

DBSA Survey Center

Less Common Medication Side Effects Survey

Summary Report: March, 2017

BACKGROUND

From 10/19/16- 11/21/16, DBSA administered a survey to gather information on the experiences people living with mood disorders have had with a variety of medication side effects. This survey focused on the level of distress nine identified side effects has caused the individual as well as who first noticed the side effect and how it has been treated, if at all.

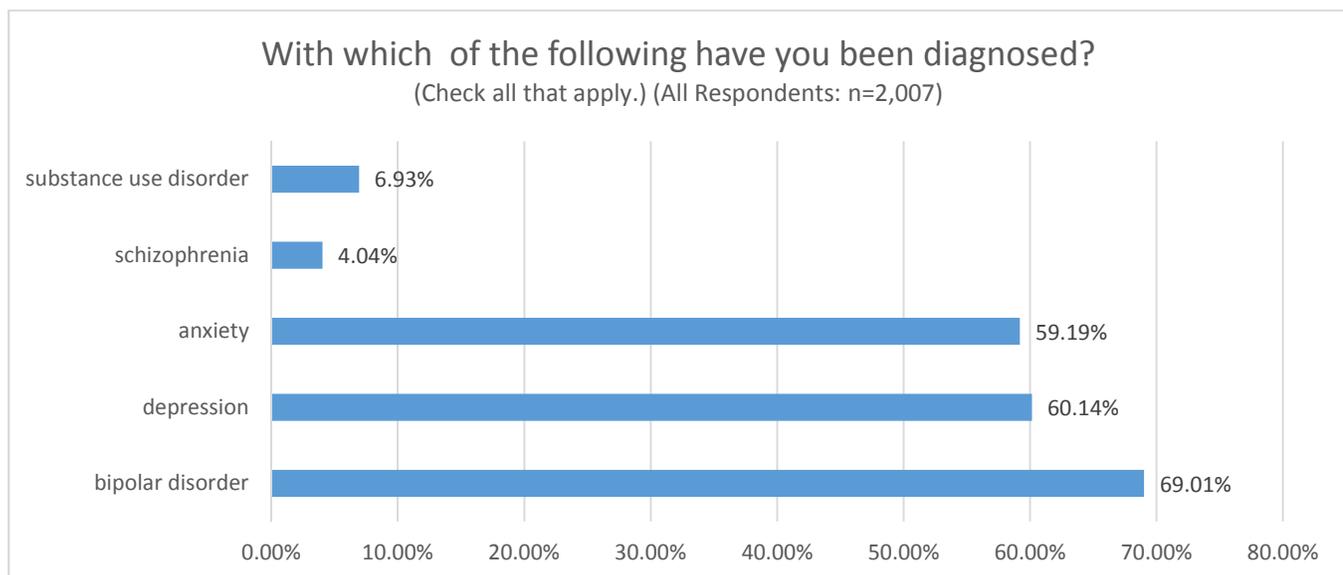
Three of these less common side effects indicate a little known condition called tardive dyskinesia (TD). This condition affects the nervous system and is often caused by long-term use of antipsychotic medications, which are sometimes used to treat bipolar disorder and depression. Side effects associated with TD usually involve repetitive, involuntary movements. While most side-effects will dissipate once medication is stopped, TD can last long after the medication has been discontinued and, in some cases, may even be permanent. Because of its unique characteristics and its impact on people living with mood disorders, DBSA placed a special focus on respondents who identified as having tardive dyskinesia.

Individuals were invited to complete the survey through DBSA's electronic newsletters distributed to individual constituents and local chapters as well as through social media and Facebook Ads. 2,007 individuals responded.

