

Statistical Report for Opioid Multiple Myeloma Pain Survey:

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Executive Summary

This report presents findings from a comprehensive survey exploring pain management and opioid use among patients with multiple myeloma. The survey, conducted through HealthTree Cure Hub, aimed to understand the frequency, causes, treatment patterns, and barriers to pain management, with a particular focus on opioid risk. The analysis segmented patients by opioid risk categories and included both parametric and non-parametric statistical comparisons.

Key Findings:

- High Prevalence of Pain: 55% of respondents reported experiencing daily pain (n = 219), and 28% took prescription medications for pain daily (n = 110) (Q1, Q2).
- Persistent Pain in Remission: Half of respondents (50%, n = 175) continued to experience pain despite being told they were in remission (Q5).
- Underreporting of Pain: 27% of patients admitted to understating their pain to their doctors, with 3% also overstating at times (Q11).
- Barriers to Effective Pain Management: Fear of addiction (37%, n = 127) and low satisfaction with pain medications (28%, n = 96) were among the most reported barriers (Q8).
- Opioid Risk Profiles: 73% were categorized as low risk, 17% moderate, and 10% high risk based on the Opioid Risk Tool (Q31).
- **Risk Profile Utility**: Higher risk patients were not more likely to miss use or have risky behaviors around prescription pain medications.

In summary: These findings highlight a critical gap in pain management for myeloma patients, particularly the large proportion who continue to experience daily or remission-resistant pain. Despite relatively low opioid risk profiles, many patients underreport pain and face significant barriers to effective treatment, underscoring the need for safer, more accessible alternatives.

Scientific Summary

Background

Effective pain management is crucial in the comprehensive care of multiple myeloma (MM) patients. Pain, whether due to disease progression, treatment side effects, or unrelated comorbidities, can severely impact quality of life. Despite advances in treatment, many MM patients continue to experience persistent or chronic pain. Opioids remain a key component of pain management, but their use is complicated by risks of dependence, side effects, and societal stigma. The Opioid Risk Tool (ORT) is commonly used to assess the potential for opioid misuse.

The burden of pain and associated opioid use in MM has not been extensively characterized from the patient perspective. This study aims to address this gap by surveying MM patients on their pain experiences, opioid use, perceived effectiveness of pain treatment, and risk factors for opioid misuse.

Study Objectives

- Characterize pain frequency, severity, and impact in MM patients.
- Assess patterns of opioid and non-opioid pain management strategies.
- Evaluate patient-reported barriers to pain treatment.
- Compare risk profiles using the Opioid Risk Tool and analyze correlations with pain experiences and management.

Study Design and Methodology

This observational, cross-sectional survey study was conducted via HealthTree Cure Hub, targeting patients diagnosed with multiple myeloma, SMM, MGUS, or related conditions. The survey consisted of 23 questions covering demographics, pain experience, opioid use, and social determinants. It also included the ORT to stratify patients by opioid misuse risk.

The survey question set was developed by Craig C. Hofmeister, MD, MPH, Emory Winship Cancer Institute and Karen Sweiss, PharmD, University of Illinois Chicago, reviewed, and adjusted by HealthTree's Patientw Advocacy Panel. The questions were deemed minimal risk and approved by the WCG Institutional Review Board.

Recruitment occurred via email to platform users, and data were collected and analyzed using R, Knitr, and LaTeX. All patients (>11,000) on the Cure Hub platform were notified that the survey was available via e-mail. First promoted on may 3rd, 2023; the data was pulled on July 29th, 2023.

Descriptive statistics and chi-square tests were used for group comparisons.

Results

Demographics

A total of 507 multiple myeloma patients initiated the survey. Of those, 473 provided age data, with a mean age of 65.8 ± 10.5 years. Among 457 respondents, 59% (n = 270) identified as female and 41% (n = 187) as male.

Racial identity was provided by 410 individuals: White (90%, n = 368), Black or African American (8%, n = 33), American Indian or Alaska Native (2%, n = 8), Asian (1%, n = 6), and others (Middle Eastern, East Indian, Native Hawaiian, etc.) accounting for less than 1% each.

Ethnicity was reported by 406 participants: Not Hispanic or Latino/a (90%, n = 367), Hispanic or Latino/a (7%, n = 30).

Marital status (406 responses): Married (77%, n = 311), Divorced (9%, n = 35), Never married (6%, n = 25), Widowed (5%, n = 22).

Education level (403 responses): Graduate/professional degree (41%, n = 167), College degree (33%, n = 133), Some college or associate's degree (17%, n = 68).

Insurance coverage was nearly universal among 322 respondents: 98% (n = 317) reported having insurance.

Risk and Psychosocial History

• Substance History (Q32): Of 362 respondents, 87% (n = 316) reported no history of illicit or misuse of substances. Others reported use of illegal drugs (7%, n = 26), problematic alcohol use (4%, n = 16), or non-medical prescription use (1%, n = 4).

- Family Substance History (Q33): Of 362 respondents, 25% (n = 92) reported family history of problematic alcohol use. Smaller numbers had illegal drug use (9%, n = 32) or prescription misuse (8%, n = 30) within their family.
- Trauma History (Q34): 11% (n = 39) of respondents indicated they had experienced a non-consensual sexual act during adolescence.
- Mental Health History (Q35): 19% (n = 68) of respondents reported a psychiatric diagnosis such as ADHD, bipolar disorder, or depression.
- Social Barriers (Q36): 15% of patients (n = 53 of 362) reported current struggles with transportation, social/emotional health, or housing insecurity, while 85% (n = 309) reported none of these concerns.

Opioid Risk Classification (ORT-Based)

Based on responses to the Opioid Risk Tool (Q32–Q40), patients were classified into the following risk categories:

- Low Risk: 73% of respondents
- Moderate Risk: 17%
- High Risk: 10%

Differences in trauma, psychiatric diagnosis, and social instability were significantly more frequent in the moderate and high-risk groups (p < 0.05). This stratification provides a validated framework to understand the risk of opioid misuse among surveyed MM patients.

Q1: Pain Frequency

Most patients (55%, n = 219) reported experiencing daily pain, 24% (n = 95) experienced it rarely, and only 10% (n = 38) reported no pain. Pain was a regular part of daily life for the majority of respondents. (Q1)

Q2: Frequency of Prescription Pain Medication Use

Half of the respondents (50%, n = 199) did not take prescription pain medications in the past 30 days, while 28% (n = 110) took them daily and 22% (n = 86) took them intermittently. This suggests a gap between pain prevalence and the use of prescribed treatment. (Q2)

Q3: Pain Severity

Among those reporting pain, the majority rated it as moderate (4-6), while a substantial portion rated it as severe (7-10). (Q3)

Q4: Source of Pain

Patients most frequently attributed their pain to myeloma (e.g., lytic lesions or fractures) or treatment-related causes like neuropathy. Some reported being unsure of the source, indicating a potential area for education and assessment. (Q4)

Q5: Pain Despite Remission

Half of patients (50%, n = 175) continued to experience pain even after being told they were in remission. This finding highlights persistent pain as a chronic concern in myeloma care. (Q5)

Q6: Opioid Use in Remission

Among those in remission, a notable portion reported continued opioid use, suggesting persistent pain management needs. Patterns varied by risk group, with higher usage among moderate- and high-risk patients. (Q6)

Q7–Q7.10: Pain Interference with Daily Functioning

Pain interfered with hygiene (Q7.1), dressing (Q7.2), toileting (Q7.3), mood (Q7.4), movement (Q7.5), eating (Q7.6), walking (Q7.7), work (Q7.8), relationships (Q7.9), and sleep (Q7.10), with $\sim 20-60\%$ of patients reporting some level of disruption in each category. High-risk patients reported more frequent limitations across all areas. (Q7.1–Q7.10)

Q8: Barriers to Pain Treatment

The most commonly cited barriers were fear of addiction (37%, n = 127), low effectiveness (28%, n = 96), and concerns of being a bother to their care team (14%, n = 48). High-risk patients reported more barriers, including social concerns and stigma. (Q8)

Q9: Pain Treatment Adequacy

30% (n = 105) of respondents felt their pain was not adequately treated, and this was more common among moderate- and high-risk groups. (Q9)

Q10: Frequency of Pain Discussions

Only 44% of patients said they discussed pain at every oncology visit, while 21% reported rarely or never doing so. High-risk patients were more likely to report infrequent communication. (Q10)

Q11: Misreporting Pain

About 24% of patients admitted to intentionally understating their pain, and 3% reported overstating it. This was more common among moderate-risk patients, often driven by fears of being seen as difficult or having treatment withdrawn. (Q11)

Q12: Reasons for Misreporting

Common reasons for misreporting included fear of being removed from current treatments, feeling unheard by providers, and concern about triggering new treatment starts. These concerns were particularly prevalent in the high-risk group. (Q12)

Q13: Pain Management by Other Providers

Outside the oncology team, 28% of patients received pain support from primary care, and 16% from a pain clinic. Multidisciplinary management was more common among high-risk individuals. (Q13)

Q14: History of Opioid Use

Nearly three-quarters of patients (73%) reported having used opioid medications at some point to manage pain. Opioid use was more common among those with high pain frequency and among higher opioid risk groups. (Q14)

Q15: Declining Opioids

46% of patients had declined an opioid at some point, with the most cited reason being fear of addiction (58%), followed by concerns about side effects and ineffectiveness. Stigma and social concerns were more frequently cited among high-risk patients. (Q15)

Q16: Reasons for Declining Opioids

Patients who declined opioids frequently cited fear of addiction, inadequate pain relief for pain medications, and concerns that it will burden family or caregiver. Social and religious factors were also reported, particularly among moderate- and high-risk patients. (Q16)

Q17: Timing of Opioid Use

Among opioid users, most reported starting opioids after their myeloma diagnosis, though a notable minority had used opioids prior. Pre-diagnosis use was more common among high-risk respondents. (Q17)

Q18: Current Opioid Use

At the time of the survey, 43% of respondents were actively using opioids for pain management. (Q18)

Q19: Opioid Denial by Providers

Only 5% of opioid users reported that a provider had at some point declined to prescribe opioids. (Q19)

Q20: Discussion of Opioid Discontinuation

Just under half of patients (47%) had discussed stopping opioid use with their oncology team. This topic was more commonly brought up with high-risk individuals. (Q20)

Q21: Opioid Education from Oncology Team

Two thirds (67%) of respondents felt well or very well educated about opioid medications by their oncology provider, while one third (33%) reported minimal or no education. (Q21)

Q22: Non-Prescription Strategies to Avoid Opioids

Patients used a range of alternative strategies to manage pain, including heat (59%), physical therapy (52%), exercise or yoga (47%), and massage/acupuncture (40%). Use of these alternatives was more prevalent in higher-risk groups. (Q22)

Q23: Opioid Use During Transplant

Among patients who received a stem cell transplant, over half reported using opioids (58%) with 15% using opioids for the first time. (Q23)

Q24: Discharge on Opioids Post-Transplant

Of those who received opioids during hospitalization, 45% were discharged on continued opioid medications. (Q24)

Q25: Duration of Opioid Use Post-Hospitalization

Among those discharged on opioids, 72% used them for less than 3 months, while 22% used them for more than 3 months. (Q25)

Q26: Concern About Addiction

One third (36%, n = 134) of patients expressed at least some concern about becoming addicted to opioid medications, with 17% (n = 65) reporting they were "very" or "extremely" concerned. (Q26)

Q27: Non-Opioid Medications Prescribed by Myeloma Doctors

Acetaminophen (48%) and NSAIDs (15%) were the most commonly prescribed non-opioid medications, followed by anticonvulsants (e.g., gabapentin or Lyrica, 15%) and antidepressants (12%). Cannabis or THC-based products were prescribed to 9% of patients. (Q27)

Q28: Overuse of Prescribed Opioids

Among those who had taken opioids, 17% admitted to using them more frequently than prescribed. (Q28)

Q29: Concurrent Use with Benzodiazepines

About 16% of patients reported taking opioids alongside medications like Ativan or Klonopin, while another 8% were unsure. (Q29)

Q30: Additional Benefits of Opioids

Beyond pain relief, some patients reported that opioids helped with sleep (37%), anxiety (12%), and depression (6%). These perceived mental health benefits were more frequently endorsed by high-risk individuals. (Q30)

Q31: Risk Behaviors Around Opioid Use

A minority of patients reported risky behaviors such as requesting early renewals (3%), stockpiling opioids (4%), or increasing their dose without provider approval (3%). (Q31)

Conclusion

This survey reveals that pain remains a pervasive and persistent issue for multiple myeloma patients, with 55% reporting daily pain and half of respondents experiencing pain even during remission. Despite the high prevalence of pain, prescription opioid use remains inconsistent—only 28% of respondents use opioids daily, and nearly half have declined them due to fears of addiction, side effects, or ineffectiveness. Patients consistently attributed their pain to either their myeloma or its treatment, and over half experienced moderate to severe levels of discomfort that interfered with basic physical and emotional functioning.

Communication gaps between patients and providers were evident: only a third of patients discussed pain at every oncology visit, and nearly 30% admitted to understating their pain, often due to fears of treatment withdrawal or not being taken seriously. High-risk patients were particularly more likely to struggle with relationship with others, understate their pain, have had prior opioid use, be declined opioids by a provider, and try alternative therapies to treat their pain. Counter to the purpose of the ORT tool, these high risk participants were NOT more likely to engage in risky behaviors with perscription pain medications. Additionally, over one third of respondents felt inadequately educated by their care team about opioid use, indicating a substantial need for improved patient-provider communication and education.

Pain management was often fragmented across providers, with many patients receiving support from both oncologists and external specialists. While opioids were commonly used, a significant portion of patients also utilized non-opioid treatments and complementary strategies, including heat, physical therapy, acupuncture, and cannabis. Notably, a majority of patients expressed concern about addiction, and a small subset reported behaviors associated with opioid misuse—which was not elevated among moderate- and high-risk respondents, questioning the relevance of the ORT framework in identifying at-risk myeloma patients.

Overall, these findings highlight a critical gap between the burden of pain experienced by multiple myeloma patients and the consistency, effectiveness, and safety of pain management strategies currently in place. Addressing this gap will require a multifaceted approach: improving provider training and patient education, enhancing cross-disciplinary pain management, and developing evidence-based alternatives that meet the unique needs of high-risk patients living with chronic or treatment-related pain.

Patient Friendly News Article

How Myeloma Patients Manage Pain—and What They're Not Telling Their Doctors

Living with multiple myeloma often means living with pain. For many patients, that pain doesn't go away—even when the cancer seems to. A recent survey conducted by HealthTree Cure Hub gathered insights from over 500 myeloma patients about how they experience and manage pain, particularly focusing on opioid use, communication with doctors, and the impact of pain on daily life.

What We Found

Half (50%) of patients still had pain even after being told they were in remission. This finding was one of the most striking—suggesting that cancer control doesn't always mean comfort. Many patients are still grappling with bone pain, nerve pain, or treatment-related side effects long after their disease is under control.

More than one in four patients admitted they had sometimes kept the true extent of their pain from their doctors. Why? Some were afraid of being seen as complaining. Others were worried they'd be taken off treatments that were otherwise helping them. In fact, 27% said they had understated their pain, and a smaller number (3%) said they sometimes overstated it.

Opioid medications like morphine or Vicodin are commonly used to treat severe pain—but they come with complicated emotions. 46% of patients reported having declined opioid treatment at some point, and more than half of them (58%) said they did so because they feared addiction. Others mentioned concerns about drowsiness, mental fog, and social stigma.

Patients also reported that pain gets in the way of daily living. Pain interfered with hygiene, sleep, walking, mood, and work. More than 50% said pain disrupted their ability to get up, move around, or rest comfortably. Only 19% felt their pain medications were very effective, and 30% believed their pain wasn't being adequately managed.

Communication was another concern. Only 44% of patients said they talked about pain with their oncology team at every visit, and 21% said they rarely or never discussed it at all.

Other key findings include:

- Nearly 81% (n = 274) of patients said pain affected their mood or emotional well-being.
- Patients commonly used non-opioid strategies like heat (59%), physical therapy (52%), and exercise or yoga (47%), and massage or acupuncture (40%) to cope with pain.
- One third of patients (33%, n = 92) said they would like more education about pain management options.
- A minority of patients (17%, n = 48) admitted to taking more medication than prescribed, particularly in higher-risk groups.
- Patients categorized as higher risk for opioid misuse were more likely to struggle with relationship with others, understate their pain, prior opioid use, be declined opioids by a provider, and try alternative therapies to treat their pain.
- Patients categorized as low risk were more likely to have issues eating from the pain they experience.
- Critically, the high risk patients were NOT more likely to engage in risky perscription pain medication behaviors.

Why It Matters

Pain doesn't just affect the body—it changes how people sleep, move, work, and interact with loved ones. When pain is underreported or undertreated, it can quietly erode a patient's quality of life. This survey shows that fears about addiction, stigma, and communication gaps may prevent myeloma patients from getting the relief they need. It also highlights the need for safer, more diverse, and better-communicated options for managing chronic pain.

