Published in final edited form as:

Subst Use Misuse. 2016 July 28; 51(9): 1116–1129. doi:10.3109/10826084.2016.1160119.

Developing an Experiential Definition of Recovery: Participatory Research with Recovering Substance Abusers from Multiple Pathways

Thomasina J. Borkman^{1,2}, Aina Stunz¹, and Lee Ann Kaskutas^{1,3}

¹Alcohol Research Group, Public Health Institute, Emeryville, CA

²Department of Sociology and Anthropology, George Mason University, Fairfax, VA

³School of Public Health, University of California Berkeley, Berkeley, CA

Abstract

Background—The What is Recovery? (WIR) study identified specific elements of a recovery definition that people in substance abuse recovery from multiple pathways would endorse.

Objectives—To explain how participatory research contributed to the development of a comprehensive pool of items defining recovery; and to identify the commonality between the specific items endorsed by participants as defining recovery and the abstract components of recovery found in four important broad recovery definitions

Methods—A four-step, mixed-methods, iterative process was used to develop and pretest items (August 2010 to February 2012). Online survey recruitment (n=238) was done via email lists of individuals in recovery and electronic advertisements; 54 were selected for in-depth telephone interviews. Analyses using experientially-based and survey research criteria resulted in a revised item pool of 47 refined and specific items. The WIR items were matched with the components of four important definitions.

Results—Recovering participants (1) proposed and validated new items; (2) developed an alternative response category to the Likert; (3) suggested criteria for eliminating items irrelevant to recovery. The matching of WIR items with the components of important abstract definitions revealed extensive commonality.

Conclusions, importance—The WIR items define recovery as *ways of being*, as a growth and learning process involving internal values and self-awareness with moral dimensions. This is the first wide-scale research identifying specific items defining recovery, which can be used to guide service provision in Recovery-Oriented Systems of Care.

Keywords

recovery; quality of life; substance abuse; participatory research; Alcoholics Anonymous; experiential

INTRODUCTION

“Recovery” is a concept having both medical and mutual aid definitions. Within the alcohol and drug treatment field, it is usually equated with abstinence or with remission from substance use disorders (see, for instance, Babor et al., 1994; Dawson et al., 2005; Hasin et al., 2002; Laudet, 2007; White, 2012); however, there is an emerging consensus that this definition is too narrow, that recovery is more than just abstinence or remission. But what is it, exactly? The “What Is Recovery?” study addresses that question from the perspective of individuals in recovery. This paper reports on the item development phase (phase 1) of that study. A participatory research approach was used to insure that the viewpoints of individuals from diverse pathways (e.g., 12 step, treatment, self-changers) and types of recovery (abstinent or moderated use) were represented.

Existing definitions of recovery

In *mutual aid* groups, the concept of recovery began with Alcoholics Anonymous whose basic text stated that “To show other alcoholics precisely how we recovered is the purpose of this book” (1939). The book introduced an abstinence-oriented 12-step “program of recovery” (p.71) spiritual in nature and encompassing a new “way of living” (p.97). Recovery, a central concept for mutual aid groups, is often used to denote the entire process of help, services and support (see Borkman, 2008), although no specific definition of recovery is offered per se.

The mutual aid movement has grown and diversified beyond AA, to other 12-step addiction groups (e.g., Narcotics Anonymous), alternative mutual aid groups that arose in reaction against 12-step groups (e.g., Women for Sobriety) and faith-based alternatives (e.g., Christians in Recovery) among others (Kelly and White, 2012; White, 2006). Many recover through a variety of pathways other than mutual aid or professionally-based treatment (White et al., 2006). These include self-changers (also described as “natural recovery”) who address substance abuse through their own efforts (Sobell et al., 2000; Toneatto et al., 1999); many self-changers do not self-identify as being in recovery, but will agree that they used to have a problem with alcohol or drugs but don’t now. Types of recovery other than abstinence-based recovery are practiced in which medication (such as methadone) assists recovery, or when individuals moderate their alcohol and/or drug use. An important goal of the “What Is Recovery?” (WIR) project was to insure that recovery definitions from all major pathways and types of recovery were sought.

Recovery in the *medical* arena implies the end of a medically-directed course of diagnosis, treatment and rehabilitation. Forty-three years after publication of AA’s basic text, the American Society of Addiction Medicine (ASAM) issued a “public policy statement on the state of recovery” (American Society of Addiction Medicine, 1982), which stated that there is no cure from alcoholism, but there is a “state of recovery” when patients have “reached a state of physical and psychological health such that [their] abstinence from dependency-producing drugs is complete and comfortable.” Because there were and are no available instruments to assess the quality of remission, researchers have continued to conflate recovery with remission: A review of the methods sections of numerous articles on

“recovery” found that “recovery typically vanishes, to be replaced, without explanation, by abstinence,” or was based on years without a diagnosis (Laudet, 2007, p.245)

A major development in the evolution of recovery definitions was the formation of two expert panels of varied stakeholders that brought together the two arenas: recovering individuals with lived experience of resolving their substance abuse problems, and other recovery advocates; and scientific researchers, policymakers and treatment providers. Each expert panel developed consensus statements which acknowledged the breadth of recovery: as “a voluntarily maintained lifestyle characterized by sobriety, personal health, and citizenship” (The Betty Ford Institute Consensus Panel, 2007, p.222) (BFI); and as “a process of change through which an individual achieves abstinence and improved health, wellness and quality of life” (Center for Substance Abuse Treatment, 2007) (CSAT). Each expert panel identified other aspects in their definition—through proposed measures (BFI) or 12 guiding principles (CSAT). Both of these working definitions offered broad definitions that (like the AA and the ASAM definitions) lacked sufficient specificity to be used in substance abuse recovery research studies.

Convergence of existing definitions

Given the importance of these four organizations (AA, ASAM, BFI, CSAT) in the addictions arena, two issues regarding their abstract recovery definitions are especially relevant to any subsequent efforts to further specify how recovery is defined: How is recovery characterized overall by each definition? What are the broad components of recovery found in each definition? Table 1 presents these issues.

“How is recovery characterized?” As shown in Table 1, each definition characterized recovery overall in slightly different ways, as: A new “way of living” (AA), a voluntarily maintained lifestyle (BFI), a process of change (CSAT), or as a “state of recovery” (ASAM).

