherence/compliance,” individuals’ experiences of participation in WRAP, and the impact of participation on medication use and relationships with traditional (non-peer) providers. The focus group protocol also queried participants about past treatment experiences, reasons individuals might reject or accept medications, and general factors contributing to engagement data which will be described in a separate article. The questions included in the current analysis are listed in Table 1. Fifty-four individuals were recruited from urban, suburban, and rural parts of Illinois for five focus groups; they were reimbursed $45 for participation and transportation.

Eligible participants needed (a) to self-identify as a consumer of mental health services and (b) to have participated in at least one full WRAP program. Although information on diagnosis, severity, and past treatment experiences were not formally collected, most participants volunteered details. Overall, focus groups represented a diverse mix of diagnoses, and the overwhelming majority of individuals described past hospitalizations as well as some form of longer-term institutional care (see Table 2).

| Table 1 |
| Focus Group Questions |

| Questions |
| What does adherence (or compliance) to treatment mean to you? What are positives and negatives to the idea of adherence? What does self-determination mean to you? Especially in terms of adherence (or compliance)? Tell me about WRAP? What is it? How does it work? How does WRAP influence your attitudes about adherence (or compliance)? Has WRAP empowered you to take ownership of your own recovery? In what way? Has WRAP changed the way you relate to your psychiatrist or medication prescriber? What about other service providers? |

Note. WRAP = Wellness Recovery Action Plan.

Open coding of focus group transcripts was followed by selective coding of emergent themes deemed relevant to the intersections outlined above (i.e., participant’s conceptual understanding of self-determination and adherence and their descriptions of WRAP’s impact on self-determination, provider relationships, and medication use). Theoretical codes were assigned after discussion among members of the core research team. To establish greater reliability, an independent coder, blind to previous discussions, recoded data. Differences were minor.

Results

We identified seven themes in our analysis, including three specific to participants’ conceptual understanding of self-determination and adherence/compliance, two that describe mechanisms mediating participation in WRAP and provider relationships, and two centered on the impact of WRAP with respect to these same variables. Table 3 provides an overview and brief examples of the themes.

Concept-Specific Themes

Unexpectedly, the vast majority of participants had never heard the term adherence. Even those who had heard of both compliance and adherence expressed little awareness that they were not simply synonymous terms. Consequently, we focused on participants’ reactions to compliance (rather than adherence) and self-determination. Overall, comments affirmed the divergent perspectives previously identified in the qualitative literature (Piat et al., 2009), with some individuals defending and others strongly criticizing compliance. A third set of responses emerged concerning ways in which compliance and self-determination might play out in complementary ways.

Self-determination and adherence/compliance are mutually opposed. Approximately half of the participants described self-determination and adherence/compliance as opposite in meaning. As one female participant put it, “with compliance you’re ordered to do something,” but with self-determination you “decide for yourself.” Others echoed this sentiment and referred to the term compliance as “prison-like,” “negative,” “intimidating,” and “incompatible with the recovery model.” As Susie explained:

I think that people having power over people is an oppressive model . . . that’s how I think about compliance. It doesn’t help people at all.
If people have already experienced trauma earlier in their life, or have been abused by someone with more power, then it doesn’t help them to heal.

Participants volunteered stories of years spent in state hospitals and group homes in which medication decisions and choices regarding food, activities, and romantic relationships were rigidly controlled by clinical staff. Many described providers’ compliance-focused attitudes as a source of personal devaluation. Self-determination and adherence/compliance can be complementary. Another group described self-determination and compliance as complementary, often suggesting a developmental relationship between the two. Several participants described a trajectory in which they had initially been “forced” to take medications (usually during a period of compromised insight), but eventually came to agree with the decision. Others noted a kind of give-and-take between external pressure to take medications and their own self-motivation.

If you are really wanting to move forward, you still put yourself under their [psychiatrist’s] authority, but it’s healthy because you’re actively agreeing. You’re going to be more compliant if you can own it. (Ellen) Others emphasized the usefulness of medication reminders and expectations that, in one participant’s words, “kept [him] on track,” particularly at times when they felt their understanding of their own best interests was compromised by psychosis or severe depression.

Compliance/adherence are sometimes necessary. A third group stressed the need for full-fledged compliance.