Next Steps

At HealthTree, we believe in amplifying patient voices. Surveys like this help bring clarity to issues that often go unnoticed in clinical care. We're committed to using these insights to improve education, support, and treatment pathways for myeloma patients living with pain.

If you're navigating myeloma and experiencing pain, know this: you're not alone, and your pain is valid. Talk openly with your care team. Ask questions. Share your fears. Better communication leads to better care—and less pain.

"The fact that over 50% of patients are still experiencing bone pain in remission is striking. We must find better, safer, and more personalized ways to manage that pain. Opioids are just one piece of the puzzle—and our community needs more options." — The HealthTree Research Team

Demographics

Question	n (%)
Age	
responses / total surveyed	473 / 507
Mean \pm SD	$65.8{\pm}10.5$
Sex	
responses / total surveyed	457 / 507
Female	270 (59%)
Male	187 (41 %)
Race	
responses / total surveyed	410 / 507
White (Original ancestry from Europe, Middle East, North Africa)	368 (90%)
Black or African American (Original ancestry from Africa)	33~(~8~%)
American Indian or Alaska Native (Original ancestry from North, Middle and South America)	8(2%)
Asian (Original ancestry from the Far East and Southeast Asia)	6 (1%)
Other	6 (1%)
Middle Eastern (West Asia and Egypt)	3 (1%)
East Indian (South Asia and India)	2(0%)
I do not wish to provide this information	2(0%)
Native Hawaiian or other Pacific Islander (Original ancestry from Hawaii, Guam, Samoa, Pacific Islands)	2(0%)
Ethnicity	
responses / total surveyed	406 / 507
Not Hispanic or Latino/a	367 (90 %)
Hispanic or Latino/a	30(7%)
I do not wish to provide this information	9(2%)
Which of the following have you ever been diagnosed with?	
responses / total surveyed	130 / 507
Multiple Myeloma	108 (83 %)
Smoldering Myeloma (SMM)	29(22%)
Monoclonal Gammopathy of Undetermined Significance (MGUS) Solitary Plasmacytoma	22(17%)
Amyloidosis & Plasma Cell Dyscrasia	6(5%) 2(2%)
Primary Plasma Cell Leukemia (PCL)	2(2%) 2(2\%)
	2 (270)
Marital Status	406 / 507
responses / total surveyed Married	406 / 507 311 (77 %)
Divorced	35(9%)
Never married	25(6%)
Widowed	22(5%)
Living with someone in marriage-like relationship	8 (2%)
Separated	5(1%)
Education Level	
responses / total surveyed	403 / 507
Graduate degree or professional school	167 (41 %)
College degree (bachelors or equivalent)	133(33%)
Some college or associate's degree	68 (17%)
Vocational or technical school beyond high school	16 (4 %)
High school graduate	17 (4%)
Some high school	2 (0 %)
Do you have Insurance?	
responses / total surveyed	322 / 507
Yes	317 (98 %)
No	5 (2%)
What type of Health Insurance do you have?	. ,
responses / total surveyed	316 / 507
	/
onfidential: For participating patients only this report contains aggregated data from patient urvey responses. Not intended for public or third-party distribution.	

(continued)

Question	n (%)
Private commercial insurance through work	141 (45%)
Medicare Part A	$124\ (\ 39\ \%)$
Medicare Part B	111 (35 %)
Medigap or Medicare supplemental	$68\ (\ 22\ \%)$
Medicare Part D	57 (18 %)
Medicare Advantage	44 (14%)
Private commercial Insurance through a personal plan	$38\ (\ 12\ \%)$
Medicaid	$9\ (\ 3\ \%)$
Other	$29\ (\ 9\ \%)$
I don't feel comfortable answering this question	1 (0 %)
Employment Status	
responses / total surveyed	287 / 507
Retired	$155\ (\ 54\ \%)$
Full-time work	$64\ (\ 22\ \%)$
On disability	$36\ (\ 13\ \%)$
Part-time work	30~(~10~%)
Contract work	2(1%)
Do you have difficulty with transportation?	
responses / total surveyed	148 / 507
No	$141\ (\ 95\ \%)$
Yes	7(5%)
How close do you live to your myeloma treatment center?	
responses / total surveyed	174 / 507
0-5 miles (0-8 km)	88 (51 %)
6-20 miles (9-32 km)	47 (27 %)
21-50 miles (33-80 km)	16 (9 %)
51-100 miles (81-128 km)	12 (7%)
Over 100 miles (128 km)	11 (6 %)

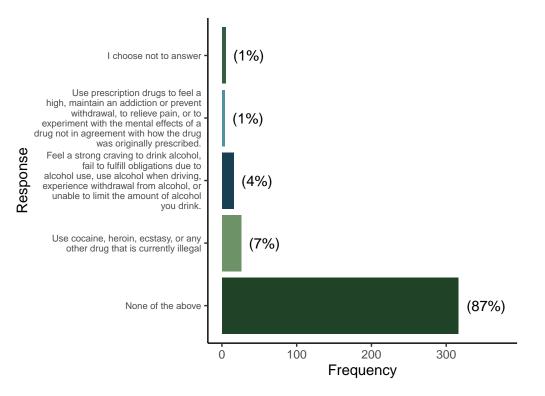
Opioid Risk Tool

Questions 32-40 will ask you questions that are taken directly out of a widely used measurement tool called the **Opioid Risk Tool**. The Opioid Risk Tool is a brief, self-report screening tool that was designed to **assess risk for opioid abuse** among patients prescribed opioid medicines for treatment of chronic pain. This tool is well established and validated and used in the clinic to determine this risk. <u>Here is the reference for this tool</u>: LR, Webster R. Predicting aberrant behaviors in Opioid-treated patients: preliminary validation of the Opioid risk too. Pain Med. 2005; 6 (6): 432.

Answering these questions <u>as honestly as possible</u> will help us understand the prevalence of high-risk opioid use among patients with multiple myeloma and validate the use of this tool in myeloma patients. This data will help us in the future as we look for ways to improve the way these opioid medicines are prescribed long-term.

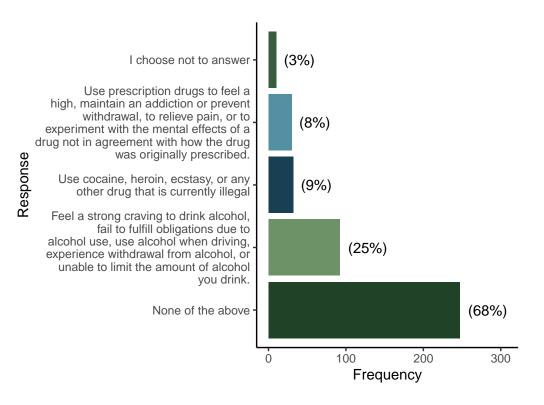
Q32: Did you Ever (Select all that Apply)

Response	n (%)
responses / total surveyed	362 / 507
None of the above	316~(~87~%)
Use cocaine, heroin, ecstasy, or any	26 (7%)
other drug that is currently illegal	
Feel a strong craving to drink alcohol, fail to fulfill obligations due to alcohol use, use alcohol when driving, experience withdrawal from alcohol, or unable to limit the amount of alcohol you drink.	16 (4%)
Use prescription drugs to feel a high, maintain an addiction or prevent withdrawal, to relieve pain, or to experiment with the mental effects of a drug not in agreement with how the drug was originally prescribed.	4 (1%)
I choose not to answer	5(1%)



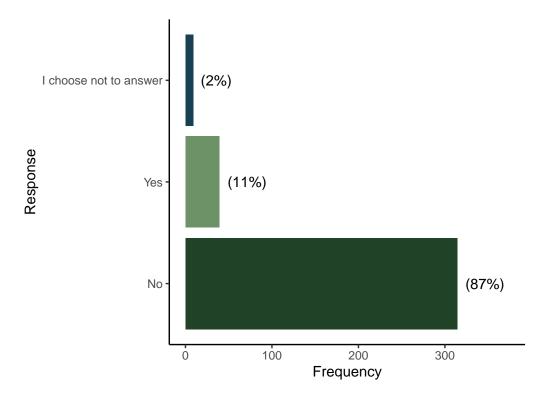
Q33: Did anyone in your family ever struggle with the following (Select all that Apply)

Response	n (%)
responses / total surveyed	362 / 507
Feel a strong craving to drink alcohol,	92~(~25~%)
fail to fulfill obligations due to alcohol	
use, use alcohol when driving,	
experience withdrawal from alcohol, or	
unable to limit the amount of alcohol	
you drink.	
None of the above	247 (68 %)
Use cocaine, heroin, ecstasy, or any	32 (9%)
other drug that is currently illegal	
Use prescription drugs to feel a high,	30 (8%)
maintain an addiction or prevent	
withdrawal, to relieve pain, or to	
experiment with the mental effects of a	
drug not in agreement with how the	
drug was originally prescribed.	
I choose not to answer	10 (3%)



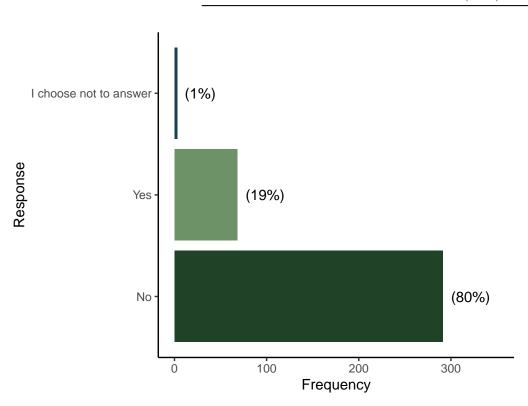
Q34: When you were an adolescent, did you ever experience a sexual act without your consent?

Response	n (%)
responses / total surveyed	362 / 507
No	314 (87 %)
Yes	$39\ (\ 11\ \%)$
I choose not to answer	9 (2%)



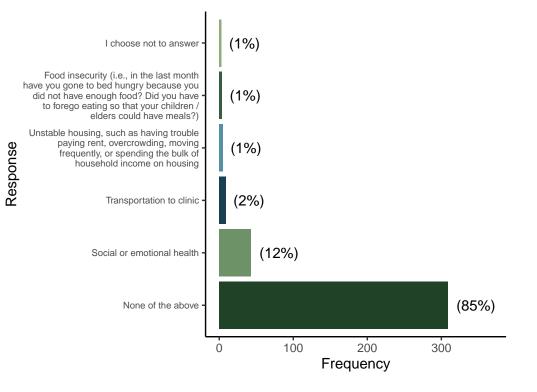
Q35 Have you ever been diagnosed with attention deficit disorder, obsessive compulsive disorder, bipolar affective disorder, schizophrenia, depression, or similar psychiatric diagnosis?

Response	n (%)
responses / total surveyed	362 / 507
No	291~(~80~%)
Yes	$68\ (\ 19\ \%)$
I choose not to answer	3(1%)



Q36: Do you struggle with any of the following? [may choose more than 1 answer] (Select all that apply)

Response	n (%)
responses / total surveyed	362 / 507
None of the above	309~(~85~%)
Social or emotional health	43 (12%)
Transportation to clinic	9(2%)
Unstable housing, such as having trouble paying rent, overcrowding, moving frequently, or spending the bulk of household income on housing	5 (1%)
Food insecurity (i.e., in the last month have you gone to bed hungry because you did not have enough food? Did you have to forego eating so that your children / elders could have meals?)	4 (1%)
I choose not to answer	3 (1%)

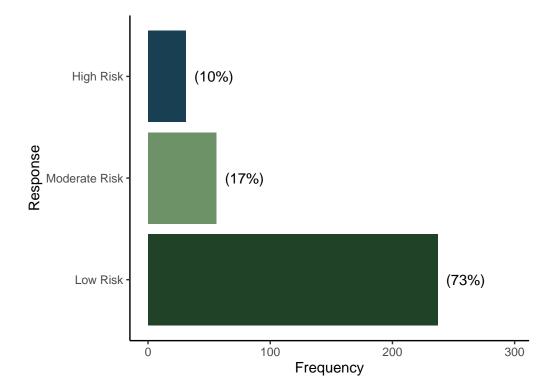


		Response	n (%)
		Not Within Risk Age Group	455 (90 %)
			34 (7%)
		Within Risk Age Group	18 (4%)
Response	Within Risk Age Group - Age Missing -	(4%) (7%)	
LL.	Not Within Risk Age Group -	0 100 200 300 400	(90%)
		Frequency	

Age in Risk Category? (Between 16 - 45 years of age)

Total Opioid Risk Scores

Response	n (%)
complete responses / total surveyed	324 / 507
Low Risk	237~(~73~%)
Moderate Risk	56(17%)
High Risk	31~(~10~%)



Survey Questions

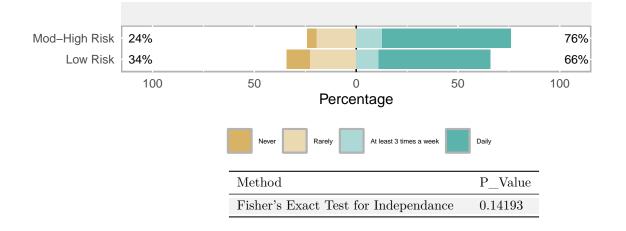
Questions 1 to 13 will ask you questions about your past and current experience with pain and pain management.

		Response		n	(%)
		responses / t Daily At least 3 tin Rarely	otal surveyed nes a week	2 4	$\begin{array}{c} 98 \ / \ 507 \\ 19 \ (\ 55 \ \%) \\ 6 \ (\ 12 \ \%) \\ 5 \ (\ 24 \ \%) \end{array}$
		Never			8 (10%)
	Never -	(10%)			
	Rarely -		(24%)		
At least 3 time	es a week -	(12%)			
	Daily -			(55	%)
	0		100 Frequen	200 cy	
		Contingency	y Table of Re	esponses versus Ri	sk Group
			Low Risk	Moderate Risk	High Risk
		Never	27 (87%)	1 (3%)	3 (10%)
		Rarely	54(76%)	9(13%)	8 (11%)
			20 (70%)	0 (10%)	5(14%)
		Daily	130 (70%)	40 (22%)	15 (8%)
		[How often d	o you currently	vexperience pain?	
loderate Risk	35% 18% 34%				
	100	50	0 Percentag	50	
loderate Risk	18% 34%	At least 3 times a week Daily [How often d	26 (70%) 130 (70%) o you currently	6 (16%) 40 (22%) / experience pain? 50	5 (1

Q1: How often do you currently experience pain? (Select 1)

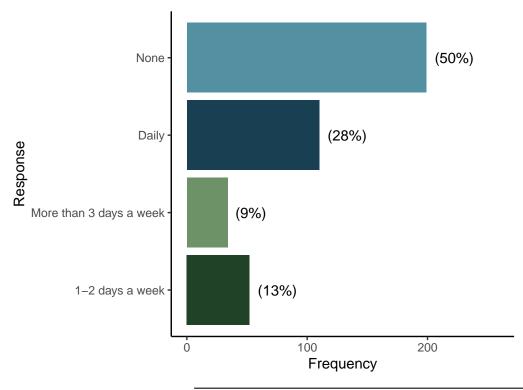
Method	P_Value
Fisher's Exact Test for Independance	0.13993

Contingency Table of Responses versus Risk Group			
	Low Risk	Mod-High Risk	
Never	27 (87%)	4 (13%)	
Rarely	54 (76%)	17 (24%)	
At least 3	26~(70%)	11 (30%)	
times a week			
Daily	130~(70%)	55~(30%)	

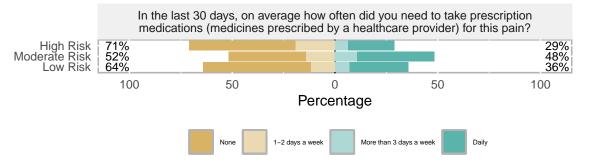


Q2: In the last 30 days, on average how often did you need to take prescription medications (medicines prescribed by a healthcare provider) for this pain? (Select 1)

Response	n (%)
responses / total surveyed	395 / 507
1-2 days a week	$52\ (\ 13\ \%)$
More than 3 days a week	34(9%)
Daily	110 (28%)
None	199~(~50~%)

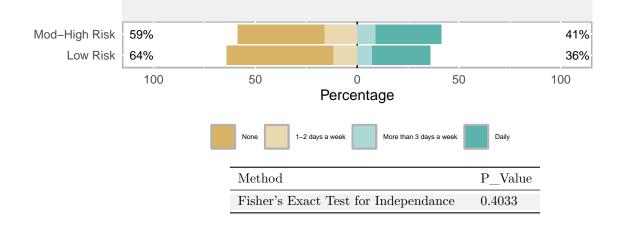


Contingency Table of Responses versus Risk Group				
	Low Risk	Moderate Risk	High Risk	
None	124 (77%)	21 (13%)	16 (10%)	
1-2 days a week	28 (67%)	8 (19%)	6 (14%)	
More than 3 days a week	17 (68%)	6 (24%)	2(8%)	
Daily	68 (71%)	21 (22%)	7 (7%)	



