Regaining Some Good in the World: What Matters to Persons Diagnosed as Depressed in Primary Care

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ABSTRACT

Research suggests that low rates of mental health service utilization are partly due to incongruence between patients’ viewpoints and the professional treatment models intended to help them. In order to shed light on this gap, this article presents the second in a series examining patients’ own perspectives on experiences that would be seen as indicators of clinical depression and treatment need. For those who screened positive for depression, possibilities for practical action varied and did not necessarily include seeking clinical help. Some participants no longer screened positive for depression one month later, in large part due to their own efforts in revising their central life aims and commitments. We discuss the implications of these findings for policy, practice, and community engagement, such as the importance of harmonizing professional care with patients’ main commitments in life—their unattained goals and efforts to regain a sense of direction in their lives—as situated in complex community contexts. This, in effect, would reverse the direction of “adherence.”

MeSH Headings/Keywords: Depression; Primary care; Phenomenology

Introduction

“You feel confident [when] they are there to be your friend… instead of ‘open your mouth and say ahh,’…[if only] they would actually take time to understand what’s going on. A simple ‘what brings you here’ instead of ‘what hurts’.” ~Participant

The identification and effective treatment of depression in primary care settings is at the forefront of current health care reform efforts in the United States. Historically, primary care services have accounted for the highest percentage of the prescription of psychiatric medications, especially antidepressants [1]. Yet primary care has typically lacked the appropriate mental health expertise to provide psychiatric care in an effective fashion. Through the combination of federal parity legislation passed in 2008 and the comprehensive health care reform efforts outlined in the 2010 Patient Protection and Affordable Care Act (ACA), this situation may change dramatically. As a result, primary care settings may begin to experience a significant influx of behavioral health professionals with appropriate training and expertise so that care for mental health and substance use disorders can be provided, in terms of both accessibility and effectiveness, on par with all other medical care [2,3].

Research suggests numerous challenges await the task of providing effective behavioral health treatment in primary care for depression, including low help-seeking rates, lack of adequate care, and mental health treatment drop out [4-6]; c.f., [7]. Studies indicate, for example, that roughly only a third to half of individuals with depression actually seek treatment [5,6], with members of ethnic minority groups doing so less than their majority group counterparts [6]. Epidemiological studies have found that roughly half of individuals with a 12-month episode of major depressive disorder received treatment, but only about 40% of these individuals actually received adequate care [8]. Finally, Edlund and colleagues found that a fifth of patients in the United States leave mental health treatment early [4], with another study showing these rates to be highest—around a third—in general medical settings [9]. Treatment dropout is of course a longstanding and pervasive problem overall in the mental health field, with some studies on psychotherapy attrition suggesting rates close to 50% [10]. Overall, research suggests that merely offering the care on-site within primary care settings may not be enough to ensure that persons with mental health problems accept, engage, and complete treatment.

There is evidence that a central reason for this apparent disconnect between the presence of behavioral health issues and the reception of effective care may be the disparate ways in which patients and professionals construe distress and depression [11-21]. For instance, Yeung et al. found significant gaps between patients and the health care system in their study of depression in a primary care clinic in a predominately Chinese American community [15]. Of the original 40 patients screened for depression, 19 had records documenting primary care
were characterized by a life situation in which participants to the patients themselves. The main findings of the first article a positive depression screen and to understand what they mean articles whose aim is to explore the experiences that give rise to mental health. The current article focusing on practice-experiences at the point of contact with services or referrals the non-engaged, affording the opportunity to explore persons’ and who also screened positive for depression during their seeking help with medical concerns in a primary care clinic for medical concerns, and meeting positive criteria for depression according to the PHQ-9 (minimum of “other depression”) [26]. Participants were asked to describe the experiences and life contexts that underpinned each response on the depression screen. We utilized data from two points in time, which was useful in examining how persons who did not engage or complete treatment were attempting to come to terms with the matters they reported in connection with the positive depression screen. The comprehensive narratives were analyzed via the procedures of phenomenological psychological analysis to determine the meaning, context, and general structure of these experiences from the participants’ own perspective [27,28]. The study received IRB approval from both Fordham University and the Albert Einstein College of Medicine, and all participants were ensured of the confidentiality of their responses and signed informed consent forms.

