

Cancer patients' perspectives on discontinuing depression treatment: the “drop out” phenomenon

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Background: Adherence is a critical component of clinical intervention utility, but little is known about how cancer patients with depression, particularly low-income, ethnic minority patients, perceive adherence to and drop out from treatment.

Aim: To explore low-income, minority cancer patient perspectives about not adhering or dropping out of depression treatment.

Methods: A qualitative substudy was conducted within the Alleviating Depression among Patients with Cancer (ADAPt-C) study. The intervention was an individualized stepped care depression treatment program provided by a clinical social worker in collaboration with a study psychiatrist. Patients randomized to the intervention were offered antidepressant medication and/or 8–10 sessions of problem solving treatment talk therapy. In-depth telephone interviews were conducted with 20 patients who had dropped out of depression treatment, using a grounded theory qualitative methodological approach.

Results: Enrolled intervention patients were predominately Latina, Spanish-speaking, and foreign born. Most patients (12/20) acknowledged they had dropped out of treatment for a variety of reasons, including dissatisfaction with treatment, poor patient-provider relations, logistical and financial barriers, cancer treatment commitments, and language barriers. However, other patients (8/20) denied they had dropped out of treatment and/or became confused about being labeled as a “dropout.”

Conclusion: A substantial percentage of low-income, ethnic minority patients who drop out of treatment for depression appear not to realize they have dropped out of treatment. Improving treatment adherence requires explanation of what constitutes adherence and the consequences of failing to do so from the perspective of both patient and provider.

Keywords: cancer, depression, dropout, adherence, minority, compliance

Introduction

Little is known about adherence among cancer patients with depression,^{1–3} particularly patients from hard-to-reach backgrounds such as racial/ethnic minority and low-income patients. Most attention has been directed to treatment success rather than to drop out, refusal, or relapse after treatment.⁴ Adherence is a critical component of clinical intervention utility; if patients do not utilize the intervention, it can become superfluous, even with strong evidence of efficacy.⁵

Although a great deal of research has been conducted on factors related to adherence to depression treatment in general,⁶ few studies have examined the phenomenon of dropout from cancer treatment among cancer patients.^{7–11} Based on a systematic review of depression treatment studies with cancer patients, we know that dropout

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rates in controlled psychotherapy trials can range up to 41%.¹² Nonadherence to depression treatment is even a major obstacle in the retention of patients with cancer in clinical trials.¹³ It was reported that side effects associated with antidepressants lead to discontinuation of therapy or a lack of patient compliance, with twice as many clinical trial patients discontinuing treatment because of side effects.¹⁴ Some patients who discontinue therapy report that they were not interested in involvement because they believed the medication was not working, that they were feeling better, or that they did not need the medication.^{15,16} Other known barriers to treatment include side effects from both chemotherapy,^{17–20} antidepressant medication treatment,^{14,21} fatigue,²² cognitive impairment,²³ and delirium.²⁴

Part of the challenge of studying adherence and dropout is that these phenomena are variably defined,^{1,25–28} typically by providers^{29,30} rather than patients. Although some studies have examined patients' reasons for dropout, the explanations are brief and vaguely described. In-depth patient perspectives are critical because such patients may fail to engage in and accept treatment for a variety of reasons rooted in their own cultural background and personal experiences,³¹ which are important to understand in order to develop strategies for reducing the rate of drop out.

This study examined the perceptions of treatment adherence and dropout in a sample of low-income, minority (predominately Latina) depressed cancer patients, who have been historically unrecognized in the clinical oncology literature. Using former participants from a randomized clinical depression treatment trial of cancer patients – Alleviating Depression among Patients with Cancer (ADAPt-C)³² – the parent study explored barriers and factors associated with depression treatment non-adherence and dropout. Specifically, this study aimed to explore low-income, minority cancer patient perspectives about not adhering or dropping out of depression treatment.

Methods

A qualitative substudy was conducted within the ADAPt-C study.³² The intervention was an individualized stepped care depression treatment program provided by a cancer depression clinical specialist in collaboration with a study psychiatrist. Patients were randomized to intervention or usual care via the recruiter providing the patient with a choice from five sealed envelopes that contained one sheet of paper indicating a study group randomly determined by computer algorithm. Patients randomized to the intervention were offered antidepressant medication and/or problem

solving treatment (PST), a cognitive-behavioral treatment which has been found effective in treating depression among Latinos, particularly when socioenvironmental stress is a significant factor.^{33–36} The initial intervention visit(s) included: semistructured psychiatric/psychosocial assessment; patient depression, psychotherapy, and antidepressant education; consideration of initial treatment choice; provision of patient navigation assistance; and included family members at patient's request. Subsequent visits provided structured PST and/or antidepressant medication monitoring. Active PST was designed to last 8–10 sessions. Homework materials were linguistically and idiomatically adapted. After acute treatment, patients received a treatment maintenance and relapse prevention program, including cancer depression clinical specialist monthly telephone contacts up to 12 months after treatment initiation to monitor symptoms (with additional in-person visits if indicated), behavioral activation support for engaging in pleasant activities, and motivational support for ongoing use of PST skills and medication adherence.