Method	P_Value
Fisher's Exact Test for Independance	0.38881

Contingency Table of Responses versus Risk Group			
	Low Risk	Mod-High Risk	
None	124 (77%)	37 (23%)	
1-2 days a week	28 (67%)	14 (33%)	
More than 3 days a week	17 (68%)	8 (32%)	
Daily	68~(71%)	28~(29%)	



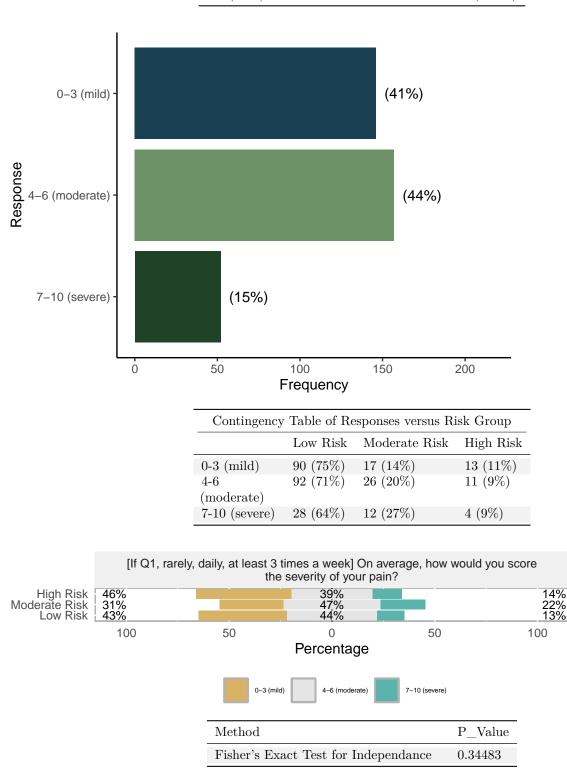
 Response
 n (%)

 responses / total surveyed
 355 / 507

 7-10 (severe)
 52 (15 %)

 4-6 (moderate)
 157 (44 %)

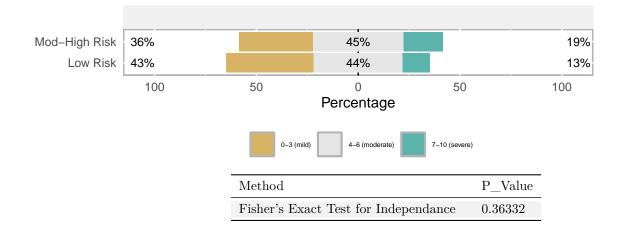
 0-3 (mild)
 146 (41 %)



Confidential: For participating patients only this report contains aggregated data from patient survey responses. Not intended for public or third-party distribution.

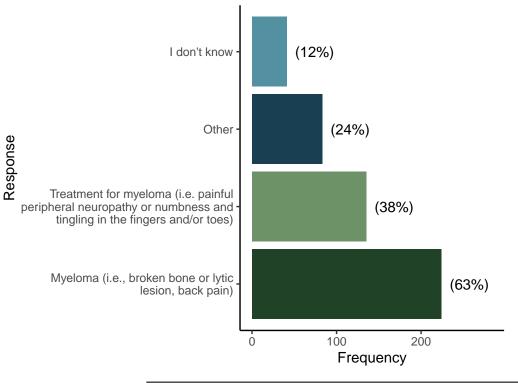
Q3: [If Q1, rarely, daily, at least 3 times a week] On average, how would you score the severity of your pain? (Select 1)

Contingency Table of Responses versus Risk Group			
	Low Risk	Mod-High Risk	
0-3 (mild)	90 (75%)	30~(25%)	
4-6 (moderate)	92 (71%)	37(29%)	
7-10 (severe)	28~(64%)	16~(36%)	



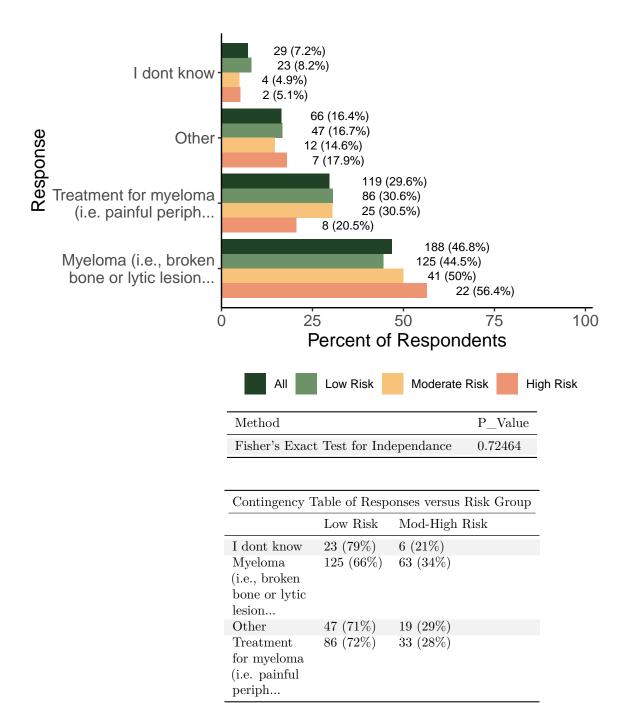
Q4. [If Q1, rarely, daily, at least 3 times a week] What is your pain caused by? (Select all that apply)

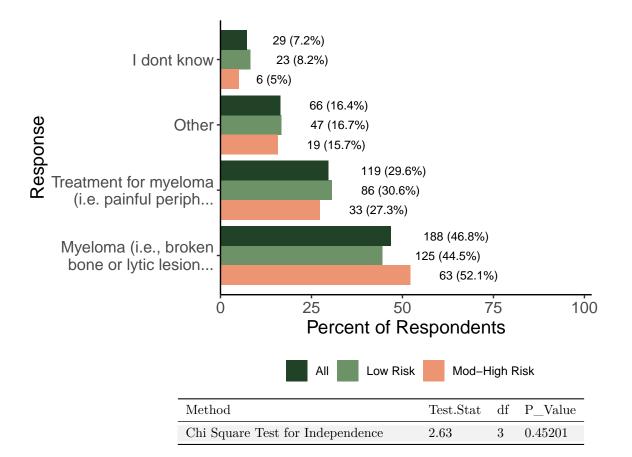
Response	n (%)
responses / total surveyed	353 / 507
Myeloma (i.e., broken bone or lytic	224 (63 %)
lesion, back pain)	
Treatment for myeloma (i.e. painful	135~(~38~%)
peripheral neuropathy or numbress and	
tingling in the fingers and/or toes)	
Other	83 (24 %)
I don't know	41 (12%)



-

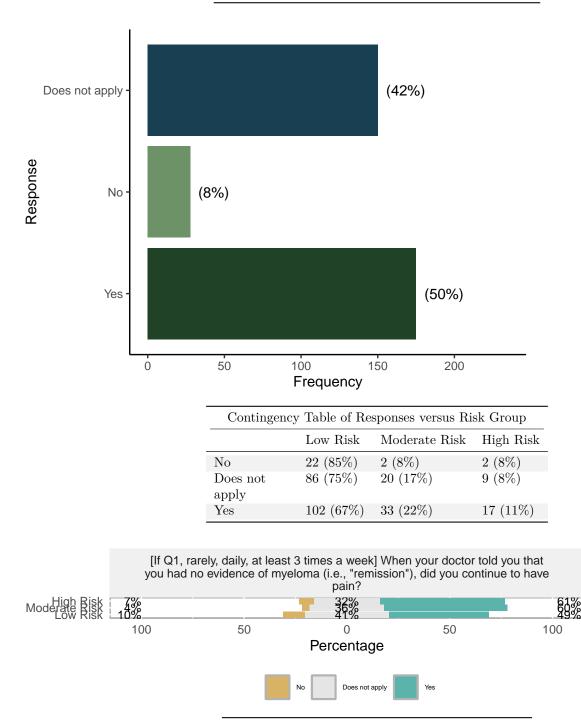
Contingency Table of Responses versus Risk Group			
	Low Risk	Moderate Risk	High Risk
I dont know	23~(79%)	4 (14%)	2(7%)
Myeloma (i.e., broken	125~(66%)	41 (22%)	22~(12%)
bone or lytic lesion			
Other	47~(71%)	12 (18%)	7~(11%)
Treatment for myeloma	86~(72%)	25~(21%)	8~(7%)
(i.e. painful periph			





Q5: [If Q1, rarely, daily, at least 3 times a week] When your doctor told you that you had no evidence of myeloma (i.e., "remission"), did you continue to have pain? (Select 1)

Response	n (%)
responses / total surveyed	$353 \ / \ 507$
Yes	175~(~50~%)
No	28(8%)
Does not apply	150~(~42~%)

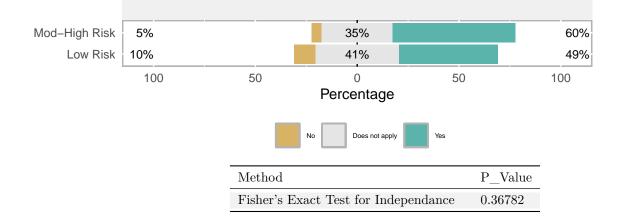


Method

P Value

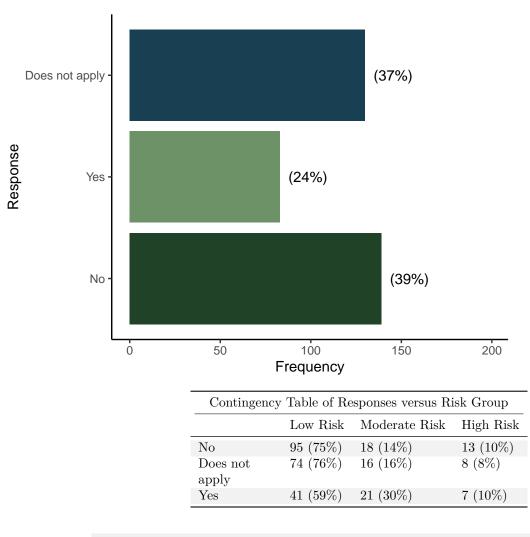
Fisher's Exact	Test for	Independance	0.36482
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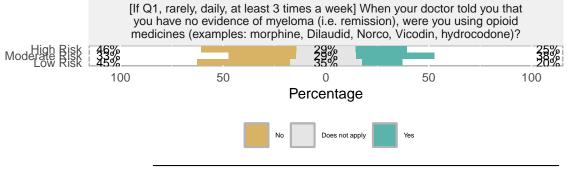
Contingency	Table of Resp	onses versus Risk Group
	Low Risk	Mod-High Risk
No	22 (85%)	4 (15%)
Does not apply	86 (75%)	29 (25%)
Yes	102~(67%)	50~(33%)



Q6: [If Q1, rarely, daily, at least 3 times a week] When your doctor told you that you have no evidence of myeloma (i.e. remission), were you using opioid medicines (examples: morphine, Dilaudid, Norco, Vicodin, hydrocodone)? (Select 1)

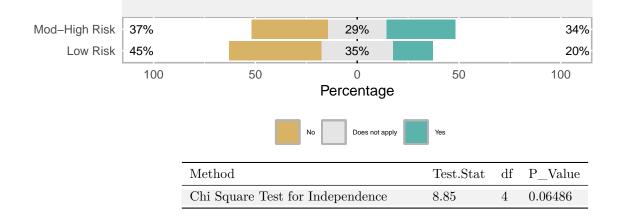
Response	n (%)
responses / total surveyed	352 / 507
No	$139\ (\ 39\ \%)$
Yes	83~(~24~%)
Does not apply	130~(~37~%)





Method	Test.Stat	df	P_Value
Chi Square Test for Independence	8.85	4	0.06486

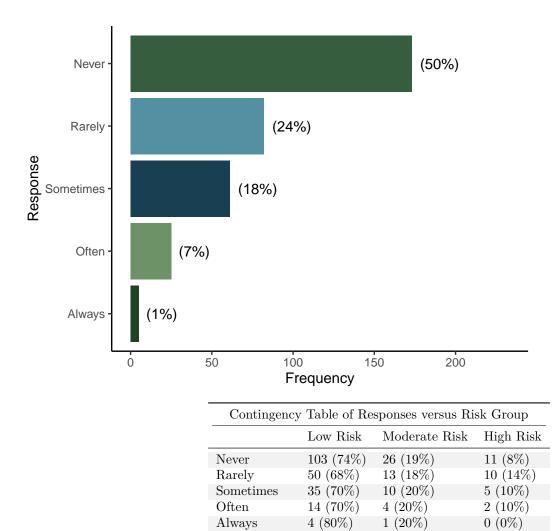
Contingency Table of Responses versus Risk Group					
	Low Risk	Mod-High Risk			
No	95~(75%)	31~(25%)			
Does not	74 (76%)	24 (24%)			
apply					
Yes	41~(59%)	28~(41%)			

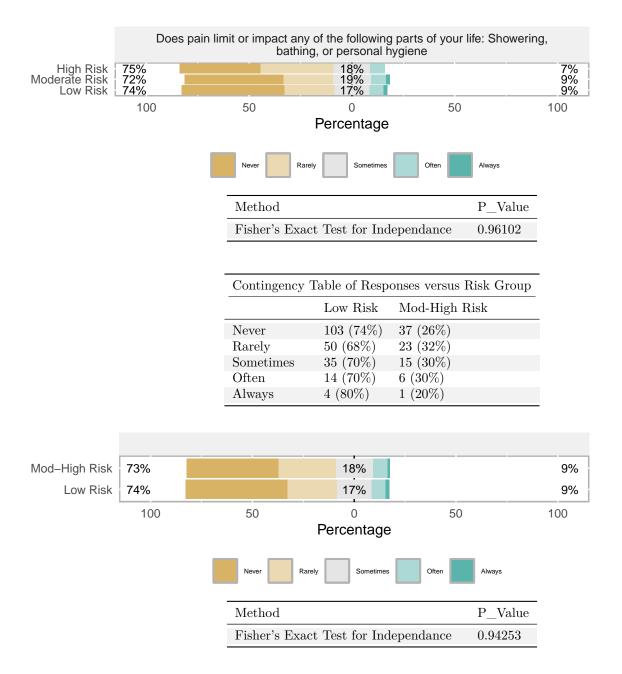


Q7: [If Q1, rarely, daily, at least 3 times a week] Does pain limit or impact any of the following parts of your life? (please do not count limitations from other reasons i.e. fatigue, lack of mobility, only limitations from pain)

Q7.1 Does pain limit or impact any of the following parts of your life: Showering, bathing, or personal hygiene

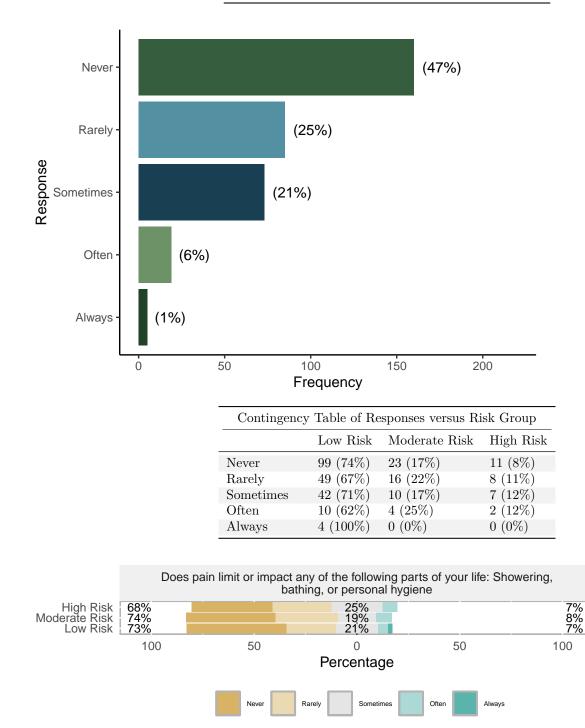
Response	n (%)
responses / total surveyed	346 / 507
Always	5 (1%)
Often	25 (7%)
Sometimes	61~(~18~%)
Rarely	82(24%)
Never	173 (50 %)





Response	n (%)
responses / total surveyed	342 / 507
Always	5(1%)
Often	19(6%)
Sometimes	73(21%)
Rarely	$85\ (\ 25\ \%)$
Never	160~(~47~%)

Q7.2 Does pain limit or impact any of the following parts of your life: Dressing/grooming



