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## Gastrointestinal stromal tumor: psychosocial characteristics and considerations

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### Abstract

**Objective**—Gastrointestinal stromal tumors (GIST) are very rare, especially within the pediatric population. The National Institutes of Health initiated a multidisciplinary clinic to bring together a worldwide group of healthcare providers with experience in the study and treatment of GIST in order to better understand the disease and to examine whether this is a population at psychosocial risk.

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**Methods**—Seven GIST clinics have been held to date. Participants completed a GIST Psychosocial Assessment containing items covering demographic factors, family stressors, general health, psychosocial concerns, psychiatric history, and self-identified needs. Our sample consists of 60 adult patients (ages 18–66) and 18 pediatric patients (ages 9–17).

**Results**—Living with pain at least a few days a week was endorsed by those whose self-reported health status was good to excellent (49% of the adult cohort and 25% of the pediatric cohort). Pain was significantly associated with anxiety, difficulties with family relationships, behavior problems, and psychotropic medication use. Body image and appearance concerns were endorsed by over half of the cohort. Post-trauma symptoms were prevalent for those newly diagnosed and those living with GIST for over 15 years.

**Conclusions**—This is the first study to explore the psychosocial impact of GIST. Individuals living with GIST experience chronic pain, post-trauma symptoms and significant anxiety along with an expressed need for interventions to help them manage their anxiety. Due to the chronic nature of this disease, the GIST population is at risk for long-term psychological distress. Psychosocial interventions in pediatric and adult care settings are offered.

### Keywords

Gastrointestinal stromal tumor (GIST); Psychosocial; Pain; Body image; Posttraumatic stress symptoms; Anxiety

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It is well understood that cancer and its treatment can cause medical and psychosocial complications that adversely affect a patient's physical, emotional, social, and cognitive functioning during and after treatment. Most studies address cancers that are frequently diagnosed in adults and children, yet there can be unique psychosocial challenges for specific malignancies that are less frequently encountered. One particular cancer type for which there is a dearth of information is gastrointestinal stromal tumors (GIST). GIST has an estimated incidence of 3,000 new cases per year in the USA with a median age at diagnosis in the 60's [1]. While the exact incidence is unknown, it is estimated that pediatric cases account for only 1– 2% of GIST diagnoses, making these tumors extremely rare in children [2]. Pediatric GIST is both biologically and clinically distinct from the adult form.

### Disease presentation

Adult patients with GIST are split evenly between males and females, and their tumors arise in the stomach in only half of cases, with occurrence in the small bowel and colon accounting for the remainder [1]. In stark contrast, females have a 2.7-fold higher incidence, which approaches 6-fold in the National Institutes of Health (NIH) clinic, in pediatric GIST. Fatigue and anemia are the most frequent clinical features at the time of diagnosis. Multiple recurrences and metastatic spread over many years is likely, but despite these findings, overall survival continues to be very high, which reflects an overall indolent clinic course [2, 3]. Tumors are almost exclusively located in the stomach. Larger tumors may cause symptoms that are generally related to the increased mass being localized to the abdominal cavity, and such symptoms would not necessarily be different from other types of tumors.

These symptoms include digestive discomfort, sensations of abdominal fullness, or abdominal pain. Abdominal discomfort and pain may also be encountered after surgery.

Frequent abdominal pain is known to be a predictor of anxiety, depression, and suicidal ideation [4]. In pediatric populations, chronic abdominal pain has been associated with social withdrawal, school absenteeism, and a poor quality of life for adolescent patients and their parents [5]. Chronic abdominal pain can also lead to restrictions in daily life, including decreased appetite, less time working or playing with friends, and less time with hobbies [6]. Suffering from frequent abdominal pain earlier in life often leads to increased utilization of the health care system as adults and also is more likely to result in an anxiety disorder later in life [7].

Recent research on the molecular biology of GIST has found that 90% of adult patients has activating mutations in the KIT or platelet-derived growth factor receptor alpha (PDGFRA) genes [8, 9]. In contrast, less than 15% of pediatric GIST tumors harbor KIT or PDGFRA mutations, thus termed wildtype. Consequently, treatment options also differ for pediatric versus adult GIST. Tyrosine kinase inhibitors that specifically target the actions of the mutations involved have recently been found to slow disease progression and increase overall survival [10–12]. Unfortunately, the vast majority of pediatric GISTs do not have the same types of mutations and the limited data available suggest that these treatments are not as effective for those with pediatric GIST [13].