Methods

This study utilized a qualitative method to elicit and analyze participants’ narratives regarding the matters that led to a diagnosis of depression, described in detail elsewhere [25]; (see also the larger study in which the present one was conducted [18]). Briefly, participants consisted of seven persons entering a primary care clinic for medical concerns, and meeting positive criteria for depression according to the PHQ-9 (minimum of “other depression”) [26].  Participants were asked to describe the experiences and life contexts that underpinned each response on the depression screen.  We utilized data from two points in time, which was useful in examining how persons who did not engage or complete treatment were attempting to come to terms with the matters they reported in connection with the positive depression screen.  The comprehensive narratives were analyzed via the procedures of phenomenological psychological analysis to determine the meaning, context, and general structure of these experiences from the participants’ own perspective [27,28].  The study received IRB approval from both Fordham University and the Albert Einstein College of Medicine, and all participants were ensured of the confidentiality of their responses and signed informed consent forms.

Results

Struggling to Transcend: Practical Options and Actions in Response to the Devalued Situation

Participants’ main concerns stemmed from their challenges in meeting the most central goals and commitments of their lives, as embedded in worldly contexts.  This was the stuff of life in the real, changing world: unemployment, ongoing relationship and custody struggles, physical health issues, and profound discouragement in a public service career.  One person struggled with the constriction of her life, freedom, and work in the aftermath of sudden panic attacks (and fears about their return).  As goals faded for these individuals, their action, energy, and lived world, now without meaningful direction or purpose, began to constrict as well. A characteristic sense of
hopelessness, sadness, immobility, passivity, self-devaluation, and alienation arose in the face of these problematic situations and thwarted goals, which remained their primary concern. It is important to emphasize here that it was their situations that concerned them primarily, and if they were concerned about their internal experience or mental life as such, these were of secondary concern. As one participant stated, “This will continue until I get a job. [With a job,] I’ll be focused and clear my head.”

There was, as alluded to in the quote above, a possibility for positive transformation of their devalued situation. That is, these troubling situations in life, work, and the community were not finished or resolved but contained within them possibilities for agency and action that engaged the person in an effort to overturn them. Successful efforts, as evidenced by the person no longer screening positive for depression during the one-month follow-up interview, included one participant changing her original goals after her self-perceived failures at work and social change (“I’m very small in this picture and there’s not much I can do. Do the best I can and get a tiny bit out of it”) and another re-establishing reciprocal relationship with affirming others after a failed relationship (“I speak to my friends and they listen to me and give me advice, and it helps me in a way [because] I let out everything I have inside”). These instances revealed the possibility of re-awakening their own agency through practical action directed at their life situations, as well as renewing their sense of belonging with others. Here, changing the situation or their perspective on the situation was the primary source of change, rather than traditional behavioural health treatment. Other attempts at practical action are detailed next, including the role of the screening items and other persons, followed by an outline of the ingredients of successful professional interactions.

Screening Items as Referring to Fledgling Attempts to Overcome the Devalued Situation

Some of the screening items themselves referred to fledgling attempts to regain a sense of gratification in the world, to focus on a new “good.” One major example of this constituent was the experience of eating. For instance, four participants reported overeating to give themselves a new gratifying aim and overcome feelings of sadness. In each of these cases, although the initial meaning of eating was pleasure and restoration of satisfaction in life, its eventual significance, given the bodily shame that accompanied overeating, was negative and led to their devaluing themselves rather than regaining a positive value in life. After being abandoned by a significant other, one participant found herself craving sweetness: “Since I have this relationship ended, I noticed I eat a lot. I wasn’t the type of person who eat a lot and crave for sweetness. Well I let myself down because I never got this big.” Another participant dealing with a challenging work situation stated, “I would normally eat a lot after work to feel better. It [was] like my only form of happiness in a way.”

