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## A qualitative analysis of adolescent, caregiver, and clinician perceptions of the impact of migraines on adolescents' social functioning

**Elizabeth Donovan**

Research Scientist, Inflexxion 320 Needham Street, Suite 100 Newton, MA 02464

**Stacey Mehringer**

Research Coordinator, Inflexxion 320 Needham Street, Suite 100 Newton, MA 02464

**Lonnie K Zeltzer**

Director, Pediatric Pain Program Department of Pediatrics David Geffen School of Medicine at UCLA Los Angeles, CA

### Abstract

Migraines dramatically affect adolescents' quality of life. One area of particular importance is the impact of migraines on adolescents' social functioning.

**Objective**—To understand the impact of migraines on adolescents' social functioning from multiple informants.

**Design**—Semi-structured interviews with adolescents who have migraines, their caregivers, and clinicians who treat adolescents who have migraines.

**Results**—Three major themes related to social functioning were identified from the adolescent interviews: The need to be alone; lack of support from siblings, and the feeling of not being understood by others. The caregiver interviews yielded three main themes related to family functioning: plans can change quickly; family life revolves around helping the child with the migraine, and parents' feelings of inadequacy in helping their child. There were two main themes derived from the clinician interviews related to perception of family functioning: importance of parental involvement, and the role of adolescents' school and social lives in migraine prevention.

**Conclusions**—There are a number of unmet needs among adolescents with recurrent migraine and their families. Interviews with adolescents, caregivers, and clinicians suggest a number of areas for intervention.

### Keywords

Adolescents; children; parents; migraine; headache; social functioning

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Approximately 6% of adolescents in the U.S. suffer from migraines (Winner, 2009). The impact of migraines on adolescents' quality of life is considerable, with recurrent pain

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Please address correspondence to: Elizabeth Donovan, Inflexxion Inc., 320 Needham Street, Suite 100, Newton, MA 02464. donovanelizabeth@gmail.com. Phone number: 617-614-0444..

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causing significant disruption to a wide range of areas of functioning (Petersen, Hagglof, & Bergstrom, 2009). A recent review of the literature found the level of impact of headache on the quality of life of children and adolescents to be substantial, most notably in days lost and affected at school (Kernick & Campbell, 2009).

Social functioning can be thought of as a subset of quality of life. While quality of life measures are typically multidimensional and incorporate physical symptoms and psychological functioning, social functioning is concerned with children's interest and performance across areas of social competence, including comfort in initiating and maintaining peer relationships, family relationships, and ease of involvement in other activities, such as school, extracurricular activities, and sports. Social connection to others can be a good indicator of current as well as longer-term emotional adjustment (Adams, Streisand, Zawacki, & Joseph, 2002). For the adolescent with migraines, social isolation might be a signal to parents and healthcare professionals of possible difficulties in disease management, adherence, or the adolescent's adjustment to the illness.

For adolescents with migraines, socializing with peers, home life and school life can all be impacted by the migraine experience. The unpredictable nature of migraine attacks can cause adolescents to miss extracurricular and social activities. Frequency and severity of migraines, as well as associated symptoms such as photophobia and phonophobia, may necessitate that the adolescent isolate himself/herself in a dark quiet room, a self-management process that can increase the likelihood of missing social and academic activities (Gregg, Cottrell, Gibson, O'Donnell, & Holroyd, 2003). A systematic review of the extant literature on social functioning and peer relationships in children and adolescents with recurrent or continuous chronic pain found that these individuals had fewer friends, were subjected to more peer victimization, and were viewed as more isolated and less likeable than their peers without recurrent or chronic pain (Forgeron et al., 2002).

Similarly to peer-related disruptions caused by migraines, family life is also impacted since plans can unexpectedly change (Hunfeld et al., 2001). The relationship between family functioning and adolescents with chronic or recurrent pain is a complicated one. A recent review (Palermo & Chambers, 2009) focused on parent and family factors—both specific parent behaviors and broader aspects of family functioning—that may contribute to children's experience of chronic pain. Individual variables, such as parenting style and parental reinforcement of pain behaviors or solicitousness, maladaptive parent-child interactions, and functioning of the family overall, contribute to the child's functioning and perception of pain. Additional differences were found based on children's age and gender.