## The GIST program at The National Institutes of Health

Treatment regimens, particularly for younger patients with GIST, have varied markedly, in part due to the lack of a substantial number of patients at any single institution. In June 2008, the NIH initiated a multidisciplinary clinic to bring together healthcare providers who have the most experience in the study and treatment of GIST. Having the opportunity to review the clinical history from as many individuals living with wild-type GIST as possible (pediatric and adult wildtype patients), along with response to prior treatments, histopathologic results, radiographic assessments and genetic/molecular analyses, provided an opportunity for scientists to determine the biological differences between older and younger patients with GIST and utilize this data to design innovative national treatment protocols. We chose to study wildtype GIST, because in contrast to adult KIT-mutated GIST in which the biology, therapeutics and natural course are well established, all of these parameters are still unclear in pediatric and wildtype GIST. In addition, the chronic nature of the disease in the pediatric setting, with repeated recurrences necessitating frequent surgeries, the co-occurrence of other malignancies that are often genetically inherited, and the anxiety that accompanies both of these circumstances, suggest that this is a population at psychosocial risk. In response to these potential multiple stressors, a component of the NIH Pediatric and Wildtype GIST Clinic consists of psychosocial screening.

## Method

### Sample

Seven GIST clinics have been held to date with 83 participants. Seventy-eight out of 83 participants who attended one of the clinics completed the psychosocial assessment (18 parents of pediatric patients age 9–17 and 60 adult patients). Of the five psychosocial assessments that were not completed, one participant was Spanish-speaking and the assessment form was only available in English, the other four declined to return the assessment form.

### Instrument

The Pre-Screening GIST Psychosocial Assessment form contains 78 items covering demographic factors, family stressors, general health, psychosocial concerns, psychiatric history, and self-identified needs. Certain questions in the instrument were adapted with permission from the Psychosocial Assessment Tool PAT 2.0 [14], including three items pertaining to post-trauma stress symptoms, and questions pertaining to concerns about mood changes and school difficulties. Sections of the assessment examined psychiatric history, psychotropic medication use, and interest in a range of possible psychosocial services. These sections of the assessment were created specifically for this study. Two versions of the form were created; one for adult patients to complete on their own (> 18) and another for parents of children under the age of 18 to complete about their child (<18). Each participant received the psychosocial assessment form along with other registration forms by mail and was asked to complete the forms prior to meeting with the clinicians. In the version for children under the age of 18, parents were asked if they had experienced any of their own post-trauma stress symptoms since their child's GIST diagnosis ("Have you had bad dreams or nightmares about your child being ill," "Have you become jumpy since your child was diagnosed with GIST," and "When you are reminded of your child being ill, do you sweat or tremble, or does your heart beat fast?") [14]. Data regarding number of surgeries were obtained through medical chart review. All patients were enrolled on NCI and NICHD protocols approved by the respective Institutional Review Boards.

### Statistical analyses

Descriptive and bivariate data analyses are presented. Chi-square analyses are used to compare two categorical variables, independent samples *t* tests are used to compare groups on continuous variables and Pearson product moment correlations are used to compare two continuous variables. SPSS version 12.0 was used for all analyses.

## Results

The majority of participants were white, female, in "good" to "excellent" health, highly educated, and from the USA (Table 1). Nine participants came from great distances, including Canada ( $n=3$ ), Germany ( $n=3$ ), Australia ( $n=1$ ), England ( $n=1$ ), and Maldives ( $n=1$ ) to attend the GIST clinic. The sample consisted of 60 (77%) adult patients (ages 18–66) and 18 (23%) pediatric patients (ages 9–17). There were a high number of participants who reported placement in a gifted program during school (22% of adult cohort, 19% of

pediatric cohort). As the age range was so wide in this sample, data below are presented separately for the pediatric and adult cohorts.

### Pediatric cohort

Most youth living with GIST were reported to be in good (50%), very good (11%), or excellent (28%) general physical health. Twenty-two percent of the parents of pediatric patients reported their child had pain occurring at least a few days a week with 75% of those reporting this pain interfered with the child's daily life (Table 1). Pain was significantly associated with anxiety or panic attacks ( $X^2(1, n=17) = 7.4, p < 0.001$ ; Table 2). While 50% of the pediatric patients has had more than two surgeries with an average of 2.3 surgeries (range 1–10), there was no significant association between pain and the number of surgeries.