Method

 P_Value

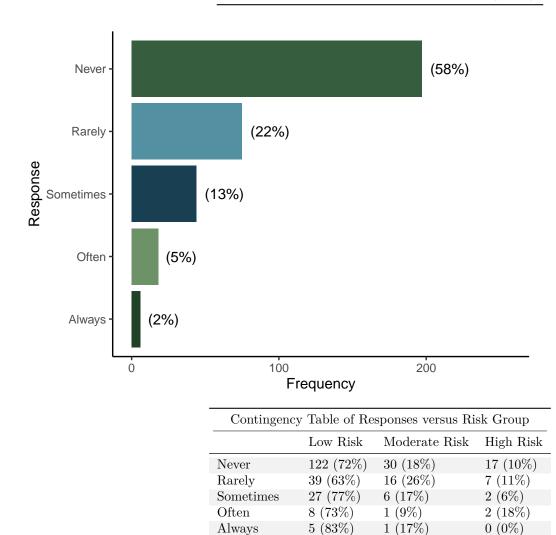
Fisher's Exac	Test for	Independance	0.89205
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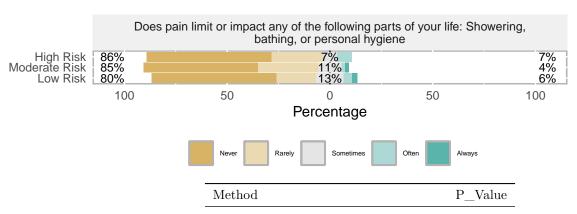
Contingency Table of Responses versus Risk Group

			Low Risk	Mod-High Risk	
		Never	99 (74%)	34~(26%)	
		Rarely	49(67%)	24 (33%)	
		Sometimes	42~(71%)	17 (29%)	
		Often	10~(62%)	6(38%)	
		Always	4 (100%)	0 (0%)	
Mod–High Risk	72%		21%		7%
Low Risk	73%		21%		7%
	100	50	0	50	100
			Percentage	Э	
			-		
		Never	arely Sometime	s Often Always	
		Method		P_Val	ue
		D.1 1 D	act Test for Ine	dependance 0.53023	h

Q7.3 Does pain limit or impact any of the following parts of your life: Toileting, bowel and bladder management

Response	n (%)
responses / total surveyed	340 / 507
Always	6(2%)
Often	18(5%)
Sometimes	44 (13 %)
Rarely	75 (22 %)
Never	197 (58%)



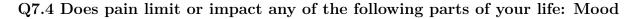


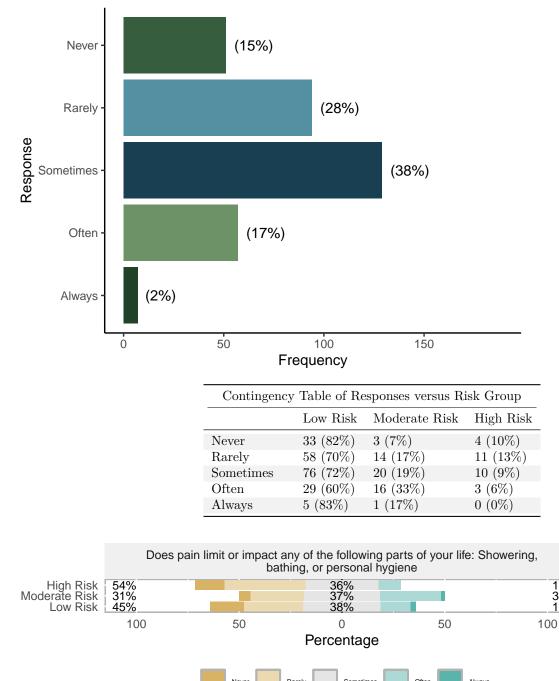
Fisher's Exact	Test for	Independance	0.76462
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Contingency Table of Responses versus Risk Group

		-		Low Risk	Mod-High F	lisk	
		_	Never	122 (72%)	47 (28%)		
			Rarely	39~(63%)	23~(37%)		
			Sometimes	27~(77%)	8~(23%)		
			Often	8~(73%)	3~(27%)		
			Always	5~(83%)	1 (17%)		
		_					
Mod–High Risk	85%			10%			5%
Low Risk	80%			13%			6%
	100		50	0	50		100
				Percentage			
			Never	Rarely Sometimes	Often	Always	
						/ iways	
		-					
		_	Method			P_Value	
			Fisher's Ex	act Test for Inde	ependance	0.57471	

Response	n (%)
responses / total surveyed	338 / 507
Always	7(2%)
Often	$57\ (\ 17\ \%)$
Sometimes	129 (38 %)
Rarely	$94\ (\ 28\ \%)$
Never	51 (15 %)



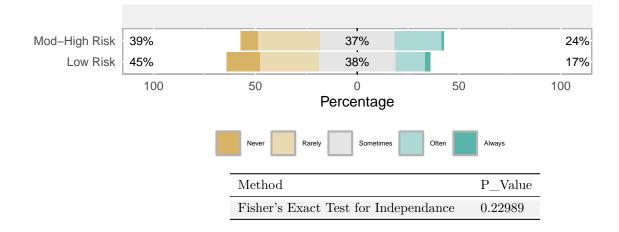


	Never	Rarely	Sometimes	Often	Always
	Method	l			P_Value
	Fisher's	s Exact Te	st for Indep	pendance	0.17041

11% 31%

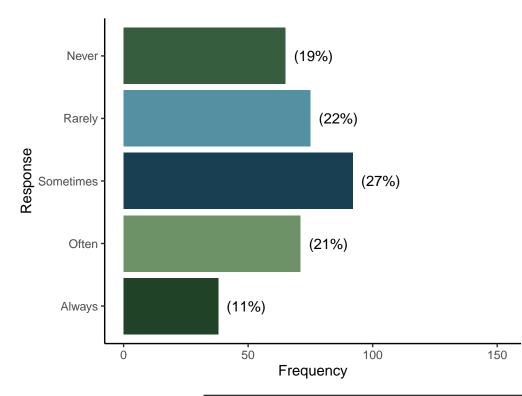
17%

Contingency Table of Responses versus Risk Group				
	Low Risk	Mod-High Risk		
Never	33~(82%)	7 (17%)		
Rarely	58(70%)	25 (30%)		
Sometimes	76~(72%)	30~(28%)		
Often	29~(60%)	19 (40%)		
Always	5~(83%)	1(17%)		

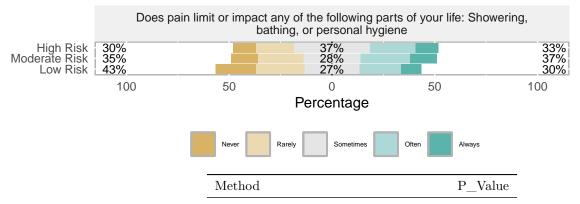


Q7.5 Does pain limit or impact any of the following parts of your life: Getting out of bed, off the floor, from sitting

Response	n (%)
responses / total surveyed	341 / 507
Always	38 (11 %)
Often	71 (21 %)
Sometimes	92~(~27~%)
Rarely	75 (22 %)
Never	65 (19%)



Contingency Table of Responses versus Risk Group				
	Low Risk	Moderate Risk	High Risk	
Never	40 (80%)	7 (14%)	3~(6%)	
Rarely	48 (74%)	12 (18%)	5(8%)	
Sometimes	55~(69%)	15 (19%)	10~(12%)	
Often	41~(68%)	13~(22%)	6 (10%)	
Always	20~(67%)	7 (23%)	3(10%)	

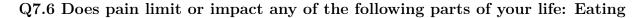


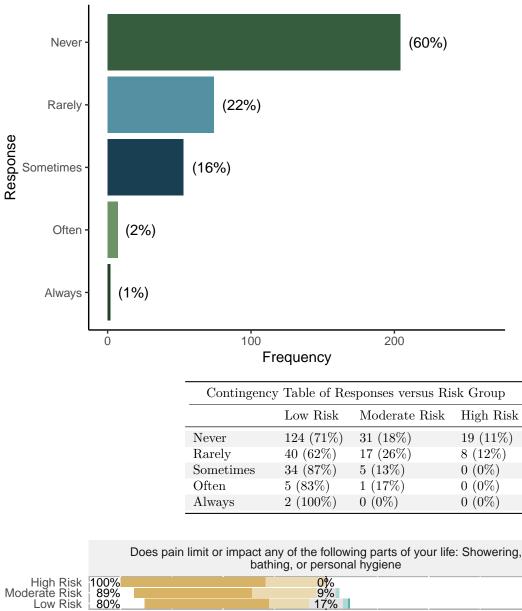
Fisher's Exact	Test for	Independance	0.89205
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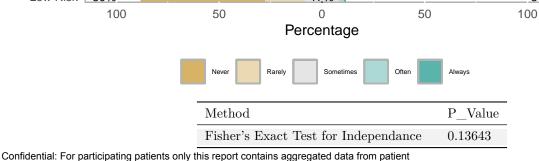
Contingency Table of Responses versus Risk Group

			Low Risk	Mod-High Risk		_
		Never	40 (80%)	10 (20%)		
		Rarely	48 (74%)	17~(26%)		
		Sometimes	55~(69%)			
		Often	41 (68%)	19 (32%)		
		Always	20~(67%)	10 (33%)		
Mod–High Risk	33%		31%			36%
Low Risk	43%		27%			30%
	100	50	0	50		100
			Percentage	Э		
			-			
		Never	Rarely Sometime	s Often Alw	vays	
		Never	Sometime		lays	
		Method		Test.Stat	df	P_Value
		Chi Square Test for	Independence	2.89	4 (0.57667

Response	n (%)
responses / total surveyed	340 / 507
Always	2(1%)
Often	7(2%)
Sometimes	53~(~16~%)
Rarely	74(22%)
Never	204 ($60~\%)$

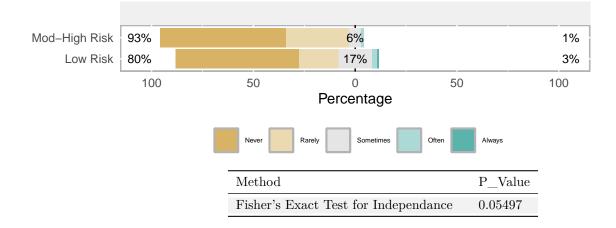




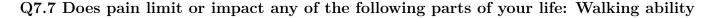


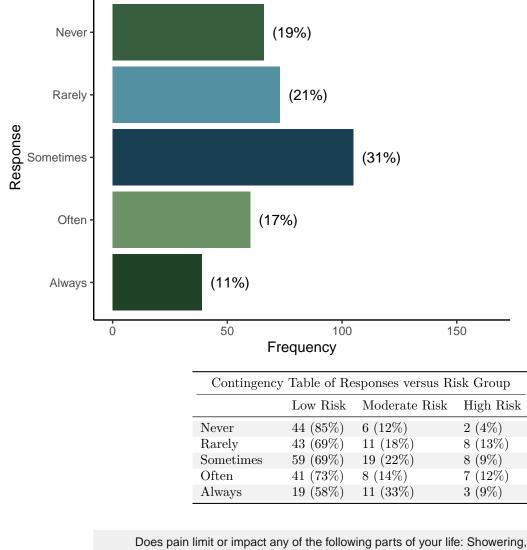
0% 2% 3%

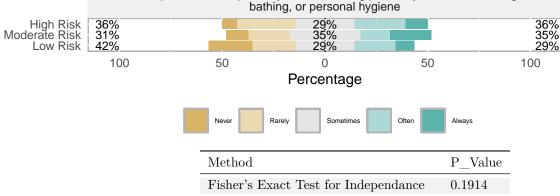
Contingency Table of Responses versus Risk Group				
	Low Risk	Mod-High Risk		
Never	124 (71%)	50 (29%)		
Rarely	40 (62%)	25 (38%)		
Sometimes	34~(87%)	5(13%)		
Often	5~(83%)	1(17%)		
Always	2(100%)	0 (0%)		



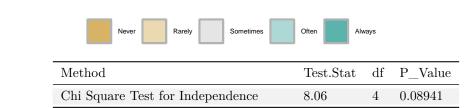
Response	n (%)
responses / total surveyed	343 / 507
Always	$39\ (\ 11\ \%)$
Often	$60\ (\ 17\ \%)$
Sometimes	105~(~31~%)
Rarely	73~(~21~%)
Never	$66\ (\ 19\ \%)$





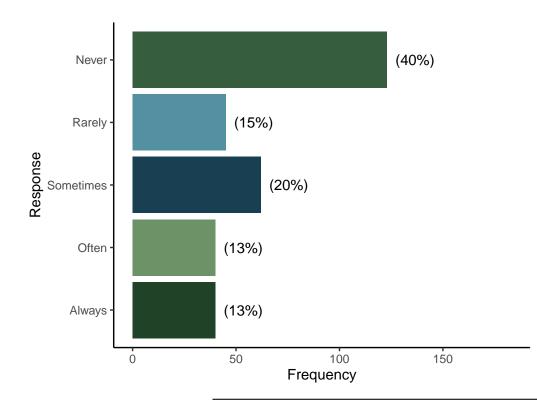


		Contingency Table of Responses versus Risk Group			-
			Low Risk	Mod-High Risk	
		Never	44 (85%)	8 (15%)	
		Rarely	43~(69%)	19 (31%)	
		Sometimes	59~(69%)	27 (31%)	
		Often	41~(73%)	15 (27%)	
		Always	19~(58%)	14 (42%)	
					-
Mod–High Risk	33%		33%		35%
Low Risk	42%		29%		29%
	100	50	0	50	100
			Percentage	e	

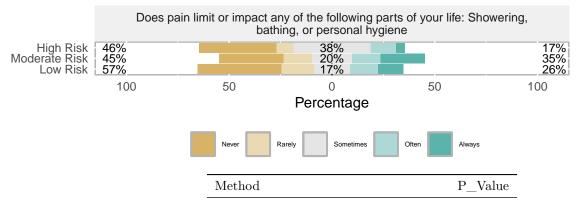


Q7.8 Does pain limit or impact any of the following parts of your life: Functioning at work normally $% \left({{\mathbf{F}_{\mathrm{s}}}^{\mathrm{T}}} \right)$

Response	n (%)
responses / total surveyed	310 / 507
Always	40 (13 %)
Often	$40\ (\ 13\ \%)$
Sometimes	62~(~20~%)
Rarely	45 (15%)
Never	123~(~40~%)



Contingency Table of Responses versus Risk Group				
	Low Risk	Moderate Risk	High Risk	
Never	77 (75%)	16 (16%)	9(9%)	
Rarely	30~(77%)	7 (18%)	2(5%)	
Sometimes	33~(63%)	10~(19%)	9(17%)	
Often	26~(72%)	7~(19%)	3(8%)	
Always	23~(66%)	11 (31%)	1(3%)	



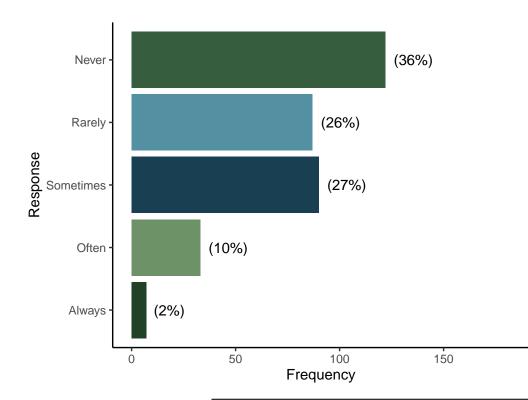
Fisher's Exact Test for Independence 0.30185	5
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Contingency Table of Responses versus Risk Group

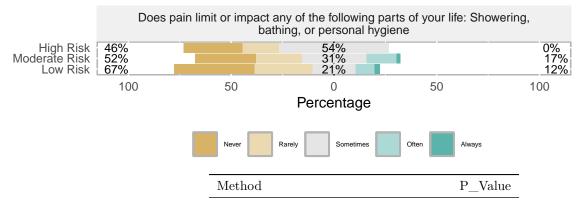
			Low Risk	Mod-High Risk		
		Never	77~(75%)	25~(25%)		
		Rarely	30~(77%)	9~(23%)		
		Sometimes	33~(63%)			
		Often	26~(72%)			
		Always	23~(66%)	12 (34%)		
Mod–High Risk	45%		25%			29%
Low Risk	57%		17%			26%
	100	50	0	50		100
			Percentage	e		
			-			
		Never	Rarely Sometime	s Often Alv	ways	
		Method		Test.Stat	df	P_Value
		Chi Square Test for	Independence	3.6	4	0.46302

Q7.9 Does pain limit or impact any of the following parts of your life: Relations with other people $% \mathcal{A}(\mathcal{A})$

Response	n (%)
responses / total surveyed	339 / 507
Always	7(2%)
Often	$33\ (\ 10\ \%)$
Sometimes	90~(~27~%)
Rarely	$87\ (\ 26\ \%)$
Never	122 (36 %)



Contingency Table of Responses versus Risk Group					
	Low Risk	Moderate Risk	High Risk		
Never	80 (77%)	16 (15%)	8 (8%)		
Rarely	58~(77%)	12~(16%)	5(7%)		
Sometimes	43~(57%)	17~(23%)	15~(20%)		
Often	19~(70%)	8(30%)	0 (0%)		
Always	5 (83%)	1 (17%)	0 (0%)		