Several also described constantly thinking and ruminating about their issues, to the point of insomnia, whether it be a betrayal in a relationship, the loss of companionship, or chronic unemployment. This process, while not necessarily leading to productive solutions, indeed reflected how engrossed people were in dealing with or addressing their life situation. The participant above who was facing relational abandonment stated she had sensed her significant other’s initial betrayals and lies in her dreams, but that these dreams—however helpful—and additional ruminations disrupted her sleep:

Whatever he [was] hiding, I find it. In my dream, I find out. The drugs, the phone calls, when he go out on certain days. When I dreamed it, it came true? That’s how I knew. It would wake me up, on top of getting overheated. I feel tired because I don’t get any sleep. I have hot flashes too so it makes it worse… And just thinking about everything that’s happening.

Seeking Belonging with Non-Alientating Others and Insisting on Respect and Understanding

Persons’ primary goals were deeply social in nature: to be with a genuine life-partner, be in the company of good friends, secure a valued role in the social world, and work towards social change. In the context of the failure to realize these goals, participants felt incapable, worthless, and devalued. Others exacerbated this sense of devaluation when not attuned to the challenges the persons faced in their situations. Individuals could attempt to transcend devaluation in the context of others by insisting on being treated with more respect and understanding in relation to their situation. One participant rejected her sister’s insensitivity by insisting on her own dignity and worthiness:

My sister thinks [my unemployment is] funny. I don’t think so. Treat me like a human being… She should treat me like a real person and not a kid; like a mature person, not a stranger, if you care about me like a sister.

Her assertion of self-worth was an effort to re-establish a “good” kind of relationship, in which she felt valued and supported (unlike how she felt in relation to employers), and indeed one that would better serve her efforts to land a job. Another participant longed for greater concern from others regarding the importance of tackling social justice issues, which formed the basis of her life goals and her own public interest work:

Why can’t they see that I really care about this? They perceive my intensity and passion as going off the deep end. And I want to say, you need to stop chilling out! You need to be less nonchalant about things and that’s why there are so many problems out there.

When faced with unsupportive relationships, some opted to go it alone in the hopes of enhancing their situation and value. The individual dealing with chronic unemployment and unsupportive family and friends went the solo route in her quest for enjoyment and meaningful activity, which even made her appreciate aspects of her current situation: “She works all the time. I at least have fun. Playing slot machines! Life is too short and you need to have fun.” Another participant wanted a life surrounded by others she loved and valued but had given up due to the loss of a relationship decades ago. Now, coupled with numerous physical issues and the loss of her mother, she often remained alone (with important exceptions being when she was able to visit her mother in the cemetery and, as will be discussed below, attend a senior center). However, aside from the company
of television, solitude left her further isolated from others and without the moments of revitalization they might provide.

Spirituality was central for some in reconnecting with others. The participant above reconnected spiritually with loved ones she had lost: “That’s why I put those pictures up. I have lots of others’ pictures there too, ex-boyfriends, nephew. I talk to my mother. Spiritually. It really does help.” One participant who struggled with a gradual life collapse (less socializing, leaving an enjoyable job and being stuck in a boring one), pervasive fears of panic attacks, and stigma regarding both, found she was able to reframe her situation and efforts to overcome it with the help of spirituality. Specifically, she hoped to serve as an inspiration for others one day: “I think I have fallen back on my spiritual side. And thinking about humanity and making it better for the next generation. To make it a little bit more acceptable for them.” Both of these participants benefited from professional guidance—one before and another after the first screen (which she sought independently and not as a suggestion during her guidance—one before and another after the first screen (which she sought independently and not as a suggestion during her visit). We will now delve into the nature of such collaborations with health care professionals.