There is more consensus across the definitions regarding their broad components. All four organizations explicitly included “abstinence.” Contributing to “community” was mentioned by CSAT as “(re)building community in one’s life” and was implicitly connoted in the others; for example, a component of ASAM’s definition was “improvement in family relationships.” BFI defined “citizenship” as “living with regard and respect for those around you.” “Health” was explicitly listed in three of the four definitions (ASAM, BFI, and CSAT), but not specified by AA. “Quality of life,” explicitly mentioned by CSAT, was implied in an expansion of the BFI definition proposing the World Health Organization Quality Of Life instrument (The WHOQOL Group, 1998) be used as a starting point to operationalize/measure recovery. In contrast, “spirituality” was the component that only AA explicitly described. BFI implicitly included spirituality by including the WHO spirituality scales among those proposed for measuring recovery (The WHOQOL SRPB Group, 2002); the WHO scales would also categorize CSAT’s principle of “emerges from hope and gratitude” as spirituality.

These components were included either explicitly or implicitly by at least three (and often all) of the organizations’ definitions of recovery. Care was taken to consider these components throughout the “What Is Recovery?” item development phase.

Objectives

Only the BFI expert panel recommended a starting point for how to measure the elements of recovery. The panel suggested that the World Health Organization Quality of Life (WHOQOL) instruments (The WHOQOL Group, 1998) and WHO Spirituality/Religion/Personal Beliefs (WHO-SRPB) instruments (The WHOQOL SRPB Group, 2002) could be used to measure some aspects of recovery, at the same time acknowledging that no single instrument exists to “adequately measure” all elements (The Betty Ford Institute Consensus Panel, 2007, p. 225). Our “What Is Recovery?” study took on the challenge of developing this instrument, which began with the item development (phase 1) reported here. The final (phase 2) results are described (Subbaraman et al., 2015) and (Kaskutas et al., 2014) and summarized on the study website <http://www.WhatIsRecovery.org>. The objectives of this paper are to describe the participatory research approach used to develop items appropriate for the phase 2 web-based survey; and to identify commonalities between specific items endorsed by individuals in recovery and abstract components (and characterizations) of dominant definitions.

Participatory Research Approach

Participatory research, a relatively recent but increasingly used methodological approach, was developed in the social sciences to increase the viewpoints and decision making of “subjects” or participants in research—in order to explore and uncover new areas about which little is known and/or to develop more nuanced research. Originally developed to deal with research in developing countries with huge cultural differences unknown to researchers and with populations suspicious of the motives of Western researchers (Green and Mercer, 2001), more recently participatory action research (PAR) or participatory research (PR) has been used in community psychology, sociology and other social sciences to study self-help groups (Borkman and Schubert, 1994; Chesler, 1991), minority groups (Green and Mercer, 2001; Le et al., 2011), and community health (Jason et al., 2004)

A frequently raised issue in PR is the extent of involvement and power of participants to affect decision-making in the research (Jason et al., 2004). In WIR, the involvement and power of recovering participants was unusually extensive, involving two kinds of recovering participants: (1) anonymous study staff with extensive research experience and doctoral degrees in statistics, public health or social science; and (2) acquaintances, convenience samples and respondents recruited through the internet who completed surveys/interviews. The PR approach focuses a spotlight on recovering participants’ contributions and highlights the innovation that occurred because of them.

METHODS

Item development involved a four-step, mixed methods process over 19 months (August 2010 to February 2012). The steps, and the contributions made in each step by participants from different pathways and types of recovery, are summarized in Table 2.

Briefly, in *step 1*, original items were identified by people in recovery, the WHO scales were evaluated, and pretest questionnaires using Likert response categories were rejected. By the

end of step 1, 167 items had been identified and new response categories devised. In *step 2*, those items were piloted in a web-based survey with a larger sample (n=238). In *step 3*, occurring simultaneously with step 2, individuals from the online survey representing the above diversity or with outlier responses (n=54) were selected for customized telephone interviews. In *step 4*, the results were analyzed in depth. New criteria for accepting/rejecting items that define recovery were identified from respondents. The 167 items were reduced and refined to a final 47.

Item Development Process

Step one – Initial item development—Preliminary items that define recovery were sought from three primary sources:

1. Individuals in recovery. Beginning with staff and colleagues we knew in recovery (n=12) we solicited their ideas of how they defined recovery and used them to informally pre-test preliminary survey versions; other recovering individuals were identified through snowball sampling (n=30) who pre-tested preliminary surveys and were interviewed. The findings of two small studies querying people in recovery were considered (Abt Associates Inc. and Heart Research Associates, 2010; Laudet, 2007). Items derived from these statements were crafted and shown to individuals for feedback, resulting in a starting bank of items. Researchers who developed the items based on this feedback included people in alcohol/drug recovery as well as research experts in alcohol and drug treatment.
2. Based on a content analysis of the primary text of Alcoholics Anonymous, we operationalized the “promises” articulated there, (Alcoholics Anonymous, 1939, pp. 83–84) which foreshadow what can be expected in recovery. We also developed items based on 12-step principles, taking care to minimize 12-step terminology that could be offensive to individuals from other pathways or types of recovery.
3. World Health Organization Quality of Life items (WHOQOL) (The WHOQOL Group, 1998; WHO-QOL Group, 2005) and the WHO Spirituality/Religion/Personal Beliefs (WHO-SRPB) instruments (The WHOQOL SRPB Group, 2002; The WHOQOL SRPB Group, 2006). The WHOQOL asks for self-reports of past 4-week functioning in six domains: physical health, psychological health, level of independence, social relationships, environment, and spirituality/religion/personal beliefs. These domains are organized into what the WHOQOL refers to as facets (topics) (The WHOQOL Group, 1998). Multiple respondents suggested that the items needed to be reframed relative to the period of substance use (e.g., *being able to enjoy life without alcohol or drugs as before*). We also learned that terms were needed that would work for those in recovery who were spiritual but not religious, were explicitly religious, or were atheists.

In addition, two domains specific to substance abuse recovery were added: abstinence and the recovery process. The abstinence items are about the use of alcohol, drugs, and tobacco. The recovery process includes items such as a *lifestyle change* or an *ongoing process*.