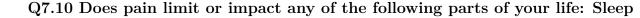
Fisher's Exact	Test for	Independance	0.02649
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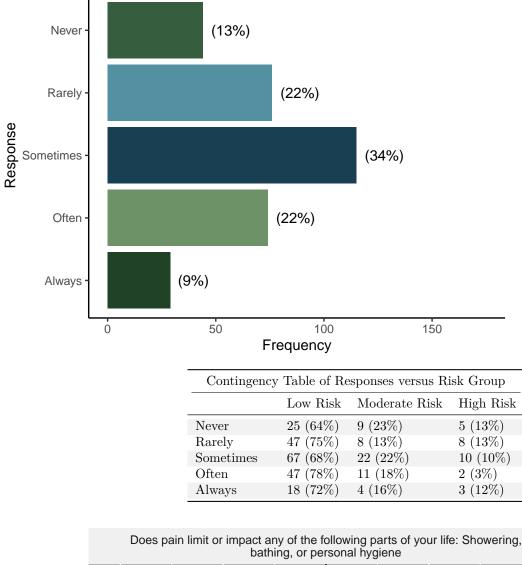
Contingency Table of Responses versus Risk Group

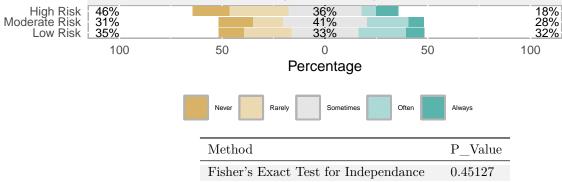
Low Risk Mod-High Risk

				~		_
		Never	80 (77%)	24 (23%)		
		Rarely	58~(77%)	17~(23%)		
		Sometimes	43~(57%)			
		Often	19(70%)			
		Always	5~(83%)	1 (17%)		
Mod–High Risk	50%		39%			11%
Low Risk	67%		21%			12%
	100	50	0	50		100
			Percentage	9		
			C			
		Never Ra	arely Sometimes	S Often	Always	
		Method			P_Value	
		Fisher's Exa	ct Test for Inc	lependance	0.04748	

Response	n (%)
responses / total surveyed	338 / 507
Always	29 (9%)
Often	74(22%)
Sometimes	115~(~34~%)
Rarely	76(22%)
Never	44 (13 %)



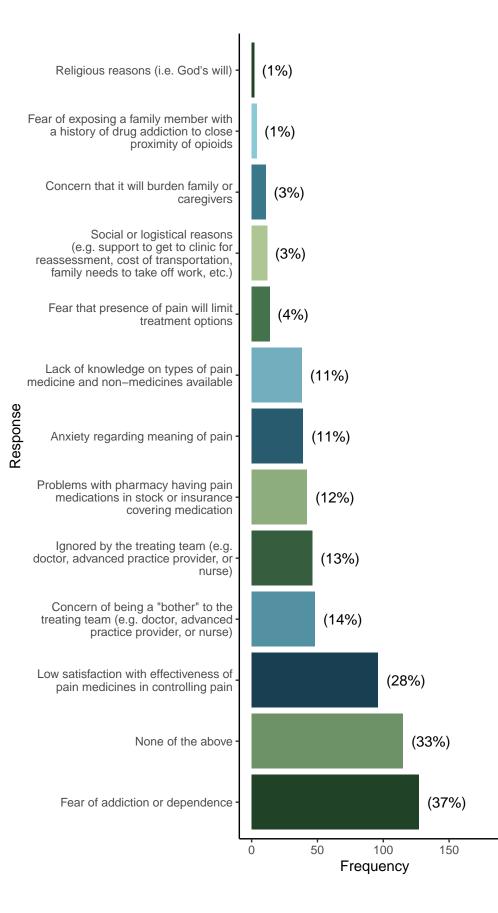




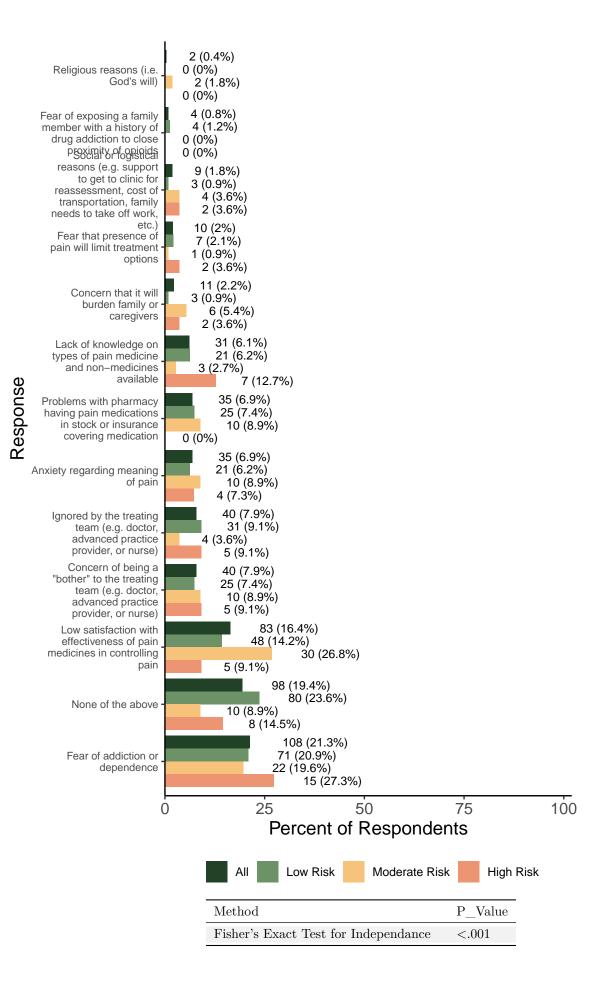
		Contingency Table of Responses versus Risk Group				
			Low Risk	Mod-High R	isk	
		Never	25 (64%)	14 (36%)		
		Rarely	47 (75%)	16 (25%)		
		Sometin	(/	32 (32%)		
		Often	47 (78%)	13~(22%)		
		Always	18 (72%)	7(28%)		
Mod–High Risk	37%		39%			24%
Low Risk	35%		33%			32%
	100	50	0	50		100
			Percentage	е		
		Never	Rarely Sometime	Often	Always	
		25.1.1			10	
		Method		Test.St	tat df	P_Value
		Chi Square Tes	t for Independence	3.42	4	0.49066

Q8 [If Q1, rarely, daily, at least 3 times a week] Which of the following have been barriers to the treatment of your pain? (Select all that apply)

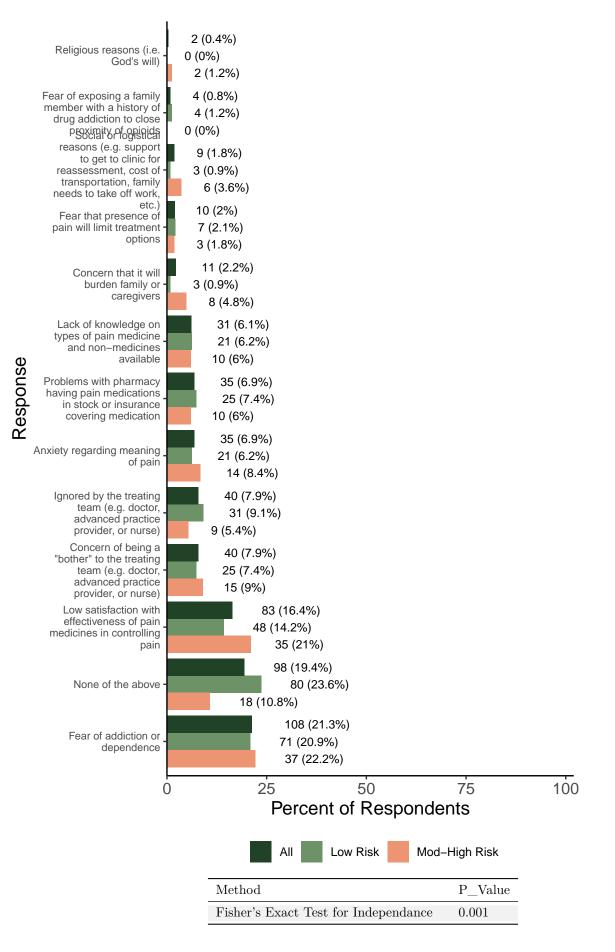
Response	n (%)
responses / total surveyed	345 / 507
Fear of addiction or dependence	127(37%)
None of the above	115 (33 %)
Low satisfaction with effectiveness of pain medicines in controlling pain	96~(~28~%)
Concern of being a "bother" to the treating team (e.g. doctor, advanced practice provider, or nurse)	48 (14%)
Ignored by the treating team (e.g. doctor, advanced practice provider, or nurse)	46 (13%)
Problems with pharmacy having pain medications in stock or insurance covering medication	42 (12%)
Anxiety regarding meaning of pain	39~(~11~%)
Lack of knowledge on types of pain medicine and non-medicines available	38 (11%)
Fear that presence of pain will limit treatment options	14 (4%)
Social or logistical reasons (e.g. support to get to clinic for reassessment, cost of transportation, family needs to take off work, etc.)	12 (3 %)
Concern that it will burden family or caregivers	11 (3 %)
Fear of exposing a family member with a history of drug addiction to close proximity of opioids	4 (1%)
Religious reasons (i.e. God's will)	2(1%)



Contingency Table of Responses versus Risk Group						
	Low Risk	Moderate Risk	High Risk			
Anxiety regarding meaning of pain Concern of being a "bother" to the	$\begin{array}{c} 21 \ (60\%) \\ 25 \ (62\%) \end{array}$	10 (29%) 10 (25%)	$\begin{array}{c} 4 \ (11\%) \\ 5 \ (12\%) \end{array}$			
treating team (e.g. doctor, advanced practice provider, or nurse)						
Concern that it will burden family or caregivers	3 (27%)	6 (55%)	2 (18%)			
Fear of addiction or dependence Fear of exposing a family member with a history of drug addiction to close proximity of opioids	$71 (66\%) \\ 4 (100\%)$	$22 (20\%) \\ 0 (0\%)$	$\begin{array}{c} 15 \ (14\%) \\ 0 \ (0\%) \end{array}$			
Fear that presence of pain will limit treatment options	7 (70%)	1 (10%)	2 (20%)			
Ignored by the treating team (e.g. doctor, advanced practice provider, or nurse)	31 (78%)	4 (10%)	5(12%)			
Lack of knowledge on types of pain medicine and non-medicines available	21 (68%)	3~(10%)	7(23%)			
Low satisfaction with effectiveness of pain medicines in controlling pain	48 (58%)	30 (36%)	5~(6%)			
None of the above	80~(82%)	10 (10%)	8 (8%)			
Problems with pharmacy having pain medications in stock or insurance covering medication	25 (71%)	10 (29%)	0 (0%)			
Religious reasons (i.e. God's will) Social or logistical reasons (e.g. support to get to clinic for reassessment, cost of transportation, family needs to take off work, etc.)	$egin{array}{c} 0 \; (0\%) \ 3 \; (33\%) \end{array}$	2 (100%) 4 (44%)	$egin{array}{c} 0 & (0\%) \ 2 & (22\%) \end{array}$			

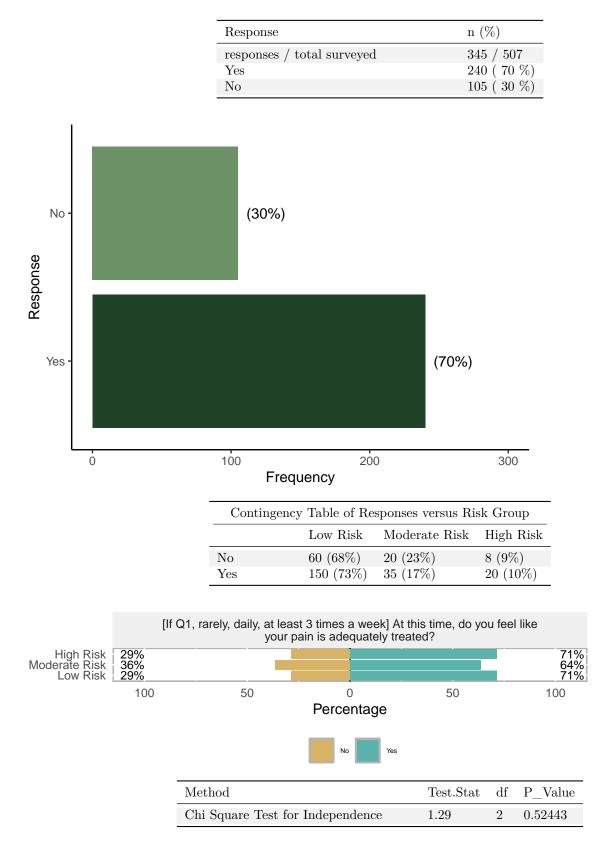


Contingency Table of Responses versus Risk Group					
	Low Risk	Mod-High Risk			
Anxiety regarding meaning of pain Concern of being a "bother" to the treating team (e.g. doctor, advanced practice provider, or nurse)	21 (60%) 25 (62%)	14 (40%) 15 (38%)			
Concern that it will burden family or caregivers	3 (27%)	8 (73%)			
Fear of addiction or dependence Fear of exposing a family member with a history of drug addiction to close proximity of opioids	71 (66%) 4 (100%)	$\begin{array}{c} 37 (34\%) \\ 0 (0\%) \end{array}$			
Fear that presence of pain will limit treatment options	7 (70%)	3 (30%)			
Ignored by the treating team (e.g. doctor, advanced practice provider, or nurse)	31 (78%)	9 (22%)			
Lack of knowledge on types of pain medicine and non-medicines available	21~(68%)	10 (32%)			
Low satisfaction with effectiveness of pain medicines in controlling pain	48 (58%)	35 (42%)			
None of the above	80~(82%)	18 (18%)			
Problems with pharmacy having pain medications in stock or insurance covering medication	25 (71%)	10 (29%)			
Religious reasons (i.e. God's will)	0 (0%)	2 (100%)			
Social or logistical reasons (e.g. support to get to clinic for reassessment, cost of transportation, family needs to take off work, etc.)	3 (33%)	6~(67%)			

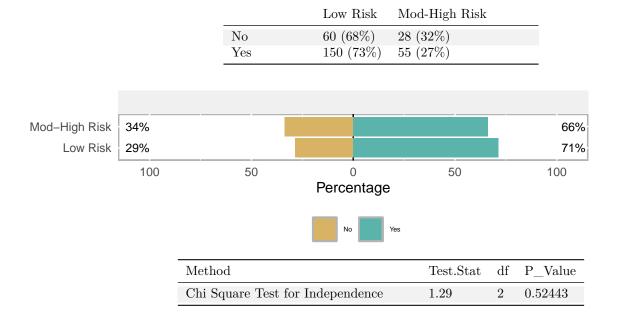


There is evidence that the barriers differ among the risk groups Confidential: For participating patients only this report contains aggregated data from patient survey responses. Not intended for public or third-party distribution.

Q9: [If Q1, rarely, daily, at least 3 times a week] At this time, do you feel like your pain is adequately treated? (Select 1)

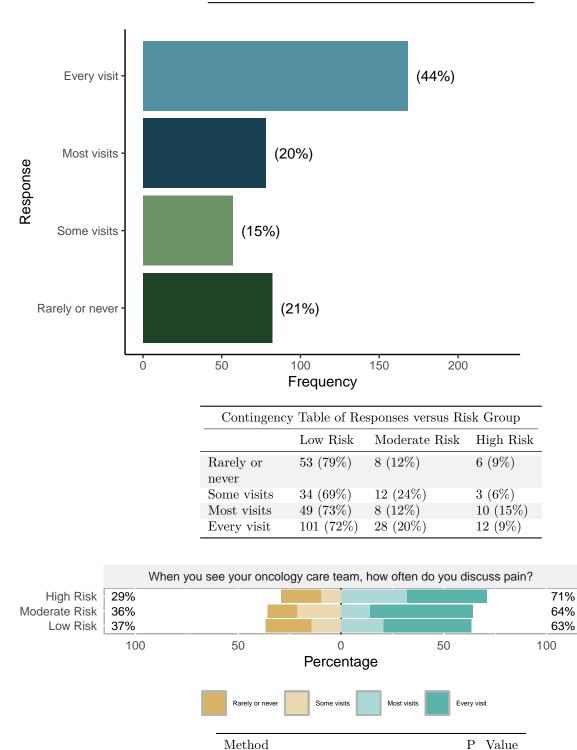


Contingency Table of Responses versus Risk Group



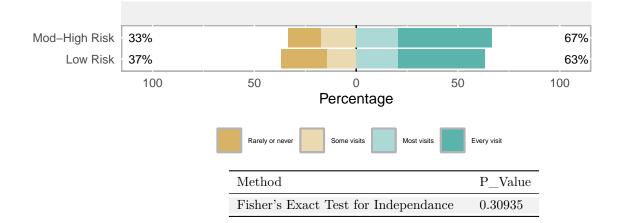
Q10: When you see your oncology care team, how often do you discuss pain?