Successful, Unsuccessful, and Partial Collaborations in Primary Care: The Role of the Other in Overcoming the Devalued Situation

As stated above, participants desired supportive relationships with people with whom they could travel through life and rely upon in tough times. These types of supportive others respected and understood their goals and values, and could be helpful in moving through their current obstacles. A helpful rather than alienating relation emerged when others’ contributions and advice were trustworthy, relevant to the patients’ meaningful pursuits, and aligned with their efforts to transcend their current situation. Sometimes, these trusted others could even perceive needs and reveal possibilities that the person had not realized or considered. Social institutions could serve this advisory function within the patients’ practical field of action. In general, the operative principle of successful collaborations in primary care specifically was a fit with patients’ desires and goals. Unsuccessful collaborations, on the other hand, were characterized by the lack of such a fit. Finally, a partial collaboration was characterized by attendance to only isolated aspects of the overall quest to restore the good and reverse the collapse. Examples of unsuccessful, successful, and partial collaborations in primary care are described next.

Unsuccessful collaborations: The following illustrates the meaning of unsuccessful collaboration, in which individuals experienced the doctor’s advice and treatment recommendations as disconnected from their valued commitments. One participant experienced her physician’s advice as incongruent with her goals of producing social change, having a leadership role in public service, and garnering the appreciation of her family through her independent efforts. She felt that the advice did not really take her goals—and their importance to her—seriously, and instead offered what she viewed as impersonal suggestions and care:

Participant: Not really. About my job—He said you either quit, have a meltdown, or take medication. And I was like “great” (sarcastic tone). It was helpful in that it’s nice to know that I could take something that might make me feel better. My friends have said “take it, take it” but I can’t bring myself to do it. I don’t want to become addicted, it could change the way I act. Anti-anxiety and anti-depression medications have bad stigmas. I don’t like that how after 20 minutes in a doctor’s office that you can prescribe something without really knowing me.

While acknowledging they may make her feel better, medication went against her desire for autonomy, self-efficacy, and individuation from her mother and sister (who were both taking anti-depressant medication). This participant was prescribed anti-anxiety and anti-depressant medications, but only filled the former because of insurance restrictions. She took one dose and said it was “working” and “kind of enjoyed it” but discontinued it precisely for those reasons. She not only feared addiction, which would push her further away from her goals, but there was a sense that these feelings brought on by the medications were illusory and signified giving up on her commitment to confront the real world. To a question pertaining to side effects, for example, she responded:

“They’re going to make me feel better? Yeah, I think that’s a lie.”

Researcher: Did your doctor counsel you or give you advice during the visit? If so, what did he say?

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Researcher: Did your doctor counsel you or give you advice during the visit? If so, what did he say?
things that make me depressed…They have activities, exercises, bingo, and computer training even.

This participant’s use of the terms “depression” and “depressed” appeared to signify emotional problems (deep sadness), extreme loneliness, and living a life of profound isolation, rather than her focus being on recovering from an illness. Her trusted primary care physician was indeed deeply attuned to those social lacks in her life, came up with creative solutions, and successfully helped her regain some good company and positive movement in her life.

Partial collaborations: Finally, partial collaborations involved professional focus on isolated aspects of experience (e.g., fatigue, sleep, etc.) but did not directly address the core of persons’ life situations. One participant, who had struggled with longstanding relationship, divorce, custody, and childcare issues, had benefited from a prescription for Paxil in the past, before the time of this study:

Well my doctor told me I looked upset so I started telling him what was going on—about not sleeping and the problems in the house, being upset all the time…and he said that has to do with not sleeping. And he suggested I should go to counselling and he prescribed the Paxil.