ADAPt-C parent grant inclusion criteria included adult cancer patients ≥ 90 days from a cancer diagnosis who were receiving acute treatment or follow-up care in oncology clinics, but did not have advanced cancer or another medical condition that limited remaining life expectancy to less than 6 months.³⁷ PST dropouts were defined as patients who had fewer than four PST sessions. PST dropouts included those who initially agreed to be randomized to the intervention, but thereafter had either verbally declined treatment or did not show up for the appointments. This included patients who had refused some sessions, but agreed to remain in the study for outcome interviews. Patients who died or were unable to be reached were not considered to be dropouts. Patients receiving antidepressant medication were dropouts if they discontinued treatment within 30 days, which is the benchmark used for determining adherence to antidepressant medication.⁷ For antidepressant medication treatment, patients could have refused further medication, but initially agreed to complete ADAPt-C parent grant outcome interviews and receive gift card incentives. In this study, we operationalized "adherence" to treatment as four or more PST sessions and continuing antidepressant medication for more than 30 days.

Twenty of the 39 patients (51.2%) eligible to participate in the study agreed to do so. Informed consent was obtained from each patient in accordance with procedures approved by the Institutional Review Board of the University of Southern California. Recruitment material and scripts were sensitive to, and addressed the fact, that these individuals

decided against continuing in a prior research study. It was possible that they could continue to decline to participate in this smaller research study as well. The materials made it unequivocally clear that they were being invited to participate in a research study because they had not continued in a prior research study. Responses to the interview guide protocol were obtained through an iterative process within each interview, or across interviews, consistent with the nature of qualitative research.³⁸ The first phase of dropout data collection involved in-depth minimally structured individual telephone interviews. Participants were recruited by telephone from culturally trained bilingual recruiters. To strengthen data accuracy, researchers conducted more than one interview. Interviews averaged 1 hour in length and were digitally recorded and later translated into English and transcribed for analysis.

Using a methodology of “coding consensus, co-occurrence, and comparison”³⁹ and rooted in grounded theory, all transcripts were analyzed using ATLAS.ti (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany). Segments of transcripts were assigned codes based on a priori theory of planned behavior,^{40,41} sensitizing concepts (ie, questions in the interview guide) with emphasis on cultural explanatory model of illness,⁴² or emergent (ie, issues raised by the respondents themselves) themes.⁴⁰

Results

Of the 242 patients who were enrolled in the ADAPt-C depression treatment intervention participation, 152 satisfied the criteria of adhering to treatment while 90 patients met the criteria for withdrawing or dropping out of treatment. Dropouts were predominately female (90%), Latino (85%), foreign-born (80%), unmarried (55%), unemployed (85%), >50 years old (65%), and in the United States >10 years (80%). Forty percent of sample had less than a 12th grade education. With regard to depression characteristics, most patients in the sample had moderate depression levels (80%). One of the two dropout patients who were prescribed antidepressant medication was taking Lexapro® (10 mg daily); the antidepressant medication that the other patient was prescribed is not known. Regarding cancer characteristics, most of sample was diagnosed with a less advanced cancer stage (70%) and were in follow-up cancer treatment (70%). Only 20% of this sample described pain. Interestingly, 45% of this sample complained of comorbid medical problems. All dropout and completer characteristics were similar to the overall parent grant characteristics.

This study's dropout recruitment efforts occurred between early January and mid-March 2008. At the time of recruitment for this study, there were 39 parent study dropouts who initially completed the baseline assessment and were randomized to the intervention. Of these 39 participants, 19 were still not able to participate for the following reasons: moved (n = 1), disconnected telephone number (n = 5), changed telephone number (n = 1), unable to be reached by telephone (n = 10), or died (n = 2). However, of the remaining 20 dropouts who were able to be reached, all were willing to participate.

It is important to look first at the term “dropout” to gain insight into how patients conceptualized the act of terminating their participation. Initial interviews with dropouts began with an inquiry about their definition and description of the term. However, in subsequent interviews, the interviewer was cautioned about using the word “dropout” during the interview, as this word had the potential to have negative connotations to the patient and/or might not have accurately reflected the patient's status according to their individual perspective. Instead, interviewers were advised to refer to dropout as “discontinuing treatment.”