Response	n (%)
responses / total surveyed	385 / 507
Rarely or never	82 (21 %)
Some visits	$57\ (\ 15\ \%)$
Most visits	$78\ (\ 20\ \%)$
Every visit	168 (44 %)



Fisher's Exact	Test for	Independance	0.29985
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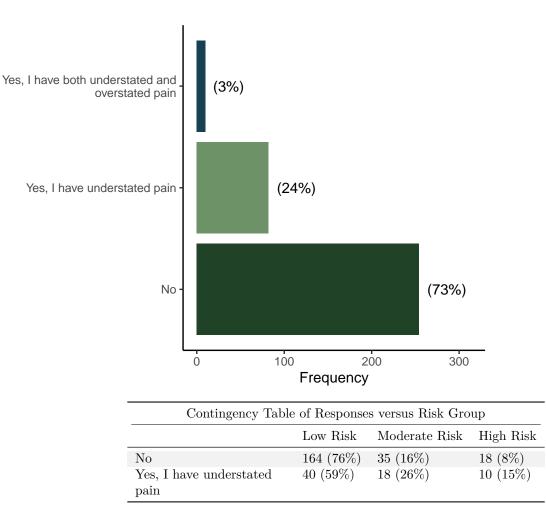
Contingency Table of Responses versus Risk Group			
	Low Risk	Mod-High Risk	
Rarely or	53~(79%)	14 (21%)	
never			
Some visits	34~(69%)	15 (31%)	
Most visits	49(73%)	18 (27%)	
Every visit	101~(72%)	40 (28%)	



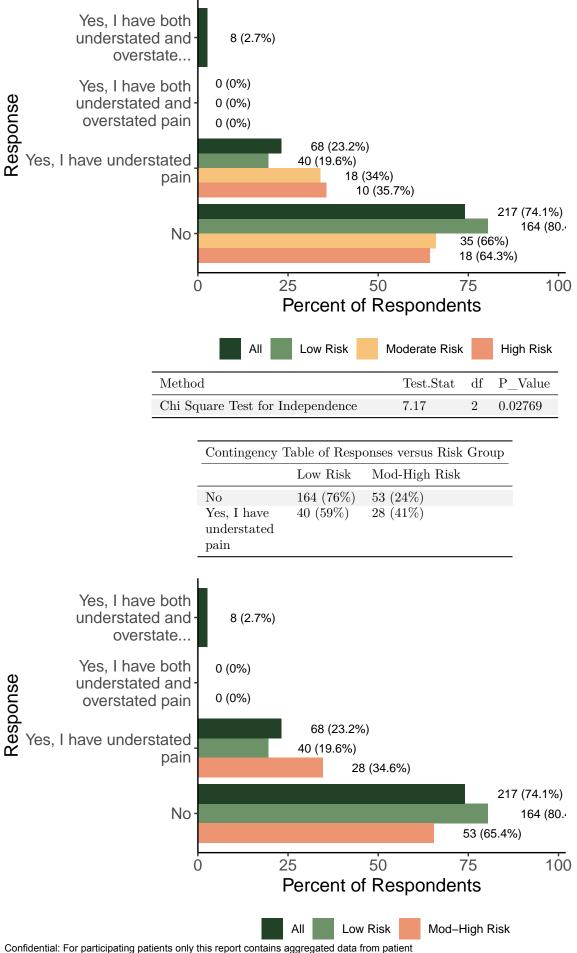
Q11: [If Q1, rarely, daily, at least 3 times a week] Have you ever intentionally overstated or understated your pain to your doctor?

Interestingly as of July 2023, no patients selected "Yes - I have overstated pain"

Response	n (%)
responses / total surveyed	346 / 507
No	254~(~73~%)
Yes, I have understated pain	82(24%)
Yes, I have both understated and	$10\ (\ 3\ \%)$
overstated pain	



Response



survey responses. Not intended for public or third-party distribution.

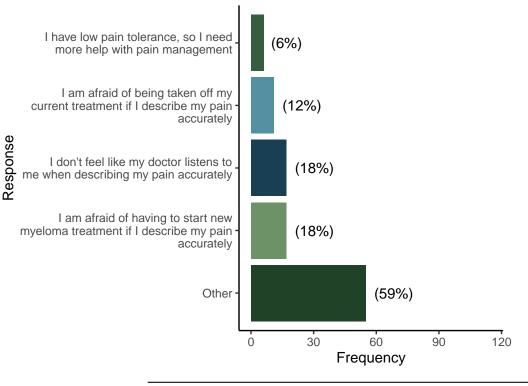
Method	Test.Stat	df	P_Value
Chi Square Test for Independence	6.34	1	0.01179

When the Moderate and High risk groups are combined, there appears to be a significant difference between the risk groups.

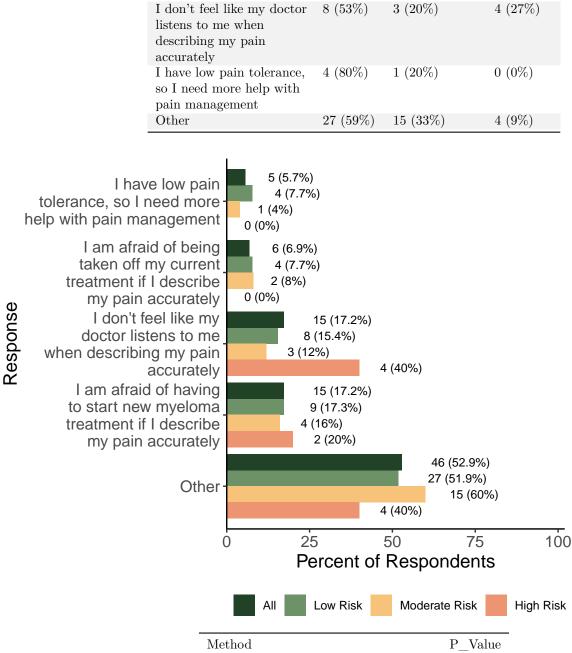
Q12: [If Q11, Yes] Why did you overstate or understate your pain to the doctor? (Select all that apply)

Need to look at other open responses for this question.

Response	n (%)
responses / total surveyed	93 / 507
Other	55~(~59~%)
I am afraid of having to start new myeloma treatment if I describe my pain accurately	17 (18%)
I don't feel like my doctor listens to me when describing my pain accurately	17 (18%)
I am afraid of being taken off my current treatment if I describe my pain accurately	11 (12 %)
I have low pain tolerance, so I need more help with pain management	6 (6 %)

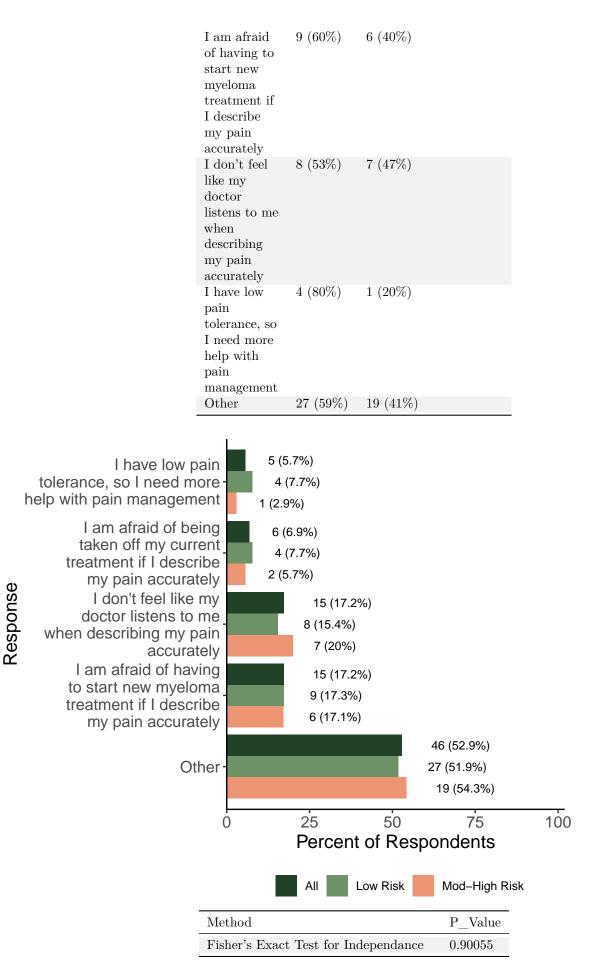


Contingency Table of Responses versus Risk Group			
	Low Risk	Moderate Risk	High Risk
I am afraid of being taken off my current treatment if I describe my pain accurately	4 (67%)	2 (33%)	0 (0%)
I am afraid of having to start new myeloma treatment if I describe my pain accurately	9~(60%)	4 (27%)	2 (13%)



Method	
Fisher's Exact Test for Independance	0.8041

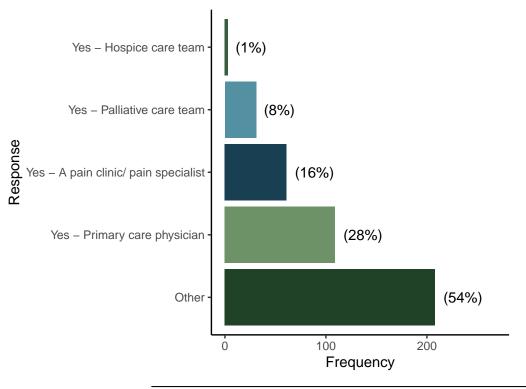
Contingency Table of Responses versus Risk Group			
	Low Risk	Mod-High Risk	
I am afraid of being taken off my current treatment if I describe my pain accurately	4 (67%)	2 (33%)	



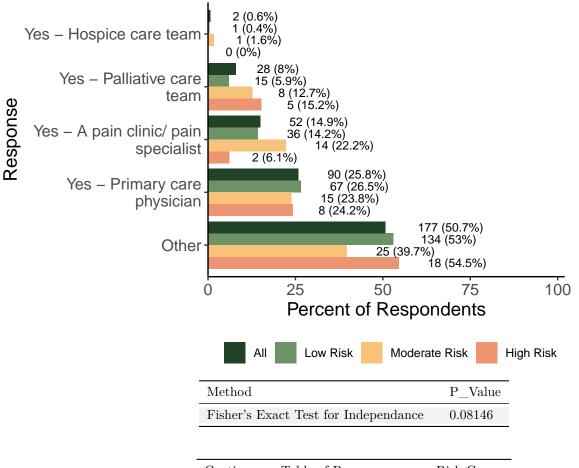
Q13: Other than your oncology care team, do other healthcare providers help manage your pain? (Select all that apply)

Need to look at other open responses for this question.

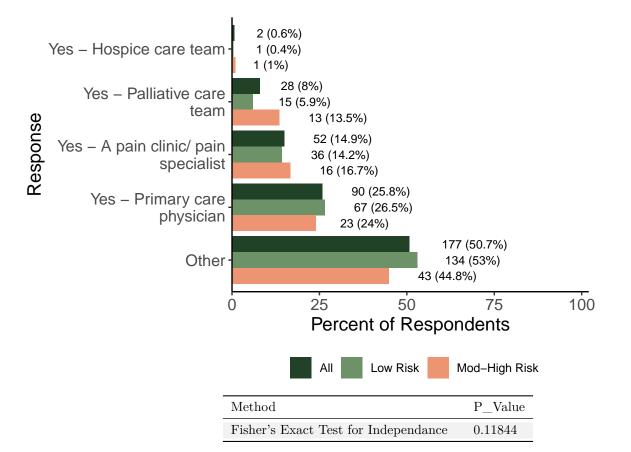
Response	n (%)
responses / total surveyed	383 / 507
Other	208 (54 %)
Yes - Primary care physician	109(28%)
Yes - A pain clinic/ pain specialist	61~(~16~%)
Yes - Palliative care team	31 (8%)
Yes – Hospice care team	$3\ (\ 1\ \%)$



Contingency Table of Responses versus Risk Group			
	Low Risk	Moderate Risk	High Risk
Other	134 (76%)	25 (14%)	18 (10%)
Yes - A pain clinic/ pain specialist	36~(69%)	14 (27%)	2(4%)
Yes - Palliative care team	15~(54%)	8~(29%)	5~(18%)
Yes - Primary care physician	67 (74%)	15~(17%)	8 (9%)
Yes – Hospice care team	1 (50%)	1 (50%)	0 (0%)



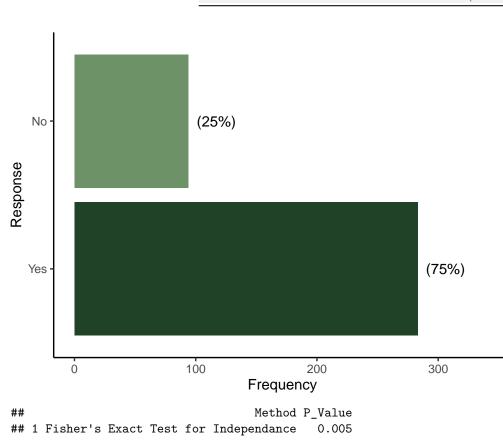
Contingency Table of Responses versus Risk Group		
	Low Risk	Mod-High Risk
Other	134~(76%)	43~(24%)
Yes - A pain clinic/ pain specialist	36~(69%)	16 (31%)
Yes - Palliative care team	15~(54%)	13 (46%)
Yes - Primary care physician	67 (74%)	23 (26%)
Yes – Hospice care team	1 (50%)	1 (50%)



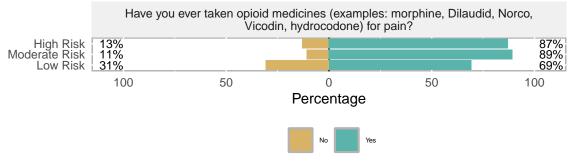
Questions 14 to 29 will ask you questions about your past and current use of opioid medicines (examples: morphine, Dilaudid, Norco, Vicodin, hydrocodone)

Q14: Have you ever taken opioid medicines (examples: morphine, Dilaudid, Norco, Vicodin, hydrocodone) for pain? (Select 1)

Response	n (%)
responses / total surveyed	377 / 507
Yes	$283\ (\ 75\ \%)$
No	94 (25 %)

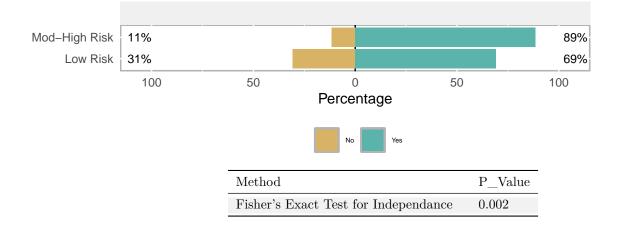


Contingency Table of Responses versus Risk Group				
	Low Risk	Moderate Risk	High Risk	
No	73~(88%)	6(7%)	4 (5%)	
Yes	164~(68%)	50(21%)	27~(11%)	



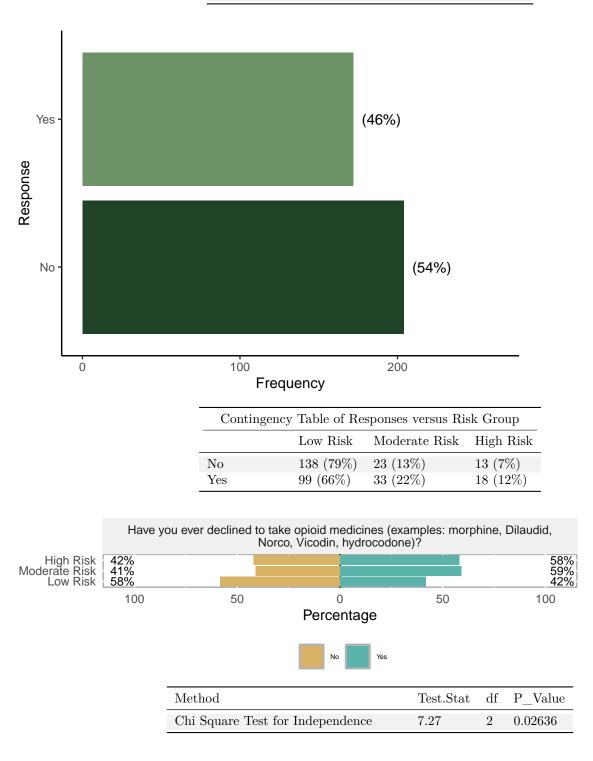
Method	P_Value
Fisher's Exact Test for Independance	0.005

Contingency Table of Responses versus Risk Group			
	Low Risk	Mod-High Risk	
No	73~(88%)	10 (12%)	
Yes	164~(68%)	77~(32%)	