Social functioning in school is difficult as adolescents with migraines have greater absenteeism than adolescents without migraines (Rees & Sabia, 2009). Families cannot “plan” for school absences by collecting classroom lessons or homework assignments in advance. On returning to school, children may be under added pressure to spend a significant amount of time completing old assignments while learning new material (Powers, Patton, Hommel, & Hershey, 2003). Functioning in school with a migraine is challenging as adolescents find it difficult to pay attention, focus and stay alert around the time of an attack (Hartmaier, DeMuro-Mercon, Linder, Winner & Santanello, 2000; Rees & Sabia, 2009). Such migraine-related academic strain can limit adolescents' ability to fully engage with friends and teachers and focus on schoolwork. Adolescents with migraines were found to have lower grades and were less likely to graduate from high school and attend college than were adolescents without migraines (Rees & Sabia, 2009).

The current qualitative study involved interviews with adolescents who had migraines, their caregivers, and clinicians to learn directly about the impact of migraines on social

functioning from the perspective of these three sets of informants. The goal was to learn about perceived barriers to communication and to functioning from these participants, as part of a larger study to develop an Internet intervention tool for this population of adolescents. The interviews with caregivers focused on the caregiver experience of the impact of their child's migraines on family life. The perspective on social disruption by clinicians with experience treating migraines in adolescents was sought to learn from a group of non-family informants.

## Method

### Participants

The convenience sample consisted of 12 adolescents with a physician-assessed diagnosis of migraine who were recruited through advertisements in local newspapers and one online community message board. Caregivers of these adolescents with migraines who were interested in participating contacted a research coordinator, who arranged a telephone screening interview. Caregivers and adolescents who met inclusion criteria (caregiver is 18 years or older; caregiver has an adolescent with a clinician-diagnosis of migraine; adolescent has been without pain for at least one day in the past seven) were emailed consent and assent forms. Eighty percent of participants who met inclusion criteria returned consent/assent forms. There were no significant demographic differences between those who did and did not return the signed forms. The adolescents ranged from 12–17 years (mean 14); half were female; seven identified as Caucasian, four as African-American, and one as Hispanic. Number of migraines in the past 30 days ranged from 0–15 (mean 4.7). Twelve caregivers (11 parents and one grandparent) ranged in age from 30–55 years of age (mean 48) and included nine females. Participants also included 12 clinicians who treated migraines in adolescents, but were not the treating clinicians of the adolescent participants. This cohort of clinicians were recruited via email by one of the authors (LZ) or by an advisory group of clinicians, and comprised 50% women, five psychologists, six physicians, and one nurse practitioner. Interested potential clinician participants were invited to contact the research coordinator, and those who met inclusion criteria (clinician treats adolescents with migraines) were emailed consent forms, with participants being those who returned written consent. All clinicians who met criteria participated. Adolescent participants were paid \$100 for their time and the caregivers and clinicians were paid \$200 each. The study was approved by New England IRB.

### Materials

The interviews were created as part of a larger study to develop an intervention tool for adolescents with migraine, with the interviews designed to broadly understand the day-to-day experience of living with, and managing, migraines. The interviews were created through a four-step process: 1. Literature review identifying the major categories of questions, 2. Initial draft of the interview, 3. Review of the draft by an advisory group of three well experienced clinicians who treat migraines in adolescents, and 4. a final set of interviews based on feedback from the clinician advisory group.

### Procedure

Adolescents and caregivers were interviewed separately at the Inflexxion study office. Clinician interviews were conducted by telephone, with the exception of one interview conducted in the clinician's office because of clinician preference. All interviews lasted about an hour. Adolescents (and therefore caregivers) were interviewed in person as it was assumed that some meaning may be lost, especially with the younger children, if the interviews were conducted by telephone. Clinicians were interviewed by telephone so as to

be able to recruit clinicians from around the country and therefore increase the chance of meeting our recruitment goal.