He did not go to individual therapy at the time, but eventually participated in family therapy (through his then-wife’s counsellor) that helped “resolve some issues with the family.” This participant stated that medication only addressed certain problems: “It just took away that anger. It didn’t change how I felt…it didn’t make me happy, didn’t make me want to cry. That upright feeling…it just took that away.” The matter-of-fact advice from his physician, which he appreciated, spoke more directly to his situation: “the whole situation with my wife…he said [If I] can’t fix it to leave it alone.” At the time of the present study, the participant continued to struggle with the care of his children, post-divorce, and remained open to treatment, but this option remained an uncertain prospect due to his commitment to, and the time demands of, parenting.

Another participant’s experience of physicians was that they were useful for attending to the bodily collapse inherent in her experience, but they did not provide a pathway toward the larger life transformation she desired: “She can deal with the physical aspects of it…headaches, aches. I mentioned to her that I don’t want to be one of those individuals that is happy to take a pill.” She later consulted a psychotherapist on her own, independent of the screen and primary care visit, to resume a life where she could freely socialize with others and return to creative and engaging work, both of which were inhibited by her ongoing fears about another (public) panic episode. Psychotherapy carried the potential to reconnect her with these important life goals and also to obtain greater awareness and determinacy of how she had gotten to this place of social isolation, boring work, and lack of freedom.

Discussion

Many people with depression do not seek or receive treatment [5,6,8] suggesting a gap between health services and the specific populations they are designed to help. In the present study, experiences that health care professionals identify as indicators of depression and need for treatment were part of a larger backdrop of individuals feeling removed from their most valued goals, which they defined in terms of their life situations. Participants saw a number of practical options to achieve important ends and thereby get back within reach of what was lost or find a new “good” in order to regain a sense of purpose and direction in the world. The nature of their difficulties, as well as the specific doctor-patient communication process, determined whether clinical help appeared as relevant to their attempts to confront and change their current situation.

Concrete Practice Suggestions

Overall, we found that at the heart of the encounter between potential patients and the health care system is a risk of incongruence: What is pertinent to the patient may not appear related to what health care can offer; what is pertinent to the health care provider may not be communicated in terms that relate to patients’ central values and goals. The findings suggest that one way to bridge this incongruence in primary care, as illustrated through the successful collaborations in this study, is to genuinely convey how doctors’ offerings relate to the same goals toward which persons are striving, so that health services are understood by the patient as serving these personally meaningful ends. This suggestion reverses the traditional meaning of “adherence”—rather than patients adhering to a treatment prescribed by a practitioner, services need to adhere to, or relate to, patients’ most meaningful pursuits and commitments as embedded in diverse settings.

The basis of identifying individuals with depression in the current study was a commonly used depression screening checklist (PHQ-9) [29,30]. The screening criteria identified individuals who were struggling through various situations, and the current descriptive approach offers further suggestions regarding how physicians might proceed from identification to a fuller recognition of the struggle in which these individuals are engaged, as a basis for exploring opportunities for collaboration. Despite the inherent turbulence and uncertainty of patients’ situations (e.g., unemployment, lack of progress in social action efforts, a life-long lived in solitude, ongoing custody issues), there were openings for a caring other to enter into their worlds and support their attempts to address these unattained goals and stifled desires. Indeed, whether others were experienced as affirming or alienating depended on their level of sensitivity to, and understanding of, the matter. Successful collaborations were determined by the relevance of the pathways offered by physicians to patients’ aims, whereas unsuccessful ones were determined by experiences of the lack of relevance. A person struggling with decades of social isolation in the aftermath of loss benefited from attending a community centre on the advice of her trusted doctor and encouragement of family and friends. A person struggling with social justice goals and confronting problematic social conditions saw medication as irrelevant to, if not obstructing, these goals. This latter case demonstrated the unintended outcome on the part of someone who was trying to help but whose advice was seen as too narrow and not addressing the person’s fundamental concerns.
The present article suggests that physicians may be able to collaborate with their patients more successfully by utilizing screening information to discuss the patient’s desires, goals, and situational context from which the positive criteria for depression emerged. This approach situates the physician in the person’s world as a caring other who understands what they are living toward, how important it is to them, and how it has come to be experienced as failing. There were some instructive examples of physicians in this study who saw right to the core of the situation and developed a meaningful connection, sometimes simply through asking “what was going on.”