Some staff treat you like a child. But some people have to be treated like children because they just don’t get it. (Fred) Others emphasized their preference for following the orders of an “expert provider.” Alex insisted, “if you have a good primary who is your friend, they have the right to tell you what to do.”

In addition to such explicit comments, many participants spontaneously used “compliance” in positive ways: For example, “when I wasn’t compliant, I wasn’t doing well and would always end up back in the hospital. Now I’m totally compliant and staying out of the hospital.”

WRAP Mediating Themes

Prior to querying participants about the impact of WRAP on medication use and provider relationships, we asked about their...

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Participant Demographics</th>
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<tr>
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<td>WRAP facilitator</td>
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</table>

*Value is mean.

Note. Full data were not available for all participants in all categories. IQR = interquartile range; WRAP = Wellness Recovery Action Plan.

<table>
<thead>
<tr>
<th>Table 3</th>
<th>Themes and Examples</th>
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<tr>
<td>Category</td>
<td>Theme and subthemes</td>
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<tr>
<td>Conceptual</td>
<td>Self-determination and compliance contradictory complementary</td>
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<tr>
<td>Possible mechanisms mediating impact on medication use and provider relationships</td>
<td>Peers are different</td>
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<td></td>
<td>Self-determination Motivation</td>
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<td>Confidence/competence</td>
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<td>Enaction</td>
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<td>Impact on medication use and provider engagement</td>
<td>Self-advocacy</td>
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Note. WRAP = Wellness Recovery Action Plan.
perceptions of how WRAP more generally works. Three dominant
themes revolved around peer-led peer support, often linked
increases in self-determination, and increased awareness.

**Peers make a difference.** When asked about how WRAP
works, participants zeroed in on the role of peer support and
leadership as well as the explicitly nonhierarchical and empathic
nature of their relationships with WRAP peer facilitators.

When you find out the people running the group have the same issues
you have, it allows you to relate to them in a way you can’t with
people who don’t. It’s very different. Not hierarchical, not like normal
mental health treatment.

Another participant contrasted her experiences working with
providers and peers: “They [psychiatrists and professionals] don’t
respect me as an authority like WRAP does. They’re the authority,
and I don’t know anything—that’s how they think.” The reciproc-
ity and shared understanding with peers seems at odds with rela-
tionships with clinicians who they often perceived as unable to
both receive and reciprocate support. Others focused on the ben-
efits of peers’ experiential know-how. Hope and inspiration were
common themes. Cherie, a woman who had spent nearly a decade in a nursing home, emphasized how participation in WRAP had
inspired her to live independently for the first time in years. She
vowed that she would never work with non-peer professionals
again, insisting, “it’s only other consumer providers who really
know how to help.” Others described the extent to which relations-
ships with peer facilitators made them feel valued, in contrast to the
low expectations they felt professional providers often held.

Increased self-determination. Participants overwhelmingly
agreed that participation in WRAP increased their subjective sense of
self-determination, a variable that was often linked to their positive
experiences of peer leadership and support, and ultimately to the
increases in self-advocacy described in the final section. We divided
these comments into three complementary categories: (a) autonomous
or self-determined motivation; (b) increased confidence and self-
efficacy; and (c) behavioral enaction (or taking control and actually
doing things for oneself). With respect to the first category, partici-
ants emphasized WRAP facilitators’ expectation that participants
were personally responsible for their recovery. Of import, participants
felt that they were both expected to “take charge,” as one young
woman put it, and given the structured support to do so. The purpose
of WRAP, as another participant put it, is:

To focus on my own recovery rather than on what’s dictated by
professionals, and to take ownership for myself. In WRAP, people
help but no one is going to tell you what to do.

The individualized nature of WRAP prompted participants to
reflect on and pursue goals that were individually meaningful to
them. “WRAP gives you back your control,” John said, and, amid
a chorus of agreement, Loretta responded, “yes, because you’re
doing what you choose to do.” Similarly, another participant
described how prior to WRAP she often did not take medications
because she felt so externally controlled; the “decisions” she made
“didn’t really feel like [hers].” However, “now that [she has] a
choice,” she confided, she feels empowered to do what is best for
her, including taking medications when she thinks she needs them
rather than engaging in power struggles with her psychiatrist.