Iterative process of developing and pretesting: As we began the process of developing, pretesting, and refining items, we created a constant, repetitive, but informal feedback loop of subjecting proposed items to evaluation by people in personal recovery and by scientific colleagues knowledgeable about measurement and substance abuse treatment research; refining and pretesting items, again and again. In the iterative process, we ultimately returned only to recovering individuals because items suggested by non-recovering individuals were often rejected by people in recovery as irrelevant or inappropriate; a good example of this is “not lying to my family about where I am going.” A total of 167 items (see Appendix) were developed through these means.

Decisions about Response Categories: The recovering individuals’ ideas about response categories for the survey questions were critical. They, in effect, rejected the standard and widely validated five point Likert Scale used in the WHOQOL instruments. Respondents with extensive exposure to 12-step meetings were simply not able to follow the explicit directions: “The next questions cover many different topics that people might include in their definition of recovery. We want to know which ones you would include in YOUR definition of recovery.” After intensive de-briefing with such individuals, we came to understand that they were both unwilling and not able to isolate their definition from a wider, more inclusive definition of recovery that they knew (from meetings or from interactions with others in recovery) was a valid definition—even though not relevant for them. In extensive consultation with the WIR study advisors and statisticians, trying different instructions, testing the work-around (not applicable), the following response categories were tested in the online survey:

- Definitely belongs in your definition of recovery
- Somewhat belongs in your definition of recovery
- Does not belong in your definition of recovery, but may belong in other people’s definition of recovery. Use this category for items that don’t belong in your definition but that you believe may belong in others’ definition and are appropriate to include in a definition of recovery as you see it
- Does not really belong in any definition of recovery. Use this last category for items you feel do not really belong in the definition of recovery, regardless of whether others might think it does belong.

In phase 1 telephone interviews, respondents overwhelmingly (86%) preferred the new response categories to the Likert scale. These answer categories were retained for the phase 2 survey.

Step Two – Phase 1 online survey—The 167 items were programed using SurveyGizmo and put on the web for intensive pre-testing, available from April 2011 to October 2011. The pre-test online survey was organized into 19 facets. Each facet ended

with an open-ended question: “Is there anything that you would ADD or CHANGE to better capture [name of facet—e.g., sexual activity or wholeness] in your definition of recovery? If yes, what would you add?” Because the large number of items (167) would result in an online survey of 50–60 minutes, items were distributed across two survey versions and rotated after approximately 50 people had completed each version.

The study and consent forms were approved by the Institutional Review Board of the Public Health Institute, Oakland, California. Informed consent for an anonymous survey was obtained at the beginning (no reimbursement). A second consent form at the end of the survey asked for contact information of individuals willing to be selected for a telephone interview, (\$25 e-gift card for a completed interview); a protocol for protecting confidentiality was described.

Recruiting a diversified sample: We increased the number and diversity of those in recovery (e.g., no treatment, self-changers) for additional pre-testing. We wanted to insure, which we did, that we had a broad spectrum of SES levels, gender, age, race, as well as various lengths of time in recovery and types of recovery (especially those defining recovery in terms of moderate use or limited use). We had to develop innovative ways to find these people.

We first recruited random samples through emailing alumni (n=72) from six treatment and recovery programs that were research partners. Next, recruitment advertisements were placed on Craigslist. To attract self-changers who do not use recovery terms to define themselves, some ads used language like “have you successfully overcome an alcohol or drug problem”...“without treatment” and/or “without using a 12-step group”. Purposive sampling of other recovery organizations were deliberately sought to obtain the viewpoints of those in medication-assisted recovery (National Association for Medication Assisted Recovery) and religious recovery (National Association of Christian Recovery). Responses were continuously monitored and selection of participants adjusted to ensure adequate diversity.

As shown in Table 3, the sample (n=238) was demographically diverse in racial/ethnic terms (35% minorities), gender (52% female) and age (27% ages 18–35 and 69% ages 36–65). The survey included participants with diverse pathways, lengths of recovery (<1 to more than 20 years), and self-definition (the majority viewed themselves “in recovery” or “recovered” (75%), “used to have a problem but don’t now” (13%) or “medication-assisted recovery (2%). The sample tended to be highly educated as only 16% had a high school education or less.

Step Three – In-depth telephone interviews—The telephone interviews were conducted concurrently with the survey. Among survey participants who had consented to be interviewed, those who were selected (n=54) represented diverse answers to the survey and ensured representation of the sample groupings. We wanted at least five interviewees in each of the major racial/ethnic groups and reached six Hispanics, nine African Americans, and five Native Americans. The telephone sample reached a broad spectrum of recovery

pathways and definitions, including some in non-abstinent recovery (eight were still drinking and four were still using drugs) and untreated individuals (n=15).

Each qualitative interview was customized based on the respondent's survey responses to elicit information typically asked in pre-tests, to probe answers to open-ended questions that suggested new ideas about the topic, to outlier responses to various items defining recovery and inconsistent patterns of responses to similar survey items. Participants were contacted by the interviewer and read the consent form confirming confidentiality; verbal consent was given; at the completion of the interview, the interviewer confirmed email contact information in order to send the e-gift card \$25.00 reimbursement.

Step Four – Analysis to reduce/refine items—Extensive quantitative and qualitative analyses were conducted with special attention to preserving the content and wording preferences of items endorsed by various pathways, types of recovery, and demographic categories.

Quantitative analyses: The distribution of the survey responses for all combinations of the four response categories was examined; the final quantitative criteria for the response distributions focused on: 1) extreme responses: Did more than 70% of the sample say than an item “definitely belongs” in their definition? If so, the item was flagged for possible inclusion. Did more than 10% say an item “did not belong” in any definition of recovery? If so, it was flagged for deletion. However, items were retained that were key to certain subgroupings (e.g., non-abstainers, self-changers). We looked carefully at items where even 5% of the sample said “it did not belong” because the bias of the survey was toward positive reaction; 2) for similar items with different wordings, the item receiving the greater endorsement was retained.

Qualitative analyses: The interviewees identified items or wording that were misinterpreted, offensive, or for whom the meaning was unknown (e.g., some with a high school education or less did not know the meaning of “abstinence” so the wording was changed to “not using”). New criteria emerged from the respondents ensuring an item would apply to a wide range of socioeconomic conditions, lengths of recovery and not be too “saintly”—avoiding a too high a bar of perfection (e.g., *having tools to try to feel peace when I need to* was chosen instead of *having inner peace*). Participants also suggested additional criteria that researchers had not considered. Repeatedly, respondents would dismiss an item as irrelevant to recovery because they were simply aspects of daily living or of being a human being, not of recovery (e.g., many of the WHOQOL items such as *being able to perform activities of daily life* or *making sure I eat and don't skip meals*).