The predominant emotional complaints reported by the parents of pediatric patients were: their child becoming easily upset (50%), experiencing mood swings (67%), and having concerns about their appearance and body image (33%; Table 3). Thirty-three percent of pediatric patients had been seen by a mental health professional (17% currently). Eleven percent of pediatric patients ( $n=2$ ) were taking psychotropic medication for depression and 11% for anxiety (ever or currently). One was prescribed psychiatric medications by their oncologist and both had medications prescribed by a psychiatrist. Almost half of the parents of youth with GIST report post-trauma related symptoms related to their child's illness. Forty-four percent of parents of pediatric patients report having bad dreams about their child being ill, becoming jumpy since their child began treatment, and racing heartbeat or sweating/trembling when they think of their child being ill. Twenty-two percent of parents had sought the help of a mental health professional for their child.

The most frequently expressed need for services included education about disease and treatment (89%), opportunities for a child to meet others with GIST (89%), opportunities to meet other parents of children with GIST (72%), integrated complementary techniques for pain management (61%), support group for the child (61%), interventions to reduce the child's anxiety (61%), nutritional guidance (56%), and art/ music/writing/poetry therapy (50%; Table 4).

### Adult cohort

The majority of adult participants reported their physical health to be "good" (31%), "very good" (31%), or "excellent" (14%). Thirty-eight percent of adults reported experiencing pain at least a few days a week, over half of which report the pain interferes with their daily lives (Table 1). Experiencing pain at least a few days per week was associated with changing moods quickly ( $X^2(1, n=58) = 8.8, p < 0.01$ ), difficulty getting along with family ( $X^2(1, n=58) = 9.0, p < 0.05$ ), crying easily or becoming easily upset ( $X^2(1, n=59) = 5.6, p < 0.05$ ), becoming easily distracted ( $X^2(1, n=58) = 6.3, p < 0.05$ ), getting anxious when separated from family ( $X^2(1, n=59) = 6.2, p < 0.001$ ), and concerns about body image and appearance ( $X^2(1, n=59) = 8.6, p < 0.01$ ). Twenty-eight percent of adults has had more than two surgeries, with an average of 1.6 surgeries (range 0–6). The number of surgeries was not significantly associated with pain. Whether or not a patient had their tumor completely resected was not associated with pain or mental health concerns.

Emotionally, approximately one third of adult participants reported each of the following: crying easily or becoming easily upset (33%), having concerns about appearance or body image (33%), and feeling sad and withdrawn (30%; Table 3). Although 40% reported having been treated by a mental health professional, only 13% indicated they are currently being treated. Fifty-two percent of adults has ever taken psychiatric medications (27% currently). Forty-three percent of adults has taken anxiety medication (20% currently) and just under 1/3 has taken medication to treat depression (12% currently). Of the adults who have been prescribed psychotropic medication, 42% was prescribed these medications by their oncologist, 29% by a psychiatrist, and 10% by their primary care physician. Post-trauma symptoms were relatively prevalent in the adult cohort. Fifty-two percent reported that they have had bad dreams or nightmares about being ill at least sometimes, 40% report having become jumpy since starting treatment, and 43% report sweating, trembling, or heart racing when reminded about their illness. Concerns with body image were associated with sweating/trembling/racing heartbeat when thinking about their illness ( $X^2(2, n=59)=6.7, p<.05$ ) and with having bad dreams or nightmares about being ill ( $X^2(3, n=59)=7.6, p=.05$ ).

The most frequently expressed need for services included: education about blood counts, treatment options and current research (77%), opportunity to meet other patients with the same illness (75%), nutritional guidance (67%), integrated complementary techniques for pain management (50%), exercise opportunities for self or family (48%), and interventions to reduce anxiety (47%; Table 4).

## Discussion

The NIH GIST Clinic is the first international program designed to examine the biologic and genetic dimensions also the only program to investigate the psychosocial aspects associated with a GIST diagnosis.

Several interesting findings emerged. The first unexpected and provocative finding was the high number of participants who reported placement in a gifted program during school (22% adult cohort, 19% pediatric cohort). This is in contrast to the 5–7% of school children placed in gifted classes within the USA [15]. The higher intellectual abilities reported may be due to the highly motivated nature of the individuals who sought out the GIST clinic and higher socioeconomic status. Genetic explanations have not been ruled out and further exploration is warranted.

Second, as expected, a statistical association was found between perceived poor health and mood, anxiety, pain frequency, and higher use of psychotropic medication. Of concern is that living with pain at least a few days a week was endorsed by those who reported their health status as good to excellent (50% of the adult cohort and 75% of the pediatric cohort). In order to better understand how pain interfered with the participants' life, we explored whether reported pain was associated with other variables. Adults and youth who endorsed experiencing pain at least a few days a week reported significantly higher mood swings. An association of pain with anxiety and difficulties with family relationships were also found in the adult cohort. Parents who reported pain interfering with their child's life, endorsed significantly more behavior problems. Additionally, those who endorsed pain were



significantly more likely to be prescribed psychotropic medication. It is well understood that pain can transform one's life and can result in the sense of loss of self, impact relationships, and one's career [16]. Pain clearly plays a role in the emotional well-being of this cohort and our findings suggest that pain management may be a key intervention that would benefit those living with GIST to cope with the emotional as well as physical effects of their disease. In fact, techniques for pain management were one of the top requested services by both cohorts.