Regarding the second category, participants noted that WRAP
increased their confidence and belief in what they could accom-
plish. WRAP, Juan said, gave him the “strength to make better
choices,” while others reported that creating a WRAP plan made
them feel more like “[their] own doctor.” The nonhierarchical
structure of WRAP seemed a major contributor to these increases
in confidence and self-efficacy.

I made progress with WRAP because I’m coworking with it—my role
is equally important and valued. I’m in charge of my WRAP plan and
I’m the expert, not a professional who doesn’t even listen to me.
(Violet)

WRAP facilitators also noted the value of facilitating a group, a
role that, in some cases, marked the first time these individuals felt
they had something important to teach others. A few facilitators
emphasized that stepping into a role with higher expectations
helped them realize the full extent of what they were capable of.

Finaly, moving to behavioral enaction, many participants em-
phasized the extent to which they actively “used” WRAP plans
to change behavior patterns and negotiate relationships with
others. Participants emphasized changes they had made because of
WRAP—taking care of an apartment or exercising, for in-
stance—as well as using their personal coping strategies to relax.

Increased awareness. Focus group participants said WRAP
increased their awareness of triggers, warning signs, and behavior
patterns as well as medication use and the role of traditional providers
in their lives. WRAP also seemed to impact “insight” and acceptance
of illness or disability. For instance, Shelly described how she initially
refused to accept that anything was wrong with her, but through
participation in WRAP she felt compelled to introspect, write about
her symptoms, and thereby come to accept that she “has a disease and
it’s okay.” This recognition, in turn, led to a more positive attitude
toward medications. Another participant, Sue, agreed that WRAP
“gave [her] the ability to see through things [she] was denying.” In
some cases, this increased awareness centered even more directly on
medication use. Mark described increased awareness of the conse-
quences of stopping his medication, ultimately realizing that consist-
tently taking medications was in his best interests. Although aware-
ness of the perceived usefulness of medications was more common,
one participant successfully discontinued all medications as a result of
WRAP, while others decreased dosages or tapered off select medica-
tions. Finally, a number of focus group participants described in-
creased awareness of the role traditional providers played in their
lives, often as a result of writing the advance directive component of
their overarching WRAP plan.
You might have a support person or a counselor or PSR [psychosocial rehabilitation] facilitators or even a psychiatrist. That person has the education level to help you determine what you need to do, also friends and family. When you write a WRAP plan [with an advance directive], it really makes you think about others and what they do for you and how important they are. (Sonya)

Others noted it was not until they were forced to list (in their WRAP advanced directive) people they would want involved in a crisis situation that they realized what an important role both medications and prescribers played in their lives and treatment.

WRAP Impact on Engagement

Our final focus group question concerned perceptions of the impact of WRAP on medication use and/or provider engagement. Overwhelmingly, participants’ responses focused on increases in self-advocacy; apart from the impacts on medication use stemming from the three previous mediating themes, changes in medication appeared to be secondary to changes in relationships with prescribers and other providers.

Increased self-advocacy with providers. Although the majority of participants described some negative experiences with traditional mental health providers and settings in the past, participation in WRAP generally seemed to lead neither to conflict nor disengagement, but rather to more assertive interaction with clinicians, particularly psychiatrists and other prescribers. For a subgroup of participants, increases in assertiveness led to greater transparency and disclosure about actual medication use or nonuse and substance abuse. Betsy said:

If I try to explain what has been best for me [to psychiatrists], they still don’t understand. So I’ll change them [medications] around to where they work best for me without telling. But WRAP has made me more honest. I often still feel they don’t really understand, but I lie to them less than I did. Now I’m more assertive because of WRAP.

Similarly, a participant with substance abuse described how WRAP led him to disclose the full extent of his problems to his psychiatrist. Once he felt the confidence to make this clear to his psychiatrist, they could far more effectively collaborate on figuring out an effective medication regimen, and assess the possible role of drug interactions.

For other participants, greater assertiveness meant asking more questions, challenging decisions, and taking a more active role in treatment planning and medication decision-making. Participants in several of the focus groups independently described the change as a growing unwillingness to simply “sign on the dotted line” when a prescriber suggested a new medication or dose increase. Many individuals attributed this newfound assertiveness to increases in confidence. For instance, “You’re able to overcome that fear when you have to speak up for yourself,” Lamar told us, “I got a little bit of esteem from WRAP and that was able to help me speak up.” Others described themselves as “better able to explain” themselves, “less intimated,” and more “self-assured.” Although in some cases greater assertiveness led to confrontations (or, as Juan put it, becoming a “pain in the butt” to his psychiatrist), others emphasized their greater sense of “diplomacy”. “Now I’m assertive without being aggressive.” While overall medication “adherence” did not change for most participants, satisfaction with medication regimens seemed to increase. As previously mentioned, one participant described WRAP as having inspired her to honestly confront her psychiatrist and subsequently discontinue all medication use.