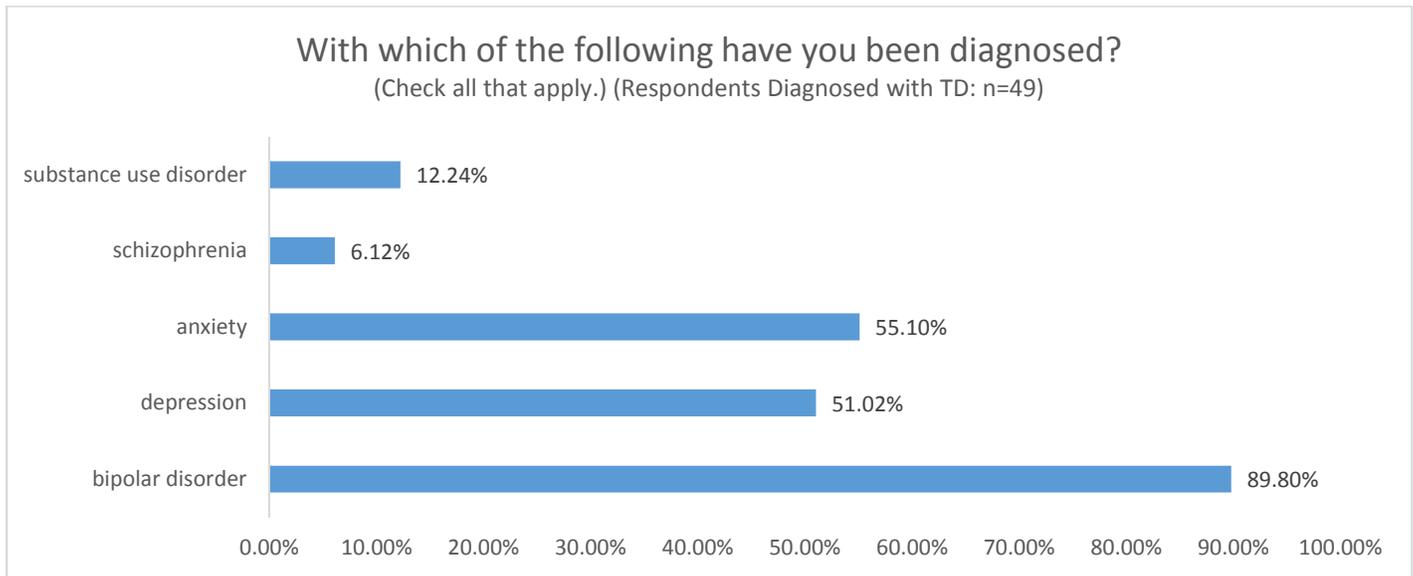
SURVEY RESULTS

DIAGNOSIS

The majority of respondents reported having multiple diagnoses, with nearly 70% experiencing bipolar disorder, 60% depression, 60% anxiety, 7% substance use disorder, and 4% schizophrenia.



Among those diagnosed with Tardive Dyskinesia (n=49), there was a much higher percentage of people experiencing bipolar disorder (89.8%) when compared with all respondents. It is more common to treat bipolar disorder with antipsychotic medications than it is for depression or anxiety, which could account for this difference.