- “Well, I can't really answer that. That has nothing to do with recovery but has to do with being a person.”

Applying the criteria allowed elimination of some items, improved re-wording and formulation of new items to consider. The iterative process was applied to the entire survey instrument, increasing the complexity because we were dealing with duplication of concepts across 19 facets.

In addition to syntactical considerations, we wanted to ensure that individuals from diverse pathways and current substance use would react differently to some items than the aggregated sample, especially to three facets: abstinence, recovery process and spirituality/religion. This resulted in new or reworded items. For abstinence: non-abstainers (*non-problematic alcohol or drug use*); medication-assisted recovery (*no abuse of prescribed medication*); moderate users (separating alcohol and drug use). For the spirituality/religion/personal beliefs facet, we designed new or modified items that appealed to: Christians and other religious people (*religious in nature*); those who reject spirituality/religion (*physical and mental in nature and has nothing to do with spirituality or religion*); or, everyone (*developing inner strength*). Almost all items having to do with daily living, energy, sex, work, physical environment, financial and legal issues were eliminated because respondents said they were not relevant to recovery and/or they had very low endorsement. In the end, the overall item reduction resulted in a pool of 47 items, most of which had been re-worded.

“Matching” WIR items and dominant definitions—Next, we examined how the specific recovery elements that resulted from the above effort related to the five components of the broad recovery definitions offered by AA, ASAM, BFI, and CSAT and to their characterization of recovery (Table 4). A protocol was developed to guide the assignment of items, which considered the specific examples and verbiage included in definitions, as well as dictionary and WHO definitions for abstinence, health, quality of life, spirituality and community.

According to this protocol, any item referring specifically to substance use was classified under the “abstinence” aspect. Items pertaining to physical and mental well-being, to cognition, to emotions, and to self-assessment, etc., were considered as various specific operationalizations of the “health” construct. Items were assigned to the “quality of life” category if they closely mirrored WHOQOL items or the spirit of the item(s). Items that were considered as best belonging to the “spiritual” construct were those that explicitly mentioned spirituality or were of an existential nature. An item was grouped under the community aspect when it referred to societal considerations (including civic, family, etc.). When WIR items could reasonably be interpreted as falling into more than one of these five aspects, they were assigned to multiple categories.

RESULTS

Our 19-month, 4-step item development process resulted in 47 items; Table 4 presents the results of the matching of the items with key components and characterization of recovery.

The *abstinence* aspect of recovery was reflected in ten WIR items. Three of these specifically refer to abstinence—from alcohol, non-prescribed drugs, and tobacco. Two others pertain to harm reduction: *no abuse of prescribed medication* and *non-problematic alcohol or drug use*. Several items placed in the abstinence category refer explicitly to the challenges inherent in either abstinence or harm reduction approaches: *handling negative feelings/being able to enjoy life ... without using drugs or drinking like I used to*. Two others represent the flip side of these challenges: *freedom from feeling physically sick* and *freedom from always wanting a drink or drug*; these were also classified under the health construct.

Several items also included under the health category deal explicitly with health; i.e., *taking care of my physical and mental health more than more than I did before*. Others address improvement in mental processes (*changing the way I think through things; reacting in a more balanced way*); self-assessment (*improved self esteem; being honest with myself*); taking responsibility (also of relevance to community); and resilience (*developing inner strength*), also considered to be spiritual.

Only three WIR items were matched to the *quality of life* (QOL) aspect: *being able to enjoy life without drinking or using drugs like I used to* (also relevant to abstinence and health); *trying to live in a place that is not overrun with alcohol or drugs*; and *a lifestyle change*. We narrowly defined QOL as it was articulated in the WHOQOL scales; alternative perspectives or measures of QOL would result in classifying many more of the “WIR” items as QOL.

Items that were classified under *spirituality* pertain to gratitude, open-mindedness about spirituality, giving back and helping others, and having tools and connections to feel peaceful, deal with difficulties, and feel “part of something bigger than me” (which also pertains to community). These also touch on the nature of recovery as being spiritual, religious, or physical and mental.

Fourteen items were classified as relevant to *community*. Several are about relationships, such as *being someone people can count on*. Others are support-related, such as *having people around who don’t use/drink*. Community items reflect civic and communal values, such as *dealing with mistakes*, and *living a life that contributes in some way, etc.*

In the assignment process, it became evident that another category was required (final column in Table 4): characterizations of recovery *overall*, i.e., a process, a way of living. Four items fell here: *recovery is a process of growth and development*; *recovery is an ongoing process*; *recovery is more than “just” not drinking or using drugs like I used to*; and *recovery is a lifestyle change* (the latter was also placed in the quality of life aspect).

Discussion

Value of participatory research in defining recovery

The participatory research approach proved to be a useful way to frame the item development phase of the study, as it highlights the significant ways that the study differed from conventional research. For example, having the experiential perspective of the recovering participants was very productive in yielding many specific elements to operationalize the abstract components of the AA, ASAM, BFI and ASAM definitions of recovery. Sharing extensive control of the item development design, pretest, and redesign phases with recovering substance abusers led to four significant methodological differences: (1) many items for the survey were developed by and/or vetted by recovering participants who extensively rejected the WHO-QOL items, even in modified form, and who contributed new items; (2) the conventional Likert scale was rejected in favor of a more workable response category capturing the communal aspect of recovery—many recover in networks and communities of likeminded people—as well as awareness of (and tolerance for) different beliefs about recovery that many hold; (3) new criteria relevant to recovery

emerged from recovering participants who rejected the daily living items of the WHO-QOL scales, telling us repeatedly that they applied to normal living and to being a human being, but not to the special process of recovery; and (4) the participatory research approach tapped internal dimensions of abstract components of recovery definitions that were in-depth, subtle, and with very specific morality (e.g., *being able to have relationships where I am not using people or being used*).

The WHOQOL scales recommended by the Betty Ford Institute expert panel as a way of measuring recovery were found to be limited. However, had we not considered the WHOQOL scales, we would not have had empirical evidence that uncovered this important point, which is of high relevance to recovery research and which we believe has not been reported elsewhere.