## Data Analysis

Using the principles of Grounded Theory (Corbin & Strauss, 2008) the interview data about barriers to engaging in self-management behaviors were coded by the research team and then quantitatively analyzed. The research team read all interviews multiple times in order to become familiar with the data. Using the principles outlined by Corbin and Strauss (2008), the team went through a process of comparing the data and revising codes in order to generate concepts. Two coders rated the concepts independently, with inter-rater reliability at 95% for adolescent data; 93% for caregiver data, and 84% for clinician data. The concepts were then examined carefully over a period of weeks to determine higher level themes. The research team met to discuss the themes and reconcile through discussion any gaps in logic.

## Results

Findings from each of the three groups—adolescents, caregivers, and clinicians—are reported. Three major themes related to social functioning were identified from the adolescent interviews: The need to be alone; lack of support from siblings, and the perception that people do not understand what it is like to have a migraine. The caregiver interviews yielded three main themes related to family functioning: plans can change quickly; family life revolves around helping the child with the migraine, and parents' feelings of inadequacy in helping their child. There were two main themes derived from the clinician interviews related to perception of family functioning: importance of parental involvement, and the role of adolescents' school and social lives in prevention.

### Adolescent themes

**Adolescents need to be alone**—Adolescents frequently mentioned that they felt the need to withdraw, often because a migraine left them in a bad mood or irritable:

- “I isolate, lock myself in a dark room, sleep”
- “Everything irritates. I avoid light and food; I am irritated by all people”
- “I don't talk to people”
- “Annoying. I can't go outside and I stay in a dark room”
- “You need to be alone when you are having one”

In addition, many adolescents expressed difficulty from their perception of not being able to be themselves around their friends:

- “People around can see the difference. I shut down; I'm in a bad mood, moody, irritable; I'm in sweatpants; it messes with my concentration. I feel crappy and bad for removing myself; guilty”
- “I don't smile as much. I'm not as playful and outgoing”
- “I feel bad when I let them down. The stress makes it worse. It's hard to explain that I've got a migraine”

**Lack of support from siblings**—While adolescents expressed regret at not being able to behave or communicate as they would like around their friends, a common theme associated with siblings was annoyance. Many adolescents expressed that siblings were not helpful at the time of a migraine and may make things worse:

- “She bothers me when I have a migraine, aggravates me. My eight-year old sister is aggravating; my two-year old sister is loud”
- “They make noise”
- “They are really loud. They argue. My brother is really loud”
- “She doesn't understand so she'll bug me about watching TV”
- “We don't get along. He almost likes that I get them. He's not sympathetic”

**People do not understand**—Adolescents frequently expressed that people—with the notable exception of parents—do not understand what it is like to have a migraine, and therefore there is little point in trying to communicate with them about the experience of having a migraine:

- “They don't understand because everybody is different. They aren't experiencing it. They may never have”
- “People don't understand how much noise and light hurts. Even if there's no yelling, it still hurts”
- “I don't talk to anyone apart from my mom because they can't do anything”
- “Nobody understands”
- “Friends can't relate. They don't understand the pain and frequency and how it disturbs quality of life”

Many adolescents made the explicit judgment that other people mistake migraines for headaches:

- “People don't understand the difference between a migraine and a headache”
- “People don't understand that it's more than a headache. It's more like the flu. It affects your whole body”
- “People don't understand the level of pain, the nausea, that it's more than a headache”

### Caregiver themes

Main themes expressed by caregivers included changes to family activities to accommodate a child who is experiencing a migraine; how the larger family dynamic changes, as well as feelings of helplessness experienced by the caregiver at the time of an adolescent's migraine attack.