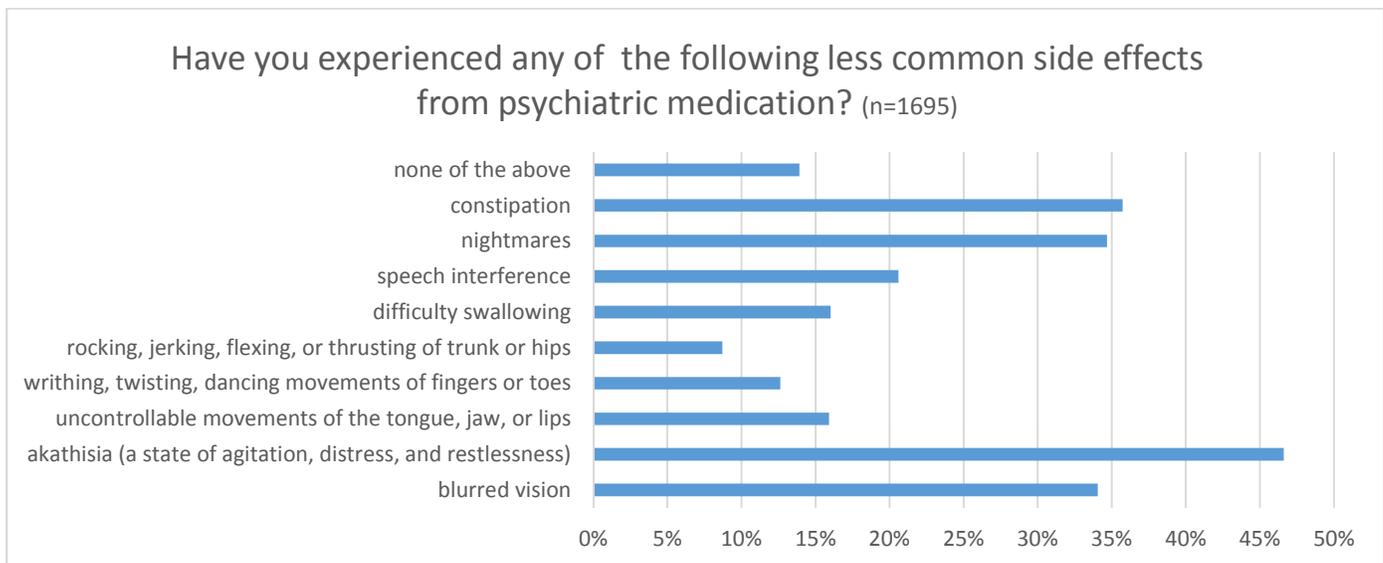


MEDICATION

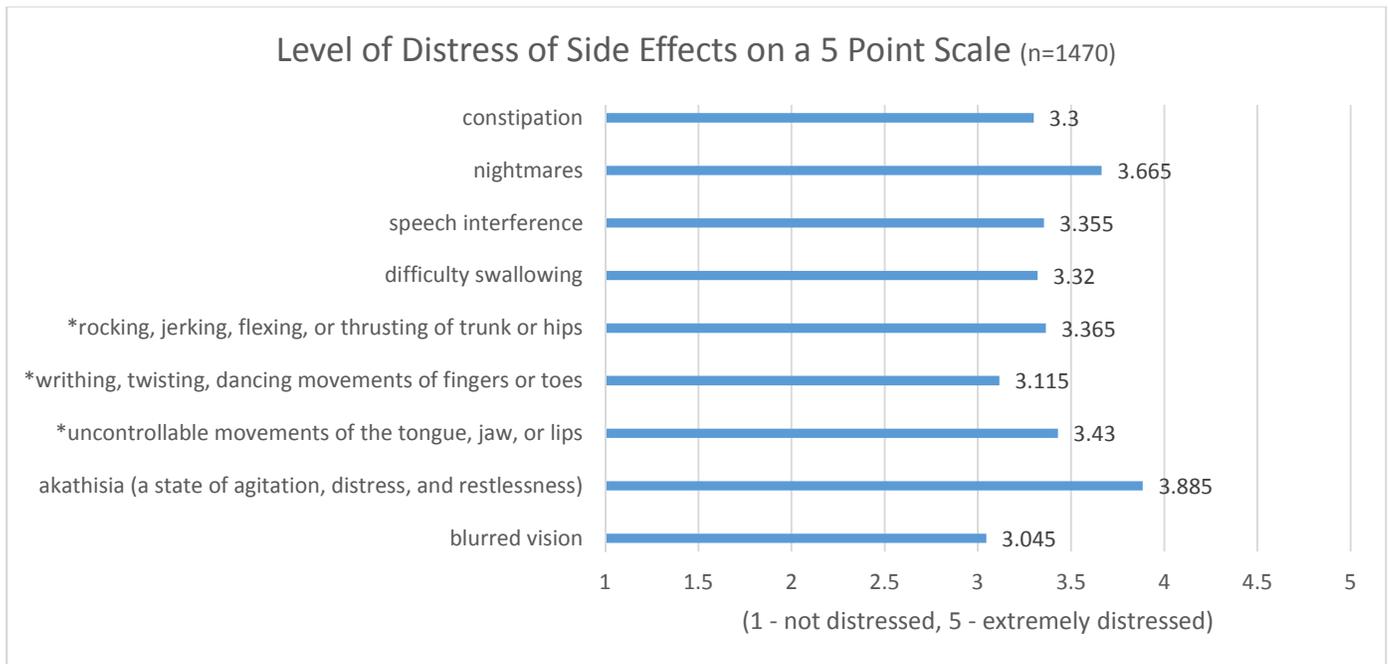
1,695 individuals reported being either currently on a psychiatric medication or had been in the past. 65% had taken or were currently taking anti-depressants, 62% are or were taking mood stabilizers, 52% are or were taking anti-anxiety medications and 48% are or were taking antipsychotic medications. 75% of those taking antipsychotic medications reported that they had been on the medication for longer than 1 year.

SIDE EFFECTS

Survey participants were asked to indicate which of nine less-commonly reported side effects from psychiatric medications they had experienced and the relative distress each caused in their life. 52% of respondents indicated they had experienced akathisia, defined as a state of agitation, distress and restlessness. In addition to akathisia, nightmares (38%), constipation (37%) and blurred vision (36%) were experienced the most frequently.