Convergence of definitions

The 47 items developed in the “What Is recovery?” study fell within all of the components and characterizations represented by the four dominant definitions. All definitions reflect the view that recovery is more than simply addressing one’s alcohol and/or drug consumption (be it through abstinence or non-problematic use). While all of the abstract definitions imply qualities pertaining to moral values and character, only the WIR items specifically detail character and moral values that together represent a new “way of being” that is supportive of life without substance abuse.

It is encouraging that there is such high convergence between the elements of recovery developed in the WIR project and the broad components of recovery in the dominant definitions. It is our hope that the specific items can be used in many arenas, including treatment programs and recovery-oriented systems of care (to guide and evaluate service delivery) as well as family members, individuals with substance abuse problems, and policymakers (to demonstrate the specific positive ways of being that recovery represents).

Breadth of what constitutes recovery

The WIR items developed in participatory research with people in recovery reflect a learning process of growth and development, and involve internal values, self-awareness, and moral dimensions. This is different from the externally-identifiable functional problems of major living that clinicians face with their patients or that researchers measure. The way(s) of being articulated by WIR definitions of recovery reflect a “process” imagery: a self-realization model *towards* becoming a self-aware, responsible, moral and more fully realized human being. This is nowhere better exemplified than by the WIR item *striving to be consistent with my beliefs and values in activities that take up the major part of my time and energy*. The WIR imagery implies that the *functionality* of concern to professional clinicians and researchers—that is, the abstinent, employed person with appropriate living space and constructive relationships with others, who takes care of his/her physical, mental, and existential health—will become realized from the “way of being” expressed in the WIR items that define recovery. These items also exemplify for the field a number of specific ways that substance abuse differs from other chronic diseases such as diabetes. Importantly, they demonstrate why recovery should not be defined as remission (per the Diagnostic and

Statistical Manual/DSM-IV) or as a lessening of problems (per the Addiction Severity Index (McLellan et al., 2006))—nor, as mentioned above, as quality of life per se.

Limitations

The “What Is Recovery?” study has limitations arising from our reliance on individuals who can use the internet. For example, such studies often have a bias toward higher-educated participants (Zickuhr and Smith, 2012) and have fewer racial minority representatives. We tried to counter this concern by reaching out to specific groups in recovery (e.g., Univision Television, and Detroit Recovery Project) but more research is needed on ways to reach study participants without sole reliance on the internet.

Acknowledgments

This study was funded by a grant from NIH (R01 AA017954). Authors would like to acknowledge the support of our formal and informal research partners, our 243 item development phase participants, and our advisors.

References

- Abt Associates Inc., Heart Research Associates. Pathways to healing and recovery: perspectives from individuals with histories of alcohol and other drug problems. Substance Abuse and Mental Health Services Association; Rockville, MD: 2010. p. 35 Archived by WebCite® at <http://www.webcitation.org/6IKraUdHd> [Accessed: 2013-07-23]
- Alcoholics Anonymous. Alcoholics Anonymous: The story of how many thousands of men and women have recovered from alcoholism. 1. The Works Publishing Company; New York: 1939.
- American Society of Addiction Medicine. Public Policy Statement on the State of Recovery. Chevy Chase, MD: 1982. p. 2 Archived by WebCite® at <http://www.webcitation.org/6IKsAZDzs> [Accessed: 2013-07-23]
- Babor TF, Longabaugh R, Zweben A, Fuller RK, Stout RL, Anton RF, Randall CL. Issues in the definition and measurement of drinking outcomes in alcoholism treatment research. *J Stud Alcohol*. 1994; 12(Suppl 12):101–111.
- Borkman, T. The twelve step recovery model of AA: a voluntary mutual help association. In: Galanter, M.; Kaskutas, LA., editors. *Research on Alcoholics Anonymous and Spirituality in Addiction Recovery*. Vol. 18. Springer; New York: 2008. p. 9–35.
- Borkman T, Schubert M. Participatory action research as an approach to studying self-help groups cross-culturally. *Prevention in Human Services*. 1994; 11(1):45–68.
- Center for Substance Abuse Treatment. National Summit on Recovery: Conference Report. Substance Abuse and Mental Health Services Administration; Rockville, MD: 2007. p. 114 DHHS Publication No. (SMA) 07-4276 Archived by WebCite® at <http://www.webcitation.org/6IML7OyMP> [Accessed: 2013-07-24]
- Chesler MA. Participatory action research with self-help groups: an alternative paradigm for inquiry and action. *Am J Community Psychol*. 1991; 19(5):757–768. [PubMed: 1763787]
- Dawson DA, Grant BF, Stinson FS, Chou PS, Huang B, Ruan WJ. Recovery from DSM-IV alcohol dependence: United States, 2001–2002. *Addiction*. 2005; 100(3):281–292. [PubMed: 15733237]
- Green LW, Mercer SL. Can public health researchers and agencies reconcile the push from funding bodies and the pull from communities? *Am J Public Health*. 2001; 91(12):1926–1929. [PubMed: 11726367]
- Hasin D, Liu X, Nunes E, McCloud S, Samet S, Endicott J. Effects of major depression on remission and relapse of substance dependence. *Arch Gen Psychiatry*. 2002; 59(4):375–380. [PubMed: 11926938]
- Jason, LA.; Key, CB.; Suarez-Balcazar, Y.; Taylor, RR.; Davis, MI., editors. *Participatory Community Research: Theories and methods in action*. American Psychological Association; Washington, DC: 2004.