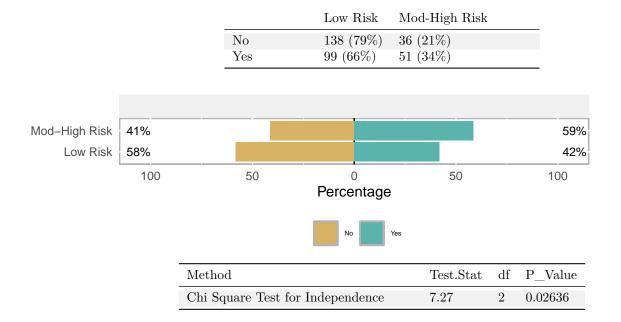


Q15: Have you ever declined to take opioid medicines (examples: morphine, Dilaudid, Norco, Vicodin, hydrocodone)? (Select 1)

Response	n (%)
responses / total surveyed	376 / 507
No	204 (54%)
Yes	172 (46 %)

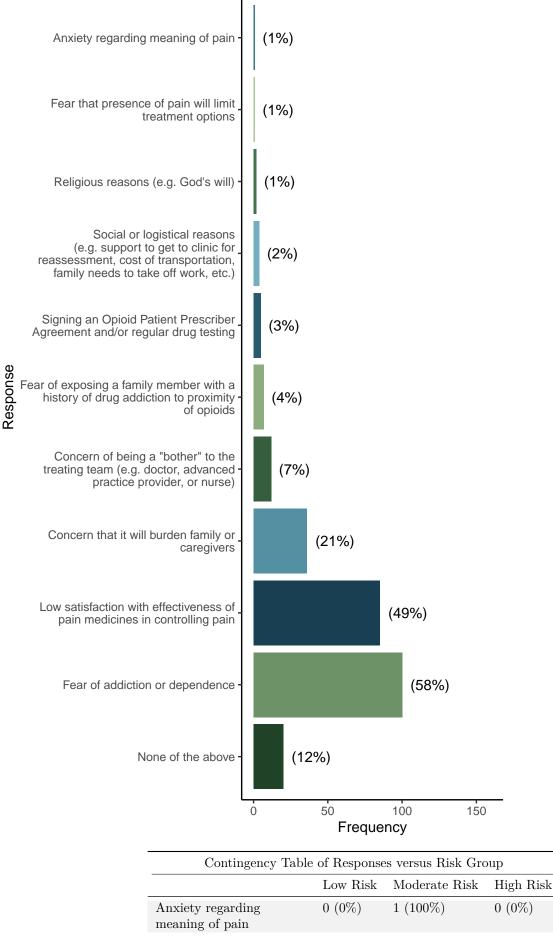


Contingency Table of Responses versus Risk Group

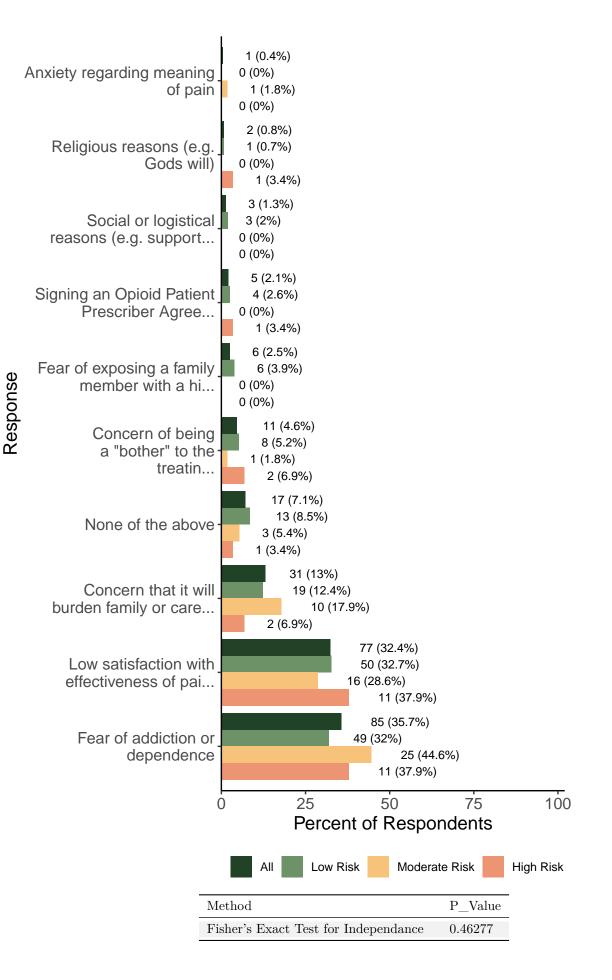


Q16: [If Q15 Yes] Why did you decline to take opioid medicines (examples: morphine, Dilaudid, Norco, Vicodin, hydrocodone)? (Select all that apply)

Response	n (%)
responses / total surveyed	172 / 507
None of the above	20 (12%)
Fear of addiction or dependence	100~(~58~%)
Low satisfaction with effectiveness of pain medicines in controlling pain	85 (49%)
Concern that it will burden family or caregivers	36 (21%)
Concern of being a "bother" to the treating team (e.g. doctor, advanced practice provider, or nurse)	12 (7%)
Fear of exposing a family member with a history of drug addiction to proximity of opioids	7 (4%)
Signing an Opioid Patient Prescriber Agreement and/or regular drug testing	5(3%)
Social or logistical reasons (e.g. support to get to clinic for reassessment, cost of transportation, family needs to take off work, etc.)	4 (2%)
Religious reasons (e.g. God's will)	2 (1%)
Fear that presence of pain will limit treatment options	1 (1%)
Anxiety regarding meaning of pain	1(1%)

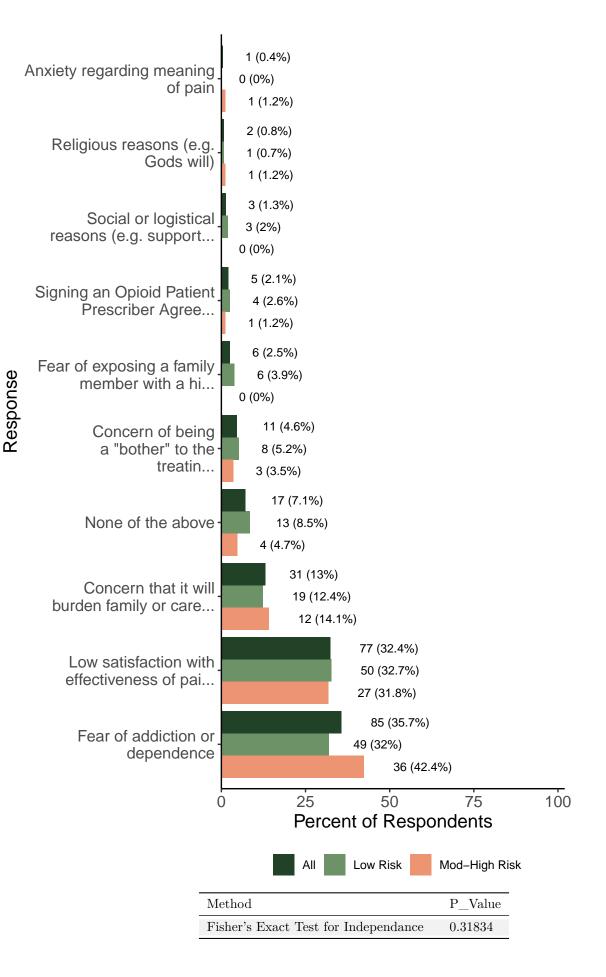


Concern of being a "bother" to the treatin	8 (73%)	1 (9%)	2(18%)
Concern that it will burden family or care	19 (61%)	10 (32%)	2 (6%)
Fear of addiction or dependence	49~(58%)	25 (29%)	11 (13%)
Fear of exposing a family member with a hi	6 (100%)	0 (0%)	0 (0%)
Low satisfaction with effectiveness of pai	50 (65%)	16 (21%)	11 (14%)
None of the above	13~(76%)	3(18%)	1(6%)
Religious reasons (e.g. Gods will)	1 (50%)	0 (0%)	1 (50%)
Signing an Opioid Patient Prescriber Agree	4 (80%)	0 (0%)	1 (20%)
Social or logistical reasons (e.g. support	3 (100%)	0 (0%)	0 (0%)

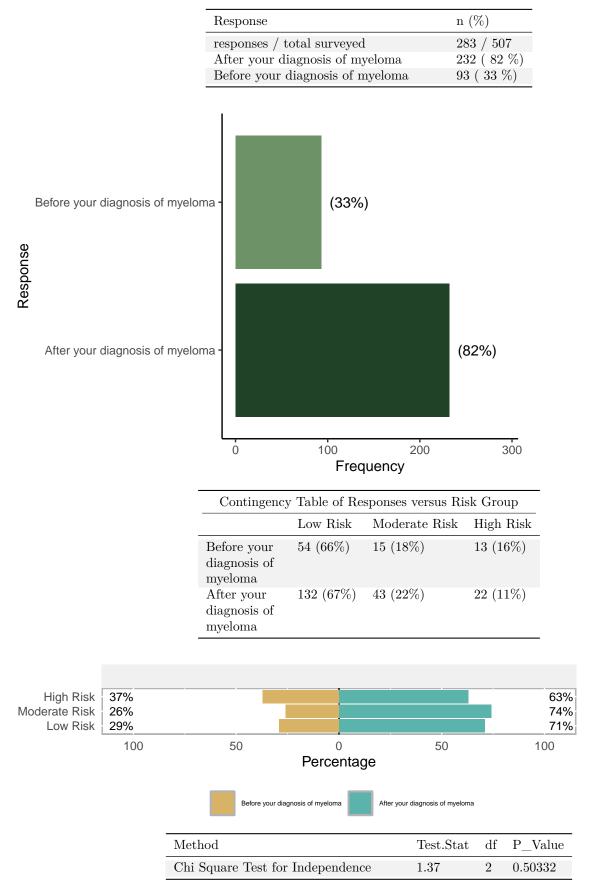


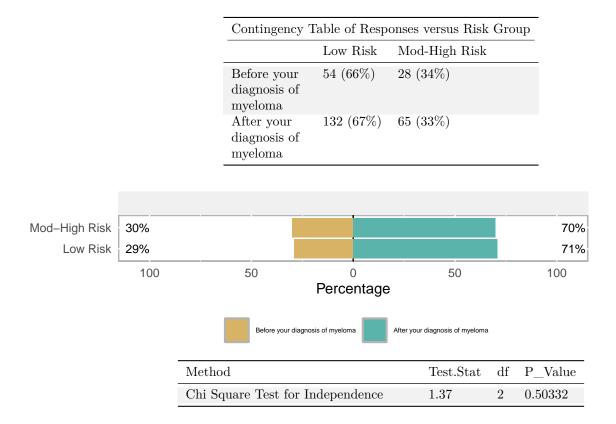
Contingency 7	Table of Resp	ponses versus Risk Group
	Low Risk	Mod-High Risk
Anxiety regarding meaning of pain	0 (0%)	1 (100%)
Concern of being a "bother" to the treatin	8 (73%)	3 (27%)
Concern that it will burden family or care	19 (61%)	12 (39%)
Fear of addiction or dependence	49 (58%)	36 (42%)
Fear of exposing a family member with a hi	6 (100%)	0 (0%)
Low satisfaction with effectiveness of pai	50 (65%)	27 (35%)
None of the above	13~(76%)	4 (24%)
Religious reasons (e.g. Gods will)	1 (50%)	1 (50%)
Signing an Opioid Patient Prescriber Agree	4 (80%)	1 (20%)
Social or logistical reasons (e.g. support	3 (100%)	0 (0%)

Table of Be Dick C ntir



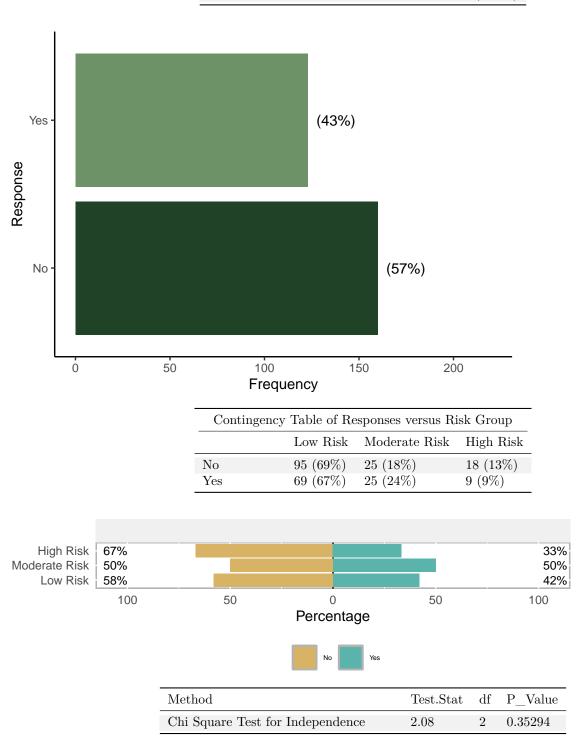
Q17: [If Q14 Yes] When did you use opioid medicines (examples: morphine, Dilaudid, Norco, Vicodin, hydrocodone)? (Select all that apply)



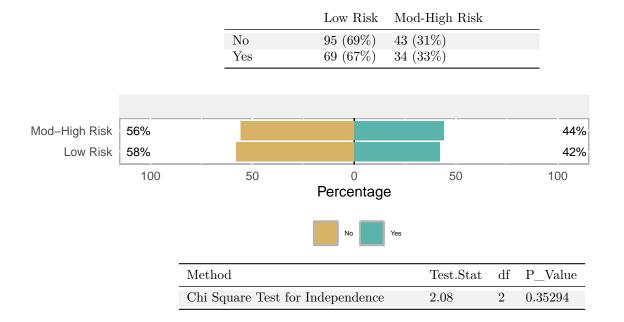


Q18: [If Q14 Yes] Are you currently taking opioid medicines (examples: morphine, Dilaudid, Norco, Vicodin, hydrocodone) for pain?

Response	n (%)
responses / total surveyed	283 / 507
No	$160\ (\ 57\ \%)$
Yes	123 (43 %)

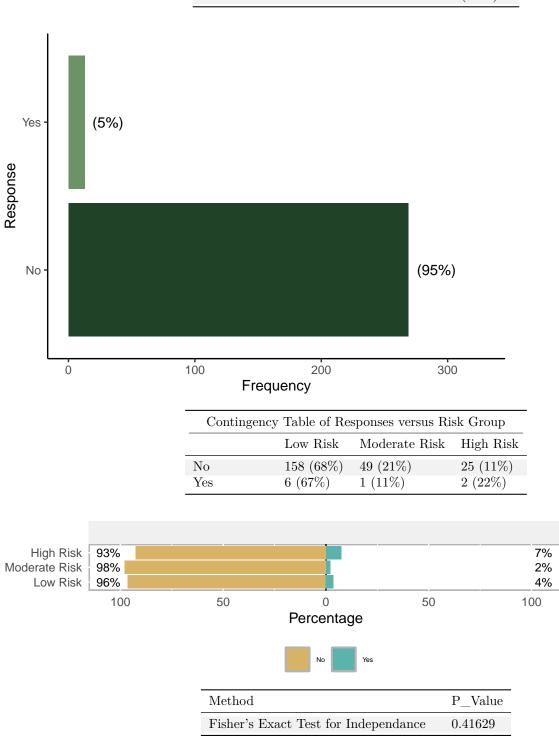


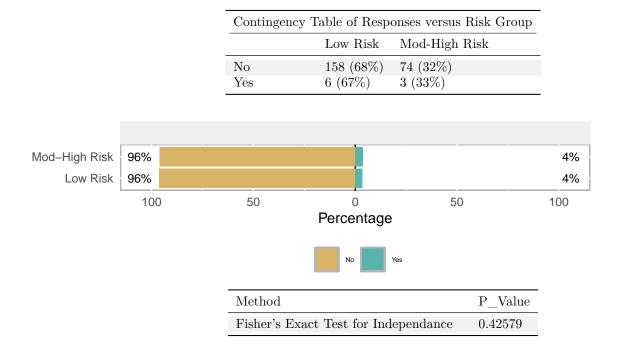
Contingency Table of Responses versus Risk Group



Q19: [If Q14 Yes] Has your healthcare provider ever declined to prescribe an opioid medicine (examples: morphine, Dilaudid, Norco, Vicodin, hydrocodone)? (Select 1)

Response	n (%)
responses / total surveyed	282 / 507
No	269~(~95~%)
Yes	$13\ (\ 5\ \%)$





Q20: [If Q14 Yes] Have you ever had a discussion with your physician or oncologist (myeloma doctor) about stopping opioid medicines (examples: morphine, Dilaudid, Norco, Vicodin, hydrocodone)? (Select 1)