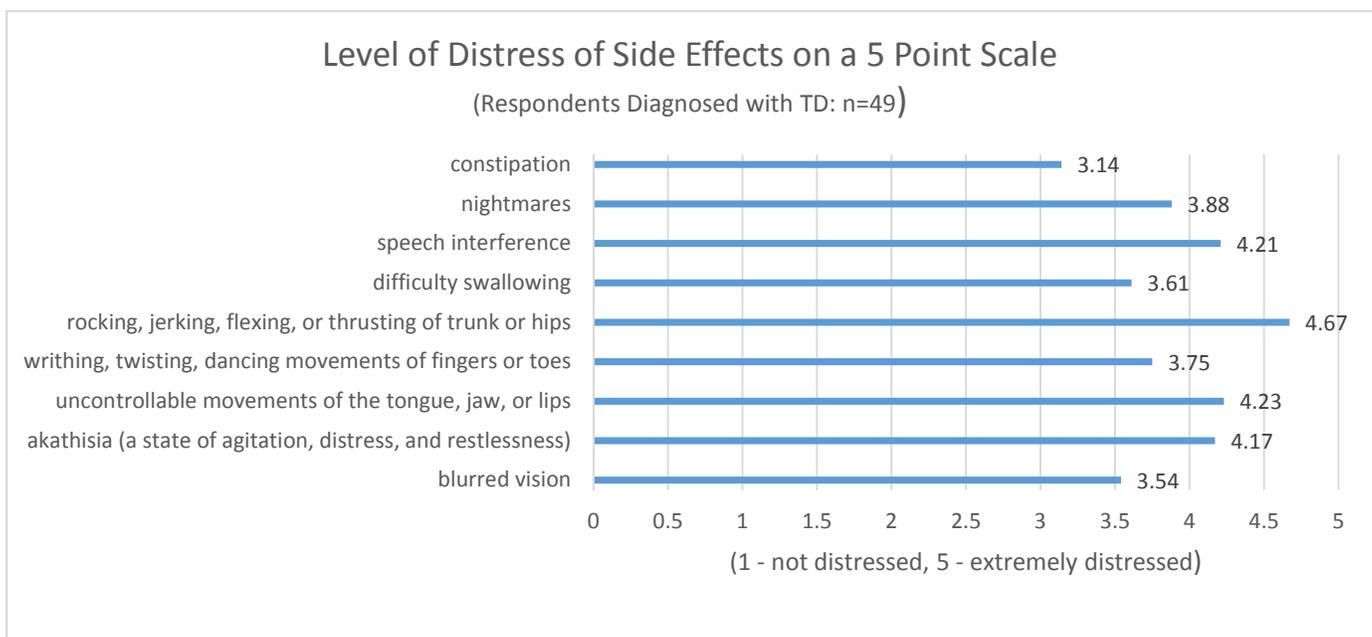


When it came to indicating how distressing each side effect experienced was, akathisia remained on top with a weighted average of 3.89, followed again by nightmares at 3.67 on a 5 point scale. Other high distress ranking side effects included uncontrollable movements of the tongue, jaw or lips (3.43/5), speech interference (3.36/5) and difficulty swallowing (3.32/5)



* side effects common in tardive dyskinesia

When looking at only individuals who had been diagnosed with Tardive Dyskinesia (TD) (n=49), there was a notably higher ranking of distress caused by side effects commonly associated with TD: rocking, jerking, flexing, or thrusting of trunk or hips (4.67/5), uncontrollable movements of the tongue, jaw or lips (4.23/5) and writhing, twisting, dancing movements of the fingers or toes (3.75/5.)