**Plans change**—Caregivers frequently mentioned that their children's migraines affected family functioning because plans would have to be cancelled or changed:

- “If he has a migraine he wants to immediately lay down. If we had plans, they get cancelled”
- “I don't know if he's joking or not if I'm trying to go out on a date and he says he has a migraine”
- “It affects the overall pace of the day – I may have to change plans”

**Family life revolves around helping the child**—While on a practical level, plans may need to be changed, caregivers also discussed how the larger family dynamic changes as a

result of one child having a migraine, with attention now being directed toward the child with the migraine:

- “Everybody gets worried about it. They get stressed because she's not feeling well”
- “This past summer she was having headaches every day. Family plans were cancelled; we like to do outdoor things. Headaches caused us to have to stay home”
- “During the migraine we are homebound until she feels better; everybody has to be quiet”
- “We stop doing family things – get everyone quiet. I stop household activity and noise”

Furthermore, some caregivers expressed awareness of the imbalance the attention caused between siblings:

- “Sometimes it disrupts family plans. It detracts attention from her older sister who may need help with something”
- “They all get worried. His younger brother gets jealous because his brother is getting all the attention”

**Feelings of inadequacy in helping the child**—Finally, some caregivers expressed feeling bad or guilty about not being able to do more to help a child cope with a migraine. Some caregivers expressed feeling helpless and unsure about what to do:

- “She's moody, miserable, I feel helpless”
- “I just feel bad that I can't do more to help”
- “I wish I could make him feel more comfortable, talk with him along the way”
- “I feel really bad when it happens and wish I could do more”
- “I wish I could help her better when she's going through it”
- “I wish I could make it less burdensome for her”
- “I wish I could put better meals on the table more often”
- “I feel bad that she feels terrible, and I can't do more to help.”

### Clinician Themes

The clinician interviews revealed two main themes related to migraines and social functioning.

**Parents have to be on board**—To begin, clinicians expressed the important role that caregivers play in supporting treatment for adolescents with migraine.

- “Parents can help motivate adolescents to take care of themselves. They need to pay attention to the child and take the condition seriously”
- “Parents have to be on board”
- “A helpful parent is someone who is willing to be on board, to participate, to support treatment – driving and paying for treatment, waking up on the weekends”

However, clinicians also expressed that parental involvement needs to strike a sensitive balance between actively encouraging a child to self-manage migraines while also promoting independence.

- “Parents need to help kids to self-manage instead of regressing, not cater to them. They need to learn how to self-manage rather have Mom or Dad fix it”
- “Parents should minimize talking about pain all the time, and not let kids get out of things because of headaches or overly rely on them”
- “They are afraid to treat them normally. They have to learn how to be tough while still validating the pain”
- “A [helpful] parent [is one] who is supportive, not pushy, and encourages independence”

**Adolescents' school and social lives prevent adolescents' from taking care themselves**—In terms of social functioning outside of the home, clinicians expressed concern that typical adolescent schedules make self-management difficult. Some clinicians also expressed that communicating about these issues may be difficult for some adolescents:

- “Parents really push kids—extracurricular and AP classes—the parent really pushes but expectations need to be adjusted”
- “The biggest barrier to them getting sleep is homework, social activity and being overly scheduled. Facebook”
- “They don't know how to talk with teachers — how to communicate with teachers and school nurses”

## Discussion

In the current study, we conducted interviews with adolescents, caregivers, and clinicians who treat adolescents with migraine, to learn about the impact of migraines on social functioning. Adolescents provided a first-hand account of the experience of managing a migraine within social contexts, and caregivers provided insight into how family life changes when a child experiences a migraine. Finally, clinicians provided a perspective based on their interactions with families. The current findings add to the body of literature that examines how recurrent pain affects the social functioning of adolescents and their families.

There were several findings of interest. First, adolescents reported difficulty communicating with others about their experience with migraines. Their experience seemed to be a push-pull between the desire to isolate themselves as a migraine self-management strategy, while needing, but not knowing how, to communicate with others about their experience. Overall, adolescents reported that they did not believe that others would understand what it feels like to have a migraine. In the case of interacting with friends, this led to negative feelings about self-image; whereas, with siblings, it led to tension and aggravation. Second, caregivers described how family life changes to accommodate a child with a migraine. In particular, sibling-related concerns were again raised with some parents choosing to discuss how siblings sometimes felt jealous or neglected as a result of the household being focused on the child with a migraine. Finally, clinicians discussed the importance of parental involvement in self-management, but cautioned that a key component was to promote their adolescent's independent self-management skills.