- Kaskutas LA, Borkman T, Laudet A, Ritter LA, Witbrodt J, Subbaraman M, Stunz A, Bond J. Elements that define recovery: the experiential perspective. *J Stud Alcohol Drugs*. 2014; 75(6): 999–1010. [PubMed: 25343658]
- Kelly JF, White WL. Broadening the base of addiction mutual-help organizations. *Journal of Groups in Addiction and Recovery*. 2012; 7(2–4):82–101.
- Laudet AB. What does recovery mean to you? Lessons from the recovery experience for research and practice. *J Subst Abuse Treat*. 2007; 33(3):243–256. [PubMed: 17889296]
- Le TN, Arifuku I, Vuong L, Tran G, Lustig DF, Zimring F. Community mobilization and community-based participatory research to prevent youth violence among Asian and immigrant populations. *Am J Community Psychol*. 2011; 48(1–2):77–88. [PubMed: 21210205]
- McLellan AT, Cacciola JC, Alterman AI, Rikoon SH, Carise D. The Addiction Severity Index at 25: origins, contributions and transitions. *Am J Addict*. 2006; 15(2):113–124. [PubMed: 16595348]
- Sobell LC, Ellingstad TP, Sobell MB. Natural recovery from alcohol and drug problems: methodological review of the research with suggestions for future directions. *Addiction*. 2000; 95(5):749–764. [PubMed: 10885050]
- Subbaraman MS, Laudet AB, Ritter LA, Stunz A, Kaskutas LA. Multi-source recruitment strategies for advancing addiction recovery research beyond treated samples. *J Community Psychol*. 2015; 43(5):560–575. [PubMed: 26166909]
- The Betty Ford Institute Consensus Panel. What is recovery? A working definition from the Betty Ford Institute. *J Subst Abuse Treat*. 2007; 33(3):221–228. [PubMed: 17889294]
- The WHOQOL Group. The World Health Organization quality of life assessment (WHOQOL): development and general psychometric properties. *Soc Sci Med*. 1998; 46(12):1569–1585. [PubMed: 9672396]
- The WHOQOL SRPB Group. WHOQOL Spirituality, Religiousness and Personal Beliefs (SRPB) field-test instrument. Department of Mental Health and Substance Dependence, World Health Organization; Geneva, Switzerland: 2002. p. 25 Archived by WebCite® at <http://www.webcitation.org/6bt9R8VEE> [Accessed: 2015-09-28]
- The WHOQOL SRPB Group. A cross-cultural study of spirituality, religion, and personal beliefs as components of quality of life. *Soc Sci Med*. 2006; 62(6):1486–1497. [PubMed: 16168541]
- Toneatto T, Sobell LC, Sobell MB, Rubel E. Natural recovery from cocaine dependence. *Psychol Addict Behav*. 1999; 13(4):259–268.
- White, WL. Let's Go Make Some History: Chronicles of the new addiction recovery advocacy movement. Johnson Institute Foundation; Washington, DC: 2006.
- White, WL. Recovery/Remission from Substance Use Disorders: An analysis of reported outcomes in 415 scientific reports, 1868–2011. Philadelphia Department of Behavioral Health and Intellectual disAbility Services, Great Lakes Addiction Technology Transfer Center (GLATTC); Philadelphia, PA: 2012. p. 159 Archived by WebCite® at <http://www.webcitation.org/6HzYwoUHz> [Accessed: 2013-07-09]
- White, WL.; Kurtz, E.; Sanders, M., editors. Recovery Management. Great Lakes Addiction Technology Transfer Center (ATTC) Network; Chicago, IL: 2006.
- WHO-QOL Group. US Version WHOQOL-100 and Importance Items User's Manual and Interpretation Guide. The World Health Organization and the University of Washington, Seattle; Seattle, WA: 2005.
- Zickuhr, K.; Smith, A. Digital Differences: Internet adoption over time. Pew Internet & American Life Project; Washington, DC: 2012. Archived by WebCite® at <http://www.webcitation.org/6HzK7wlzK> [Accessed: 2013-07-09]

Appendix: Items used in phase 1 survey - 167 items in facet order

Abstinence

- 1 Abstinence from alcohol and non-prescribed drugs

2 Abstinence from alcohol, from non-prescribed drugs, and from tobacco

3 Not replacing one addiction with another (like gambling)

4 Having a healthy fear of drinking again

5 Something that can only happen once you're abstinent

Positive Feelings

6 A second chance at a better life

7 Being able to feel content without help from alcohol or drugs

8 Being able to be happy without having a drink of a drug

9 Fully realizing that my life is better without alcohol or drugs than it ever was with it

10 A sense of hope

11 Appreciating the positive things in my life

12 Realizing that being optimistic improves the quality of my life

13 Accepting the things I cannot change without letting them devastate me

14 Recognizing which things in my life I can change and which things I cannot change

Thinking

15 Being aware of what is happening in my life

16 Being present for my life ("showing up")

17 Being able to live in the moment

18 Living in the present

19 Being able to make thoughtful choices

20 Being able to think (more) clearly

21 Addressing damage I did when drinking and using drugs

22 Taking responsibility for my decisions.

23 Taking responsibility for my actions.

24 Being honest with myself.

25 Being honest with others.

26 Not being so wrapped-up in the past or the future that I miss the here-and-now.

27 Being able to deal with things that used to stump me.

28 Wanting to be informed and educated and learning how to go about it.

Self-Esteem

29 Appreciating my abilities

30 Appreciating the person that I am.

31 Knowing I have value to others and to the world

32 Appreciating what I have accomplished in getting clean and sober

33 Not hating myself so much like I used to

34 Learning to love myself

35 A realistic appraisal of my abilities and my limitations

36 Increased self-awareness

37 Tending to my appearance

38 Accepting my body, "warts and all"

Negative Feelings

39 Learning that we all have bad spells, but it's how you handle it that makes the difference

40 Dealing with negative feelings or depression without using drugs or drinking

- 41 Being able to do what I have to do even on days when I feel negative or depressed
42 Learning not to let worries consume me
43 Not giving into the impulse to feel sorry for myself so much
44 Realizing that I hurt myself when I am resentful

Inner Peace

- 45 Having tools to try to feel peace when I need to
46 Being able to feel peace when I need to
47 Having inner peace
48 Freedom from always wanting a drink or drug
49 Having spiritual strength to get through difficult times
50 Feeling inner spiritual strength

Recovery Process

- 51 More than just abstinence, it is a process of growth and development
52 More than just abstinence, it is having a program to live by
53 Having more choices in life because I am not a slave to addiction
54 Setting constructive goals
55 A continuous process that never ends
56 A lifestyle change

Daily Living

- 57 Being able to perform the activities of daily life
58 Taking responsibility for keeping-up the housekeeping and similar chores
59 Making sure I eat and don't skip means a lot
60 Taking care of my pets
61 Taking responsibility as a parent to protect and care for my children
62 Being able to relax and enjoy myself clean and sober
63 Being able to have fun and enjoy life without getting high
64 Expanding my leisure activities