TREATMENT STRATEGIES FOR ADDRESSING SIDE EFFECTS

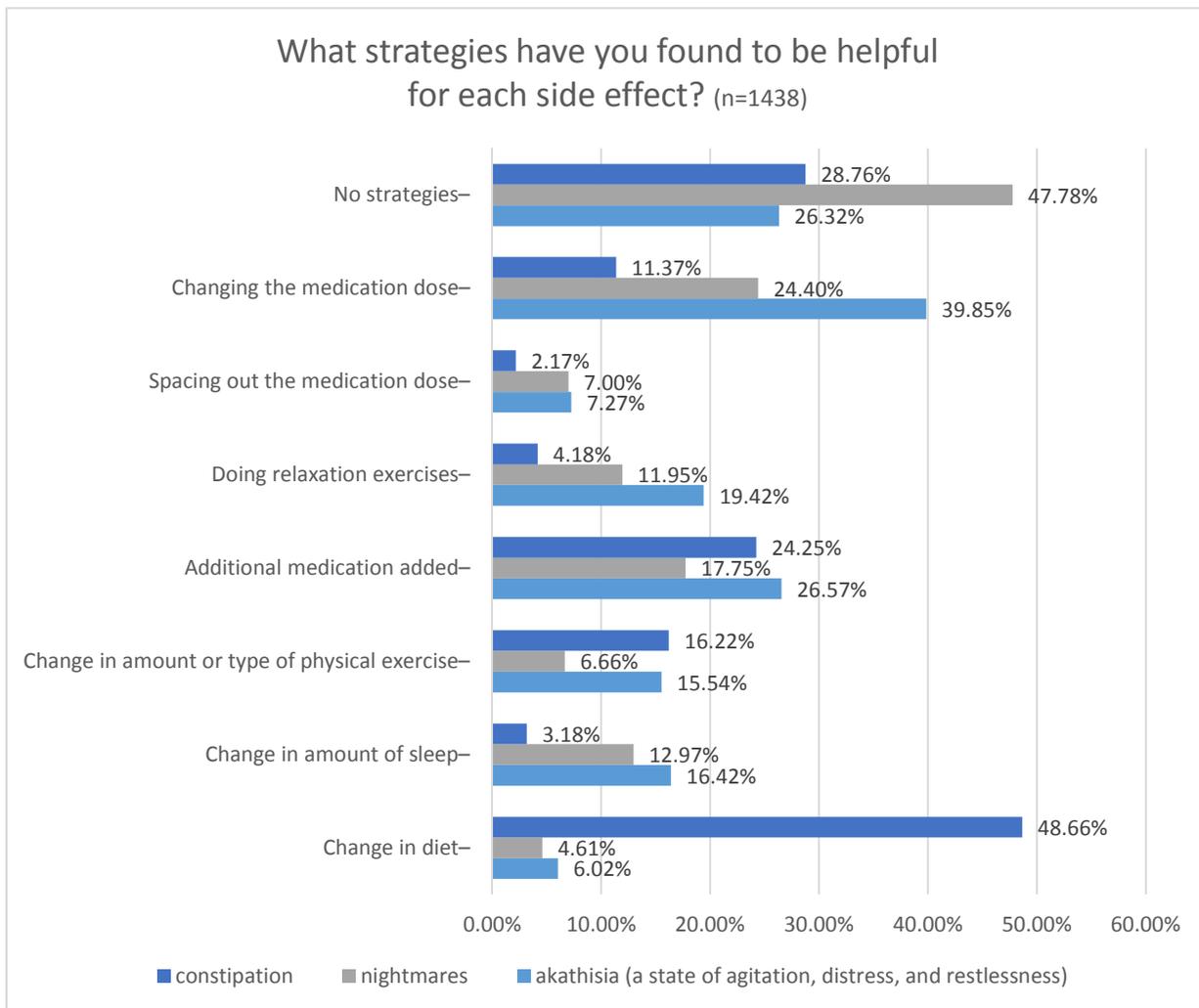
Survey participants were asked to share what strategies, if any, they had found helpful in dealing with side effects they were experiencing. Looking at the three most commonly reported side effects (akathisia, nightmares, and constipation), changing the medication dose and adding another medication were most helpful.

For those experiencing akathisia, 39.9% reported changing the dose of the medication was the most successful strategy, followed by adding another medication at 26.6%.

Those experiencing nightmares seemed to have found the least strategies helpful with nearly 50% indicating none of the listed strategies had been helpful. Changing the medication dose was reported to be helpful for about 24% of the respondents and adding another medication at 17.8%.