Discussion

Surprisingly few studies have investigated the impact of stand-alone peer-led interventions on medication use and engagement with prescribers and other traditional providers. The project reported here helps address this gap and raises important questions for future research. First, participants’ narratives replicate some of the tensions found in the broader literature (Piatt et al., 2009; Sibitz et al., 2011). Different groups of participants affirmed or sharply criticized the concept of compliance, with still others describing a more complicated developmental trajectory in which strong external motivations or influences (including coercion) were integrated with their own goals and values over time. Similarly, some participants described WRAP as increasing their awareness of the importance of medications, while others were inspired to discontinue medication use or decrease doses and even to disengage with professional treatment altogether.

Despite these differences, participants overwhelmingly affirmed the value of WRAP in boosting confidence and self-esteem, substantially increasing awareness of triggers and supports, facilitating development of sustained self-determination, and promoting greater self-advocacy with prescribers and other providers. Participants’ widespread acknowledgment of the importance of self-determination, seemingly a near-universal benefit of participation in WRAP, underscores the potential importance of further investigations of autonomy support and autonomous motivation with respect to engagement and behavior change (Deci & Ryan, 2000; Mancini, 2008). Finally, regardless of the medication and treatment decisions they ultimately made, narratives suggested high levels of commitment to personal recovery. WRAP thus appears to support development of a robust personal awareness of what does and does not work for a given individual, and the confidence to advocate for a treatment plan that aligns with these individualized goals, rather than a “mindless” carte blanche to do anything (Corrigan et al., 2012).

Participants’ comments and narratives also underscore not only the warmth and empathy of peer facilitators but also the value of non-hierarchical and egalitarian relationships more generally, a point repeatedly made by proponents of peer-led services (Davidson et al., 2012; Yanos, Primavera, & Knight, 2001). Thus participants attributed many of the positive changes described above to sustained interactions with peers who treated them as friends and experts, with whom they could reciprocate support, rather than ‘mere’ patients or passive service recipients (Ware, Hopper, Tugenberg, Dickey, & Fisher, 2008). Unsurprisingly, such sentiments were most strongly expressed by individuals whose lives were most saturated with hierarchical relationships; that is, participants living in group homes, state hospitals, or other institutional settings. These sentiments support findings of self-determination theorists who have posited a sense of interpersonal “relatedness” and emotional reciprocity as a fundamental human need (Ryan & La Guardia, 2000).

Several limitations that impact interpretations of our findings need to be addressed. First, the majority of participants were WRAP facilitators, and most others had participated in WRAP groups multiple times. Some participants underscored their perception that the changes they experienced only occurred after their third or fourth WRAP group. Impacts reported here thus reflect the
experiences of individuals with a high level of long-term investment and participation in WRAP, and may not generalize to consumers taking a single WRAP sequence. Second, although a few young adults participated in the focus groups, the majority were older middle-aged women. WRAP may function differently among young adults, given unique developmental issues, as well as the relative recency of first contact with the mental health system (Kaplan, Salzer, & Brusilovskiy, 2012). Likewise, members of different cultural groups may respond differently to WRAP, particularly members of collectivistic cultures that place less stress on autonomy and self-determination and more strongly value explicitly hierarchical relationships.

Overall, our research findings underscore the importance of further exploring both the tensions and the potential synergy between self-determination-oriented peer-led recovery interventions and traditional service engagement. Future research on medication use and health behavior change would benefit from investigating not only clinician—patient interactions or individual attitudes, but also the influences of consumer—peers and alternative mental health program participation and leadership. Participants’ stories also affirm the importance of acquiring a sense of meaningful personal expertise with respect to symptoms, medication choices, and treatment planning—perceived expertise that traditional mental health services often inadequately supports. Future investigations might assess the conditions under which “traditional” services can support not only greater autonomy but also this sense of socially and clinically valued “expertise by experience.”

References


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