Patient interviews were characterized by definitive statements such as, “I decided to stop the treatment.” Twelve of the 20 patients interviewed acknowledged that they had dropped out of treatment, citing several reasons and circumstances related to dropping out of treatment. These included the following: cancer-related (which included the emotional impact of the cancer diagnosis [n = 20] and cancer treatment commitments [n = 11]), depression treatment-dissatisfaction (n = 9), informational (which included study misunderstandings [n = 6]), instrumental (which included transportation problems [n = 14], financial issues [n = 11], employment-related concerns [n = 11], and caregiving demands [n = 3]), cultural (which included language communication problems [n = 7] and discrimination from providers [n = 5]), and systems-related (which included service-related logistical issues [n = 13] and patient-provider problems [n = 10]). These barriers were not mutually exclusive; instead they were often described in combination (Unpublished data, 2011).

The remaining eight patients either disagreed that they had dropped out of treatment, perceived the term to be misleading because it implied a willful or voluntary response to an uncontrollable situation, or were confused by the term and uncertain as to whether it applied to their own situation. For example, one participant said, “Did I dropout? No, I didn't dropout. I became busy and I figured I started missing calls.” Similarly, another said, “Like I have repeated, I didn't stop

any treatment.” Another participant expressed that she had not chosen to dropout so therefore was not comfortable with this label, “It wasn’t dropping out because I didn’t not want to get help ... It’s not like it was under my power. You know what I mean? You can say [dropout] if you want to but I don’t feel like I want[ed] to get out of the study.” Similarly, another participant thought the label sounded negative, “I think that I dropped out but I don’t know – it does not sound good.”

Some participants did not understand what was being asked and called the question “weird;” one participant said that her continuation with other treatment meant that she had not dropped out. One participant said, “I don’t know what to tell you. I’m confused. I can’t answer that question. You can ask me a thousand times. I can’t answer it.”

Discussion

In this study, the majority of low-income, ethnic minority cancer patients identified as having discontinued treatment for depression acknowledged that they had indeed “dropped out” of treatment. Their reasons for doing so are consistent with barriers cited in other studies of adherence to depression treatment. However, this study also revealed that the label of “dropout” is not always true to the patient’s perspective on discontinuation of depression treatment, and in fact is sometimes contrary to the patient’s understanding of what occurred. Some patients denied dropping out of treatment, asserting that they were continuing to receive services. Other patients suggested the term did not accurately reflect their decision to leave treatment because it implied a voluntary action when their own perception was that the act of withdrawing from treatment was anything but voluntary. Still other patients were confused by the term and unsure as to whether or not they were still in treatment.

Although not specifically mentioned by any of the participants in this study, a potential reason for failing to acknowledge treatment dropout might be that patients got all they needed out of the treatment and were satisfied with the treatment they received. From a research perspective they dropped out of treatment, but from a phenomenological perspective, they completed what they needed to complete. Another reason may have been that some patients may not have been able to remember the sequence of events leading up to their discontinuation. Also, some patients may have, in fact, been currently in treatment with another provider so they may have perceived themselves to still be in treatment, even though they were not technically in the treatment program to which they had consented. Due to the potentially negative and/or stigmatizing connotation of

the term (eg, “high school dropout”), it may be important in future studies to choose alternative terminology or to at least approach patients who discontinued treatment with a more exploratory approach regarding their decisions. An alternative term which has received increased usage over the past decade or so is “concordance”, which is described as a more equal relationship between physician and patient.⁴³

There are several limitations to our study that deserve mention. First, study participants were not selected at random from the group of ADAPt-C participants who satisfied criteria for dropout status and thus may not be representative of the broader population of low-income, minority cancer patients who withdraw from treatment. Thus, the results obtained may not generalize to either population. Second, as a qualitative study, both collection and interpretation of data is susceptible to subjective bias and preconceived ideas of the investigators. Third, there might have also been translational issues, with the term “dropout” not being directly translatable into Spanish. Finally, we did not investigate the potential influential roles of type and tolerability of antidepressant medication and/or cancer treatment in adherence to depression treatment.

Conclusion

Improving adherence to treatment for depression among low-income, ethnic minority cancer patients requires more than addressing known barriers to treatment such as language and cultural differences, lack of transportation and health insurance, and dissatisfaction with care received. It also requires an understanding of how patients define adherence and dropout or withdrawal from treatment. Embedded within these definitions are rationales for decisions and behaviors that may be interpreted by providers as lack of adherence, but interpreted by patients as either evidence of adherence or an involuntary action that represents neither adherence nor dropout. Understanding the motives underlying such involuntary actions or the rationale for describing such actions as evidence of adherence is essential to developing patient education programs and psychoeducational interventions that can improve adherence to depression treatment in this medically underserved population. In addition, it is important to consider the important role of social support (ie, family, healthcare providers), as a vehicle for helping to interpret and facilitate communication for depressed cancer patients. Family, friends, and healthcare providers can provide valuable emotional and instrumental support to help facilitate treatment adherence.

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