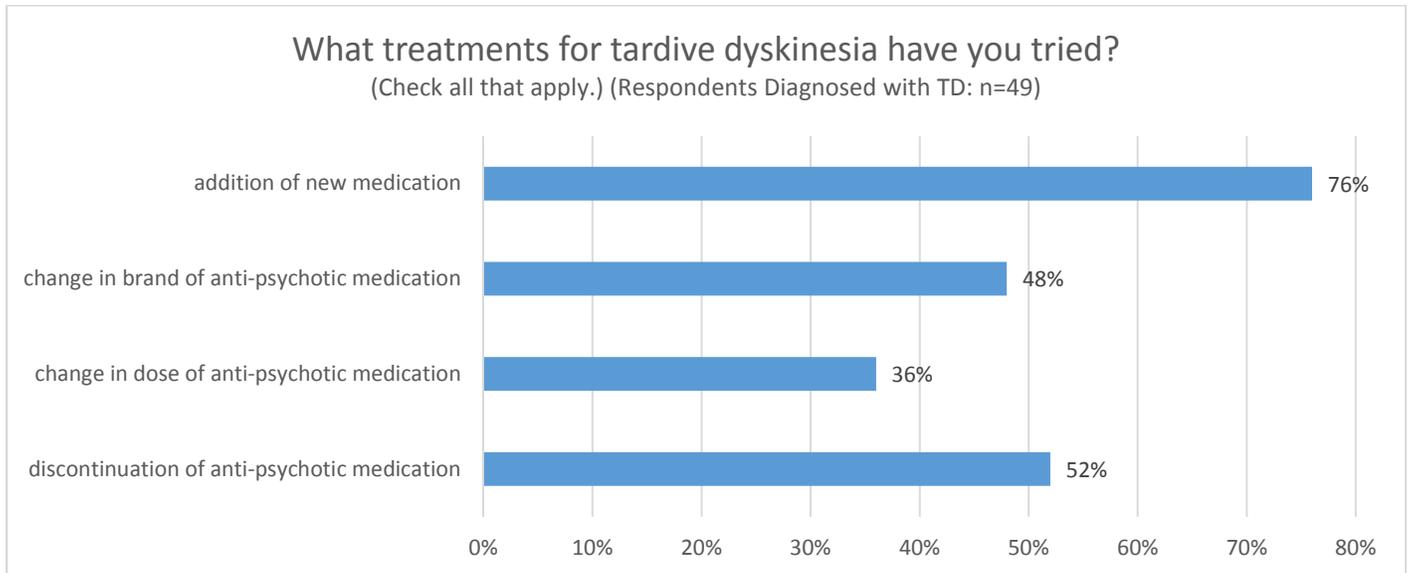
Those who had experienced constipation indicated that a change in diet (48.7%) was the most effective strategy they had used.

For each of these side effects, it is interesting to note, the amount of people indicating that no strategies had been helpful was very high.



Survey participants were asked about with whom, if anyone, they had talked to about their side effects. 84% of respondents had discussed the side effects with their psychiatrist; 55% had shared with a family member; 42% with a talk therapist; and 41% had discussed their side effects with a primary care physician.

Similarly to all respondents, those who had been diagnosed with tardive dyskinesia (TD) also found relief through adding medications (76%) and, to a lesser extent, changing their medication dose (36%). Some had also tried discontinuing the antipsychotic (52%) or changing the brand of medication they were on (48%).



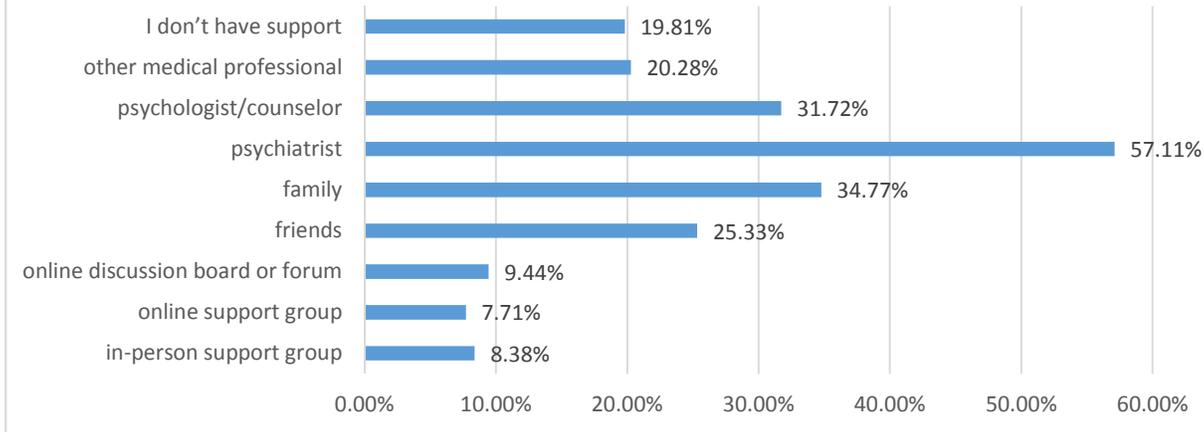
75% of those who have lived with tardive dyskinesia were diagnosed by a psychiatrist. Only 9% had been diagnosed by a neurologist. This is an interesting finding as it is usually common practice to have a diagnosis of tardive dyskinesia confirmed by a neurologist.