Third, as surgery is the frontline treatment for GIST and 37% of the adult participants had multiple surgeries, we also explored whether pain may be associated with the number or effects of surgery (partial or complete gastrectomy). We did not find an association. Not surprisingly, the group who endorsed pain most often were those whose disease had recurred (39%), followed by those who had not had their tumor resected (36% vs 50%, ns), which almost always correlates with extensive tumor burden at the time of diagnosis, and was lowest among those who were in remission (27%). Those who had not had their tumor resected also reported higher post-trauma symptoms and greater sadness and withdrawal. Better mental health for those who underwent resection may be due to a sense of security associated with knowing the disease has been surgically removed from the body. Similarly, breast cancer patients who underwent lumpectomy have been found to score significantly worse than mastectomy patients in terms of differences in mood disturbance for a period of time post baseline [17]. Whether pain is associated with treatment was not investigated in this study. Treatment toxicity from tyrosine kinase inhibitors such as imatinib (Gleevec®) or sunitinib (Sutent®) (nausea, diarrhea, fluid retention, fatigue) can clearly affect quality of life and nutritional choices, therefore studying the quality of life in the GIST population and the impact of treatment toxicities on mental health is clearly warranted. In fact, we were not surprised to see between 50% and 70% of patients endorse a need for nutritional services or more complimentary approaches to learning to live with pain and abdominal discomfort.

Fourth, while only two children were taking psychotropic medications, we were pleased to see that a psychiatrist prescribed the medication. This finding differed in the adult cohort in which only 29% of current psychotropic medication use (for depression or anxiety) was prescribed by a psychiatrist and the rest by internists or oncologists. The rate of medication being prescribed to treat anxiety and depression in this cohort is high (over a third of those who attended the clinic were currently taking medication for anxiety and/or depression), another finding that suggests that this is a cohort experiencing considerable emotional distress. Other indicators of distress include the endorsement of body image and appearance concerns by one third of the sample, a finding significantly associated with crying or becoming upset easily. Moreover, a relatively high endorsement of posttraumatic stress symptoms (nightmares, jumpiness, and trembling/fast heart beat) for both newly diagnosed and those living with GIST for over 15 years suggests distress as having long-term effects. Perhaps this is a population not considered to be at high risk of distress within the oncology community due to a more indolent or less aggressive disease course than other cancers.

Fifth, the participants were very clear about what services they feel would be useful to them. These include pain management, interventions to reduce anxiety, support groups and other mental health services. While if asked, all patients living with cancer may feel such services

would be useful to them, this study tied areas of distress to interventions believed to improve quality of life. Screening is a first step and we recommend that these patients be screened routinely, not just during medical emergencies. In the climate of limited resources, routinely identifying and addressing psychosocial risks, rather than addressing acute problems as they occur, may result in a more efficient use of resources [18].

### Limitations

This study is the first of its kind to study the psychological sequelae of youth and adults with wildtype GIST. There are several factors, however, which may limit the ability to generalize these findings. Only those who chose to participate in the GIST clinics were eligible to participate in this study, possibly resulting in self-selection bias. These patients may be healthier or more motivated to seek out support related to living with GIST than those who were not able to travel in order to participate in these clinics. The current sample included a very wide age range and time from diagnosis and it was not feasible to examine the psychological factors associated with living with GIST without separating youth from adults. While GIST is rare and our sample size represents one of the larger published studies on the disorder, our pediatric cohort was quite small ( $n=18$ ), limiting the power of the analyses within this subsample. Finally, the majority of the participants were white, female and highly educated. This may not represent the wider population of individuals living with GIST.

### Conclusion

This is the first study to explore the psychosocial impact of wildtype GIST. Our results suggest individuals living with GIST experience significant anxiety and have an expressed need for medication and other interventions to help them manage their anxiety. Pain also plays an important role in the emotional well-being of this cohort. Chronic pain in those living with GIST may contribute to higher health care costs, fewer annual hours worked, and school absence. Moreover, due to the indolent nature of pediatric and wildtype GIST, this population is at risk for long-term psychological distress and is in need of psychosocial interventions in pediatric and adult care settings. Future studies should use both parent and child reports to examine all aspects of quality of life. Longitudinal studies could help better understand the long-term impact of GIST on both pediatric and adult cohorts.