Working

- 65 Having work that is consistent with my beliefs and values
66 Being able to get along with co-workers
67 Being able to hold down a job

Health

- 68 Dealing with pain and discomfort without drinking or using non-prescribed drugs
69 Not relying on unprescribed drugs or alcohol when I am hurting emotionally
70 Not having all the aches and the sick feeling I had constantly because of my drinking or using
71 Taking medicine the doctor prescribes, the way it was prescribed
72 Not trying to "con" the doctor to prescribe drugs
73 Getting the medical care I need to be as healthy as is possible for me, all things considered
74 Freedom from thinking about drinking or using drugs all the time
75 Getting the mental health care I need
76 Showing up and cooperating with social and welfare services to get the help I need
77 Following the doctor's orders and taking medication as prescribed instead of deciding I know better
78 Recognizing the medical and dental care I need and trying to get those services

- 79 About recognizing when I really need help from social and welfare services versus when I can make it on my own steam

Energy

- 80 Having enough energy for everyday life without feeling rundown all the time from drinking or drug use
- 81 Taking responsibility for how busy I get and for all the things I commit to
- 82 Making sure I do not run myself ragged
- 83 Not giving-in to the tendency to just sit around a lot of the time
- 84 Recognizing when I am tired and need to take a break or rest
- 85 Taking responsibility for getting the sleep and rest that I need
- 86 Accepting that it is hard for me to sleep, at least sometimes, and figuring out how to deal with that without drinking or using drugs
- 87 Trying other ways to help me sleep besides taking sleeping pills, other drugs or alcohol

Spirituality or Religion

- 88 Spiritual in nature, and has nothing to do with religion
- 89 Having personal beliefs about a higher power that give meaning to one's life
- 90 Having faith in a higher power
- 91 Having religious beliefs that give meaning to one's life
- 92 Having faith in God
- 93 Having personal beliefs about a higher power that give me the strength to deal with difficulties in life
- 94 Having religious beliefs that give me the strength to deal with difficulties in life
- 95 Being able to rely on the knowledge that there's something greater than me
- 96 Drawing comfort from the knowledge that I am part of the whole of humanity, something so much greater than I am
- 97 Spiritual strength and guidance derived solely from the shared experiences of others in recovery
- 98 A spiritual path derived solely from the shared experiences of others in recovery
- 99 Feeling connected to a spiritual being or force that helps me to make sense of, and to accept, what happens to me and to others
- 100 Having a connection to a spiritual being or force to provide me with comfort or reassurance
- 101 Feeling connected to a higher power that helps me to make sense of, and to accept, what happens to me and to others
- 102 Having a connection to a higher power to provide me with comfort or reassurance
- 103 Being able to tell my problems to, and seek guidance from, a power greater than myself

Relationships

- 104 Having satisfying personal relationships
- 105 The capacity to develop satisfying personal relationships
- 106 Addressing damage I did when drinking and using drugs
- 107 Changing my social network
- 108 Making responsibility for my part of satisfying personal relationships
- 109 Having healthy personal relationships
- 110 Not putting myself first all the time
- 111 Making healthy personal relationships a priority in my life
- 112 Being able to have relationships where I am not using people

Social Support

- 113 Learning how to get the kind of support from others I need
- 114 Creating a "family" from supportive friends in recovery

- 115 Having the kind of friends you can count on when you need them
116 Being there for others
117 Being the kind of person that people can count on
118 Putting healthy boundaries on how much I help others
119 Making myself available to help family and friends even when its inconvenient to me
120 Having people to help me get back on track when I am tempted to go back to my old ways
121 Placing limits on how much help I ask for so as not to be a burden
122 Realizing I can't do it alone, and that I don't have to do it alone
123 Having people around me who know how to get through life without drinking
124 Being in a community of other people who share how they get through life without drinking and using drugs

Sex

- 125 Having my sexual needs fulfilled but not at the expense of my partner
126 Being satisfied with our sex life, my partner and me
127 Facing and working on resolving difficulties with my sex life
128 Being able to have sex without drugs or alcohol
129 Seeking an emotional connection with sexual partners (not just having sex for sex's sake)
130 Learning not to take advantage of people sexually

Wholeness

- 131 About realizing the connection between my mind and body
132 Having beliefs that help me to connect what I do, what I think, and what I feel
133 Living in a way that is consistent with what I feel and think
134 Striving for balance in my activities, relationships, and feelings
135 Reacting to life's ups and downs in a more tempered and balanced way than I used to

Meaning

- 136 Having a real sense of purpose in my life
137 Taking care of other people and other living beings
138 A new found meaning in my life
139 Realizing my life has a purpose
140 About helping other people to stay clean and sober
141 About giving back
142 Being able to benefit myself by helping others
143 About finding meaning in my own life by helping others
144 About making sense of where I've been and who I am today
145 Not being so self-centered
146 Realizing that my struggles with alcohol and drugs are something of value for helping other people
147 Being helpful
148 Caring for people and things other than myself
149 Being able to appreciate things like nature, beauty, art, or music
150 Treating other beings and the environment with care
151 Doing things I don't get credit for, nor benefit from
152 Being grateful

Financial and Legal

- 153 Taking steps to confront my financial difficulties

- 154 Becoming more financially self-supporting
155 Having a “prudent reserve,” or savings for a rainy day
156 Not being so afraid when faced with financial difficulties
157 Not having to be afraid if stopped by the police
158 Having tools and resources to help me when faced with financial difficulties
159 Taking responsibility for addressing the legal problems caused by my drinking or drug use

Physical Environment

- 160 Finding a safe and secure living environment
161 Taking responsibility for living in a safe place
162 Living in an environment that is not alcohol and drug infested
163 Being able to have a place of my own
164 Being able to make a home for myself and my family
165 Not living on the streets anymore, or not having to camp out on other people’s couches
166 About making choices to live in a place where I will not be concerned with a lot of traffic or noise
167 Taking responsibility for getting transportation when I need it
-

Characterization of and Components of recovery definitions: Alcoholics Anonymous (AA), American Society of Addiction Medicine (ASAM), Betty Ford Institute Consensus Panel on Recovery (BFI), Center for Substance Abuse Treatment (CSAT)