The current study was conducted as part of a larger study to test the feasibility of an online self-management tool. While the sample size was appropriate for the overall goals of the larger study, it does not permit results to be generalized to the larger population, also a common limitation to qualitative research more generally. All families resided in the Northeast, a geographic confounder that also limits generalizability.

Our findings provide several implications for future interventions. First, a number of self-management skill-building interventions have been found to be effective for adolescents with migraine (Cottrell, Drew, Gibson, Holroyd & O'Donnell, 2007; Trautman & Kroner-Herwig, 2009). Our results suggest that a special focus on communication skills in order to increase social support may be an important component of these types of interventions. Themes from the adolescent interviews in our study suggest that isolation and lack of social support are concerns in this young population, as adolescents expressed feeling little social support from friends or siblings at the time of a migraine. Results from the clinician interviews suggested that adolescents would also benefit from learning how to communicate with school teachers and nurses about their needs.

Second, our results echoed themes reported in numerous other studies regarding the tremendous amount of stress that is placed on family functioning when a child suffers from episodic or chronic pain (Lewandowski, Palermo, Stinson, Handley, & Chambers, 2010). Our results further support the need for family-based interventions. Clinicians specifically expressed the need for caregivers to strike a sensitive balance between remaining engaged in care while promoting independent self-management skills, while caregivers in our study expressed not knowing how to help, and feeling bad and worried about not being able to do more. The results support the need for training for caregivers to learn how to promote self-management skills in adolescents with migraine, as well as how to engage in self-care.

Third, our results also suggest that in the case of families where a child suffers from episodic migraines, it may be beneficial to include siblings in interventions in order to help them find a meaningful family role in relation to their sibling with migraines. A major theme among the adolescent participants was tension with siblings at the time of a migraine. No adolescent participant expressed that a sibling was helpful or provided a source of comfort. Some caregiver participants independently expressed the belief that siblings may feel neglected, or jealous of the attention paid to a sibling during a migraine attack. Increased family functioning is associated with decreased child pain, (Lewandowski, Palermo, Stinson, Handley, & Chambers, 2010) further highlighting the benefit of intervention that includes attention to sibling relationships.

Social functioning is impaired as a result of recurrent pain. The present qualitative study provided further insight into the experience of adolescents with migraines with suggestions of how interventions may target specific areas of difficulty.

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**Table 1**

Demographic characteristics of adolescents (N=12)

Adolescent Characteristics		Frequency	Percentage
Gender	Male	4	33.33%
	Female	8	66.67%
Race	Caucasian	7	58.33%
	African American	4	33.33%
	Hispanic	1	8.33%
Age	12–14	6	50%
	15–17	6	50%
Age Diagnosed	7–9	4	33.33%
	10–12	6	50%
	13–16	2	16.67%
#of Migraines in the last 30 days	0–2	5	41.67%
	3–5	3	25%
	6–8	2	16.67%
	9–15	2	16.67%

**Table 2**

Demographic characteristics of caregivers of adolescents with migraine (N=12)

Caregiver Characteristics		Frequency	Percentage
Gender	Male	3	25%
	Female	9	75%
Race	Caucasian	5	41.67%
	African American	5	41.67%
	Hispanic	2	16.67%
	Other	0	0%
Age	Under 39	2	16.67%
	40 & Over	10	83.33%

**Table 3**

Demographic characteristics of clinicians who treat adolescents with migraine (N=12)

Expert Characteristics		Frequency	Percentage
Gender	Male	6	50%
	Female	6	50%
Race	Caucasian	8	66.67%
	African American	3	25%
	Asian/Pacific Islander	1	8.33%
Degree	PsyD	1	8.33%
	LPN	1	8.33%
	MD	6	50%
	PhD	4	33.33%
Job Role	Director of clinic	3	25%
	Nurse	1	8.33%
	Academic	2	16.67%
	Neurologist	2	16.67%
	Other	4	33.33%