Because our findings suggest that behavioural health services in particular might not be experienced as an option by many patients on their own, it is important that physicians provide recommendations and treatments on the basis of a shared understanding and a direct connection to patients’ lives. After all, the notion of behavioural health care may appear incongruent to many in the community [11,18,21], who, in the present study, were mostly directed towards future goals and dealing with challenging worldly circumstances. Given this focus, natural supports like local community centres, family, friends, and vocation can also be discussed [11,31], in addition to existing intervention options and allied interdisciplinary team help (social work, psychology, etc.). This broad-based and holistic approach is in line with the spirit of person-centered medicine [21,23].

Finally, care providers could also acknowledge and align with the positive and healthy ways individuals are already attempting to regain purpose and direction in their lives. In the present article, these practices included establishing relations with more welcoming and supportive others after failed intimate relationships and reframing goals to match expectations during disappointing career developments. These led to what could be considered by some professionals as “spontaneous recovery from depression.” Previous studies in primary care have similarly found the presence of these kinds of agentic efforts in patients’ own management strategies [11]. Aligning with these efforts directly relates to recovery-oriented practice in the context of health care reform, with its emphasis on a person’s own agency, goals, and strengths, fortified by the resources of health care and everyday social supports [3,31].

Limitations and Future Research

Limitations regarding the study’s recruitment and data collection are outlined in the first article, (25) and include: sparse data sections due in part to time and setting limitations and a lack of interviews with individuals meeting criteria for severe depression. Findings and limitations of the present study also suggest future avenues of research. More research may be needed on how physicians can make a connection, gather personal information, and frame a productive collaboration. Further, more studies that follow patients over time, including those experiencing “spontaneous recovery,” would be useful. Research differentiating freshly screened individuals from those with longer histories of engagement with the mental health system is warranted, e.g., [32] as well as additional research on doctor-patient conversations to identify precise moments of connection and incongruence [21]. Quantitative analysis of the frequency of key findings in the general population, such as the number of individuals who successfully transcend the situations detailed above, are another avenue of investigation. Future research may also seek to develop complementary screening measures or items pertaining to situational context, a suggestion that Galasiński’s study of lay persons’ interactions with depression assessments also suggests [14].

It should be mentioned here that further exploration of the role of problematic social conditions mentioned by some participants (e.g., social injustice, unemployment, financial issues, and traumatic histories involving sexual abuse and gender-based violence) may help broaden the picture of what we are seeing and suggest the need to ally health care with more community-based initiatives for social change. Complex, problematic social realities are themselves worthy targets of intervention [33-36].

In the context of health care reform and a growing integration of primary care with behavioural health, the present article offers knowledge of the kinds of issues that might arise in the patient-provider encounter. Despite risks of incongruence, we found that there remains an opening for a supportive other to delve into the thickets of persons’ suffering, understand its direct relation to patients’ most valued dreams, and, as their trusted confidant, enter into a fruitful collaboration with them—all in an effort to help them regain a sense of the good in the world. To be sure, the situation that frontline health care providers and primary care physicians themselves face is not an easy one. Not only are they dealing with increasing time demands, but they often serve the role of trusted advisor, sometimes the only one, to individuals who are facing a significant amount of pressure from the world. The present study offers a few suggestions and for fortifying the frontline care provider’s everyday efforts to directly—and therefore more quickly—start diving into the life and community issues that their family practice patients face, and get them connected to social supports, relevant treatments, others in the interdisciplinary team, or people in the community who may be able to assist in furthering personal and community well-being.

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