Table 1

	AA (1939)	ASAM (1982)	Betty Ford Inst. (2007)	CSAT (2007)
How do they define recovery?	abstinence-oriented 12-step "program of recovery" that is spiritual in nature and encompasses a new "way of living"	"state of recovery" when "patients" have "reached a state of physical and psychological health such that [their] abstinence from dependency-producing drugs is complete and comfortable"	"a voluntarily maintained lifestyle characterized by sobriety, personal health, and citizenship."	"a process of change through which an individual achieves abstinence and improved health, wellness and quality of life"
Recovery characterized as	New way of living	"state of recovery"	"maintained lifestyle"	"process of change"
Components of definition				
abstinence	Sobriety	"abstinence"	"Sobriety"	"Abstinence"
health	Not specified	"Physical and psychological health," "self care"	"Personal health"	"Improved... health and wellness"
quality of life		"Complete and comfortable abstinence"	[WHO quality of life measures]	"Improved... quality of life"
spirituality	"Spiritual experiences"	Not specified	"Spirituality"	"Emerges from hope and gratitude"
community	Fellowship and service	"Improvement in family relationships," "Willing to share recovering state"	"Citizenship"	"(re)building community in one's life"

* quote marks used to signal actual verbiage in the published definitions

Table 2
Four steps of phase I methods, contributions of recovering participants and by pathways and types of recovery

Steps of Phase I Methods	Contribution made by recovering participants	Pathways and Types of Recovery of contributing participants
Step 1 1a. Identify new items with interviews & questionnaires	Create items that define recovery	Staff & colleagues in recovery (n=12), snowball sample (n=30). Pathways: treatment, no treatment, 12-step groups; no mutual aid groups. Types of recovery: abstinent, moderate use
1b. Evaluate WHO items	Revise items to reflect <i>after</i> recovery	Staff and colleagues (n=12) Same pathways as above
1c. Pretest items in questionnaires with Likert scale responses	Likert scale inadequate; New response category: "May belong in others' definition"	Staff in recovery (n is anonymous); snowball sample (n=30)
Step 2 Pilot test 167 items in online survey	Complete online survey n=238	Pathways: alumni of 6 treatment & recovery organizations (n=72); Craigslist (n= 91); NAMA (n=5); NACR (n=13). No 12-step exposure (n=35). No treatment (n=63). Non-abstinent recovery (n=27).
Step 3 Qualitative telephone interviews to pretest items & develop criteria	Selected participants from survey complete customized telephone interviews (n=54). New criteria for selecting items	Non-abstinent recovery (n=12), abstinent recovery (n=39), medically assisted (n=3). AA (n= 40), non 12-step (n= 10). Treatment (n=36), no treatment (n=18)
Step 4 Analysis of Quantitative survey & qualitative interview data	New criteria: items of daily living are not recovery; don't set bar too high; include newcomers & oldtimers	Pathways & types of recovery in Steps 2 & 3. Demographics (n=238): minorities (35%); High school or less (16%); females (52%); age 18–35 (27%); length of recovery: less than 1 year (17%), more than 5 years (45%).

Table 3

Sociodemographic and recovery characteristics of pretest online survey (n=238)

		n	%
Ethnicity	Hispanic	17	7
Race	Black	53	23
	American Indian	11	5
Gender	Women	125	52
Educational level	High School or less	37	16
	Some college or vocational	110	47
	College & advanced degrees	85	37
Age	18–35	64	27
	36–65	162	69
	66+	8	3
Self-Definition	In Recovery	139	57
	Recovered	47	18
	Used to have a problem	31	13
	In medicated assisted recovery	4	2
	Other	23	10
Length of time in recovery	Less than 1 year	34	17
	1–5 years	70	37
	5+ years	87	45
Treatment	No formal treatment	63	27
	Treatment	170	69
12-step group exposure	No exposure to 12-step	35	15
	1–90 meetings	59	30
	90+ meetings	139	70

Table 4

Relevance of recovery items to components and characterization of AA, ASAM, BFI, and CSAT recovery definitions--47 items, 5 components and recovery overall

	Abstinence	Health	Quality of life	Spirituality	Community	Characterizes Recovery Overall
No use of alcohol	X					
No abuse of prescribed medications	X					
No use of non-prescribed drugs	X					
Being able to deal with situations that used to stump me		X				
Being honest with myself		X				
Being able to have relationships where I am not using people or being used					X	
Changing the way I think through things		X				
Striving to be consistent with my beliefs and values in activities that take up the most of my time		X			X	
A realistic appraisal of my abilities and my limitations		X				
Handling negative feelings without using drugs or drinking like I used to	X	X				
Taking care of my mental health more than I did before		X				
Getting along with family or friends better than I did before					X	
Having people around me who know how to get through life without drinking or using					X	
Not replacing one destructive dependency with another	X	X				
Being able to enjoy life without drinking or using drugs like I used to	X	X	X			
Dealing with mistakes					X	
Freedom from feeling physically sick because of my drinking or using	X	X				
Trying to live in a place that is not overrun with alcohol or drugs			X		X	
Living a life that contributes to society, to your family or to your betterment					X	
Having tools to try to feel inner peace when I need to				X		
Improved self-esteem		X				
A process of growth and development						X
Being the kind of person that people can count on					X	
Reacting to life's ups and downs in a more balanced way that I used to		X				
Developing inner strength		X		X		

	Abstinence	Health	Quality of life	Spirituality	Community	Characterizes Recovery Overall
Taking responsibility for the things I can change		X			X	
Learning how to get the kind of support from others that I need					X	
Taking care of my physical health more than I did before		X				
Being grateful				X		
About giving back				X	X	
Appreciating that I am part of the universe, something bigger than me				X	X	
Becoming more open-minded about spirituality than before				X		
About helping others to not drink or use drugs like they used to					X	
Feeling connected to a spiritual being/force that helps me deal with difficulties in life				X		
Spiritual in nature and has nothing to do with religion				X		
Religious in nature				X		
Physical and mental in nature and has nothing to do with spirituality of religion		X				
No use of tobacco	X					
Non-problematic alcohol or drug use	X					
More than "just" not drinking or using drugs like I used to						X
A balance of living in the present but not at the expense of the future		X				
Freedom from always wanting a drink or drug	X					
Living in a way that is consistent with what I feel and think					X	
About making sense of where I've been and who I am today		X				
Appreciating the positive things in my life		X				
An ongoing process						X
A lifestyle change			X			X