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**Table 1**Demographic information and health characteristics ( $n=78$ )

	<b>Pediatric cohort (<math>n=18</math>)</b>		<b>Adult cohort (<math>n=60</math>)</b>	
	<i>N</i>	% <sup>a</sup>	<i>N</i>	%
Gender				
Male	4	22.2	15	25.0
Female	14	77.8	45	75.0
Race/ethnicity				
White	11	61.1	52	86.7
African-American	5	27.7	1	2.0
Hispanic	1	5.6	2	4.0
Asian/Pacific Islander	1	5.6	3	6.0
Other	0	0	2	0
Age (mean, range)	14	9–18	38	18–66
History of gifted placement in school	4	22.2	13	21.7
# Abdominal surgeries (average, range)	2.3	1–10	1.6	0–6
Financial difficulties	9	50.0	29	48.3
Frequency of pain <sup>a</sup>				
Every day	1	5.9	11	18.6
A few days a week	3	17.6	12	20.4
About once a week	2	11.8	4	6.8
Infrequently	11	64.7	32	54.2
Pain interferes with patient's daily life	3	16.7	17	28.3

<sup>a</sup>Totals do not always equal 100 due to a small number of missing cases

**Table 2**

Correlation of pain with psychological variables

Psychological variable	Pain	
	Pediatric cohort	Adult cohort
Bad dreams/nightmares about being ill	-.47*	.66****
Jumpy since starting treatment	-.03	-.42****
Sweat/tremble/fast heartbeat when reminded of being ill	.21	.62****
Ever treated by MH professional	.27	.32**
Currently treated by MH professional	-.00	-.06
Every prescribed meds for anxiety	.32	.80****
Currently prescribed meds for anxiety	-.19	-.15
Ever prescribed meds for depression	.32	.61****
Currently prescribed meds for depression	-.19	-.19
Changes mood quickly	.43	.39***
Difficulty getting along with family	.20	.31**
Upset about going to doctor/dentist	-.03	.30**
Cries/becomes upset easily	.39	.33**
Easily distracted	-.17	.33**
Anxiety/panic attacks	.70****	.25
Sad/withdrawn	-.17	.19
Drugs/alcohol/other substances	-.17	-.16
Anxious when alone or separated from family	-.17	.41****
Difficulty making/keeping friends	-	.18
Concerns with body image	.14	.36***

Negative correlations indicate that the symptom was associated with less pain; positive correlations indicate that the symptom was associated with greater pain

\*  $p < 0.10$ ;

\*\*  $p < .05$ ;

\*\*\*  $p < 0.01$ ;

\*\*\*\*  $p < 0.001$

**Table 3**

## Mental health characteristics

	<u>Pediatric cohort</u>		<u>Adult cohort</u>	
	<i>N</i>	%	<i>N</i>	%
Mood changes quickly	12	66.7	12	20.0
Cry or easily upset	9	50.0	20	33.3
Anxiety/panic attacks	2	11.1	14	23.3
Sad/withdrawn	1	5.6	18	30.0
Body image concerns	6	33.3	20	33.3
Receiving mental health treatment	3	16.7	8	13.3
Taking medication for anxiety	2	11.1	12	20.0
Taking medication for depression	2	11.1	7	11.7
PTSD symptoms since diagnosis (at least sometimes) <sup>a</sup>				
Bad dreams/nightmares	8	44.4	30	51.7
Jumpy	8	44.4	24	40.0
Sweat, tremble, fast heart beat when reminded of illness	8	44.4	26	43.4

<sup>a</sup>The patients' parents answered these questions based on their own experience of these symptoms in contrast to other questions, which they answered with regard to their child's experiences

**Table 4**

## Requested services

	<u>Pediatric cohort</u>		<u>Adult cohort</u>	
	<u>N=18</u>	<u>%</u>	<u>N=60</u>	<u>%</u>
Education about disease, blood counts	16	88.9	46	76.7
Meet others with GIST	16	88.9	45	75.0
Meet other parents whose child has GIST	13	72.2	N/A	N/A
Pain management	11	61.1	30	50.0
Support group for child	11	61.1	N/A	N/A
Interventions to reduce anxiety	11	61.1	28	46.7
Art/music therapy, expressive writing/poetry	9	50.0	14	23.3
Nutritional counseling	10	55.6	40	66.7
Counseling for child (self/family for adults)	8	44.4	23	38.3
Exercise	7	38.9	29	48.3
Support group for self/family	5	27.8	21	35.0
Financial assistance	5	27.8	20	33.3

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