Individuals living with tardive dyskinesia reported that symptoms of repeated movements of the tongue, jaw, or lips (55%); followed by akathisia (43%) led them to seek professional help. Nearly 60% of participants indicate that they were the first one to notice symptoms.

Among our sample of those living with tardive dyskinesia, nearly all (91%) stated that they began experiencing TD side effects while taking an antipsychotic medication. 56% felt that they began experiencing symptoms within the first year they were on the antipsychotic.

Survey respondents (n=1544) where they received support dealing with their side effects. 57% reported that their psychiatrists were a support for them followed by family at 35%, psychologists/counselors at 32%, and friends at 25%. Responses indicated minimal use of in-person and online support groups (approximately 8% each) or discussion boards and forums (9%) for support. Notably, nearly 20% of respondents reported that they have no support. This may indicate a need for more education around side effects, as well as a greater focus on how to discuss side effects.

Where do/did you get support for dealing with medication side effects? (Check all that apply.) (n=1544)



DEMOGRAPHICS

Females made up 78% of survey participants, followed by males (20%), trans-gender or other at approximately 1% and another 1% who preferred not to disclose or did not identify with a gender. Females reported experiencing all of the medication side effects more than males. Females also reported being diagnosed with tardive dyskinesia (TD) significantly more than males.

48% of respondents were between the ages of 40-60. Another 40% were younger than 40, and the remaining were older than 60 (11%) or preferred not to disclose (1%). Of note, nearly 60% of those who had been diagnosed with TD were between the ages of 30-50 years old. We expected to see older individuals experiencing TD more frequently. However, our sample size was small (n=49) and the online methods of survey collection may have skewed to a slightly younger demographic.

85% of participants classified themselves as white, 6% as Asian, 2% black or African American, 1% American Native or Alaska Native. Asian American and Native Hawaiian or other Pacific Islander each came in at less than 1% of participants. Nearly 5% chose not to disclose their race.

When asked about their employment and/or student status, 46% were employed either full or part time, 11% were students, 12% were retired, and 35% reported that they were currently not employed or a student. 65% shared that they were not receiving disability benefits and 76% had insurance coverage.

The demographic breakdown in all categories stayed consistent regardless of the side effect experienced.

SUMMARY AND DISCUSSION

The results of this survey indicate that side effects from psychiatric medications are a very real problem for many. Of the 1,695 individuals who completed the survey, nearly 90% shared that they had experienced at least one of the less common side effects noted in this survey. All of the side effects were reported as being, at a minimum, distressing (3 on a 5 point scale) indicating that they all are significantly impacting the individuals' lives.

For people who had experienced akathisia, the distress level neared 4 on a 5 point scale (3.9/5). Individuals with tardive dyskinesia indicated that the distress level from the side effects most commonly associated with TD were even higher (all reported at greater than a 4 on a scale of 1-5.).

It was also telling to see that for a large percentage of the side effects, respondents had not found any helpful strategies for dealing with the side effect(s). From this survey, it is unclear whether individuals had tried all of the strategies provided and found them to not be helpful or if they hadn't yet been tried.

The results showing that the individual, rather than the clinician, was first to notice side effects of TD (60%); that the symptoms presented within the first year of taking an antipsychotic medication (56%); and that nearly 20% of respondents had found no source of support for dealing with their side effects all point to the need for more education around side effects, as well as a greater focus on how to discuss side effects with clinicians.

DBSA hopes to utilize the information gained through this survey to develop resources to:

- provide a greater understanding of less common medication side effects, including tardive dyskinesia.
- educate on strategies individuals may wish to try to alleviate these side effects.
- help individual have more effective discussions about side effects with their health care providers.