				Respons	se	n	(%)
				response No Yes	es / total surveyed	10	88 / 507 00 (53 %) 8 (47 %)
Response	Yes - No -				(47%)	3%)	
		0		50 F	100 Frequency	1	50
				Contin	gency Table of Re Low Risk	sponses versus Ri Moderate Risk	sk Group High Risk
				No Yes	58 (71%) 47 (64%)	18 (22%) 18 (24%)	6 (7%) 9 (12%)
			[If Q1/ (myelom	a doctor) about st	ver had a discussio opping opioid medi Norco, Vicodin, hydi	n with your physicia cines (examples: mo rocodone)?	n or oncologist orphine, Dilaudid,
Mc	Hiql derate	h Risk Bisk W Risk	40% 55%				68% 45%
			100	50	0 Porconta	50	100
				Method	Percentag	ye _{Yes} Test.Sta	t df P_Value

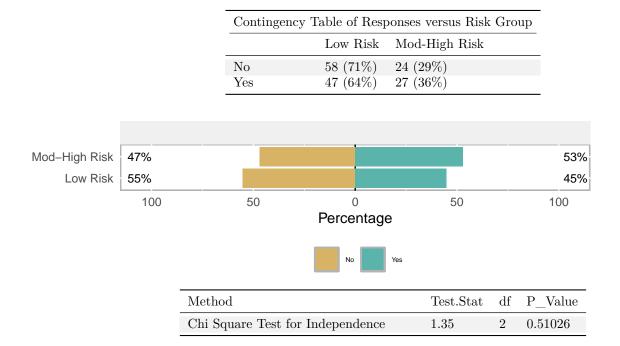
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Chi Square Test for Independence

1.35

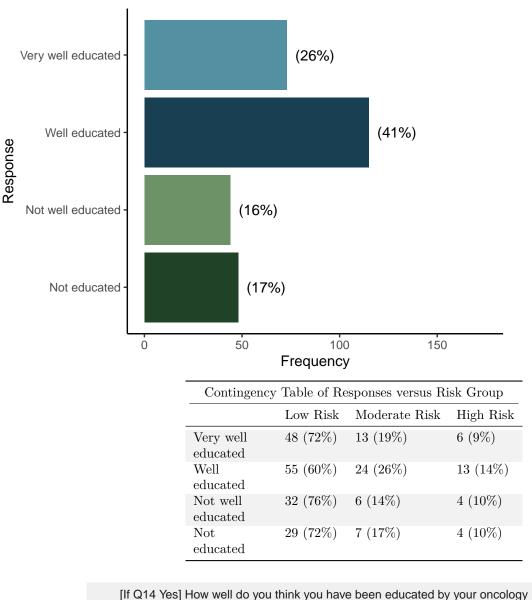
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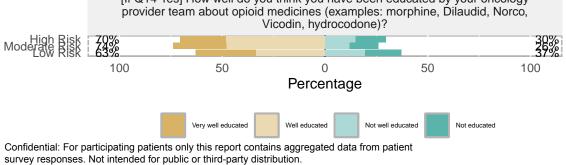
0.51026



Q21. [If Q14 Yes] How well do you think you have been educated by your oncology provider team about opioid medicines (examples: morphine, Dilaudid, Norco, Vicodin, hydrocodone)? (Select 1)

responses / total surveyed	280 / 50
Not educated	48 (17 %
Not well educated	44 (16 %
Well educated	115 (41
Very well educated	73 (26 %

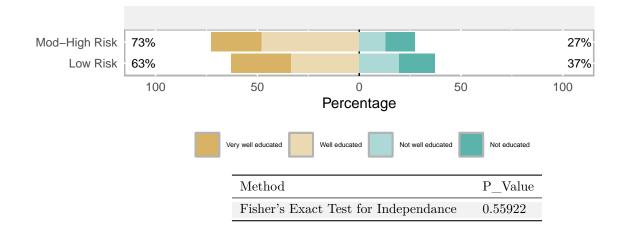




88

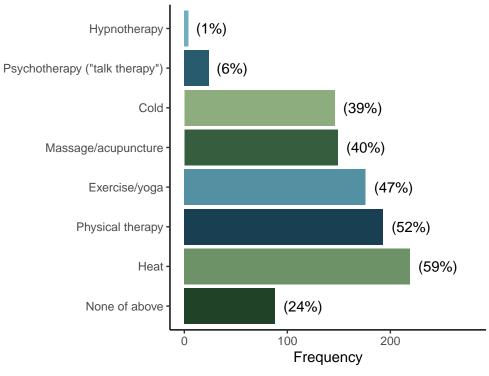
Method	P_Value
Fisher's Exact Test for Independance	0.58821

Contingency T	able of Resp	oonses versus Risk Group
	Low Risk	Mod-High Risk
Very well educated	48 (72%)	19 (28%)
Well educated	55~(60%)	37 (40%)
Not well educated	32~(76%)	10 (24%)
Not educated	29 (72%)	11 (28%)

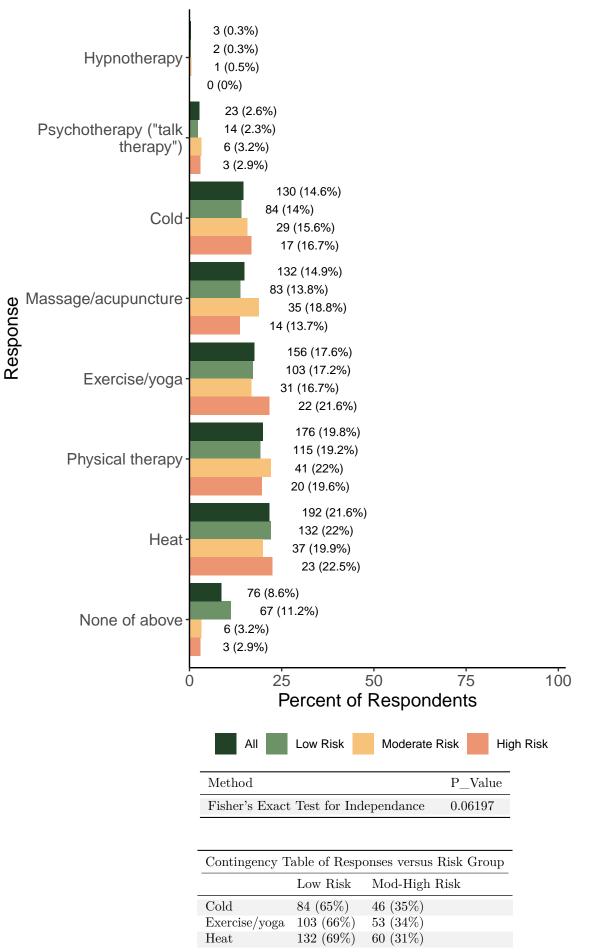


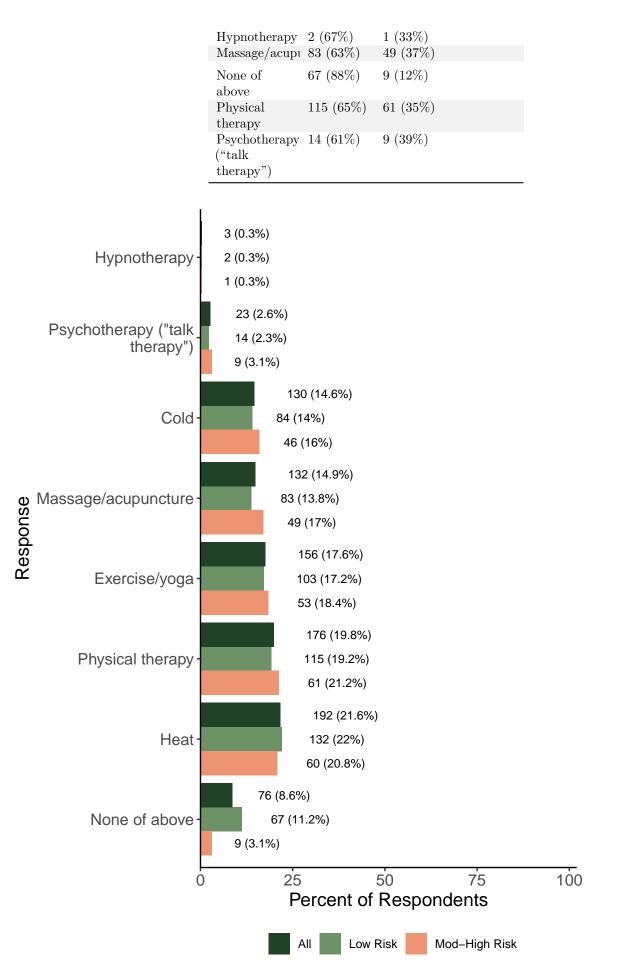
Q22: Have you ever used any of the following non-prescription strategies to avoid or delay taking opioid medicines (examples: morphine, Dilaudid, Norco, Vicodin, hydrocodone) for pain?

Response	n (%)
responses / total surveyed	373 / 507
None of above	88 (24 %)
Heat	219~(~59~%)
Physical therapy	193~(~52~%)
Exercise/yoga	176(47%)
Massage/acupuncture	149~(~40~%)
Cold	146 (39%)
Psychotherapy ("talk therapy")	24 (6%)
Hypnotherapy	4 (1%)



Contingency Table of Responses versus Risk Group			
	Low Risk	Moderate Risk	High Risk
Cold	84~(65%)	29(22%)	17 (13%)
Exercise/yoga	103~(66%)	31 (20%)	22~(14%)
Heat	132~(69%)	37~(19%)	23~(12%)
Hypnotherapy	2(67%)	1(33%)	0 (0%)
Massage/acupuncture	83~(63%)	35~(27%)	14 (11%)
None of above	67 (88%)	6 (8%)	3(4%)
Physical therapy	115~(65%)	41 (23%)	20 (11%)
Psychotherapy ("talk	14~(61%)	6(26%)	3~(13%)
therapy")	· · ·		

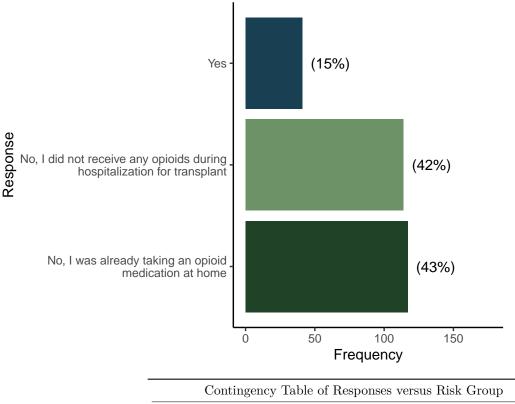




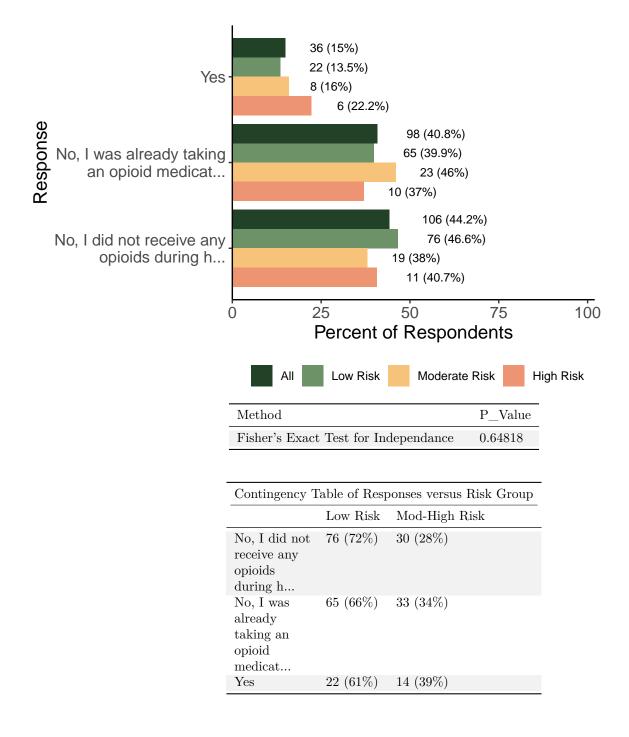
Method	P_Value
Fisher's Exact Test for Independance	0.0055

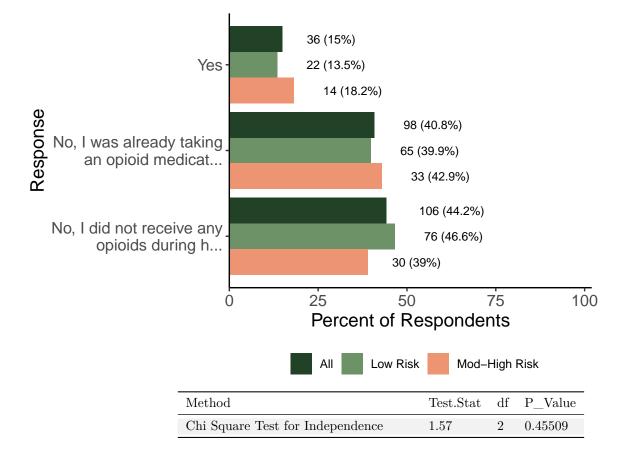
Q23. [If Q14 Yes] If you were hospitalized for stem cell transplant, was this the first time you received an opioid medicine (examples: morphine, Dilaudid, Norco, Vicodin, hydrocodone)? (Select 1)

Response	n (%)
responses / total surveyed	272 / 507
No, I was already taking an opioid	117 (43 %)
medication at home	
No, I did not receive any opioids during	114 (42 %)
hospitalization for transplant	
Yes	41 (15%)



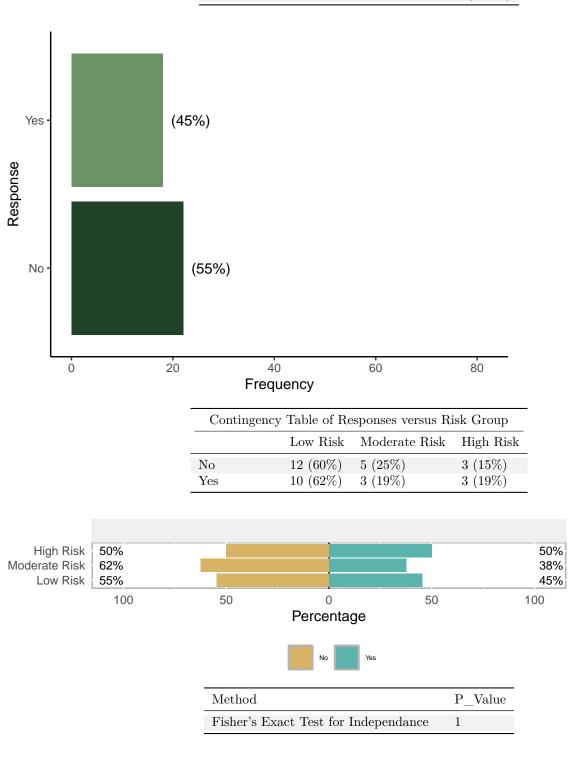
Contingency Table	of Response	es versus Risk Gro	oup
	Low Risk	Moderate Risk	High Risk
No, I did not receive any opioids during h	76 (72%)	19 (18%)	11 (10%)
No, I was already taking an opioid medicat	65~(66%)	23~(23%)	10 (10%)
Yes	22~(61%)	8 (22%)	6(17%)



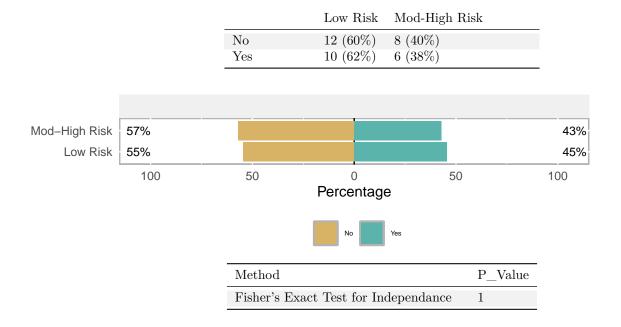


Q24. [If Q23 Yes] Were you discharged from the hospital on an opioid medicine (examples: morphine, Dilaudid, Norco, Vicodin, hydrocodone)?

Response	n (%)
responses / total surveyed	40 / 507
No	22 (55 %)
Yes	18 (45 %)

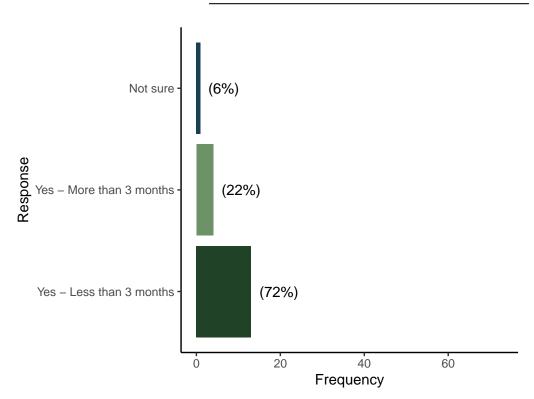


Contingency Table of Responses versus Risk Group



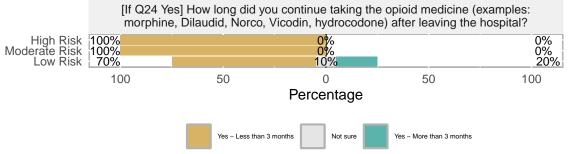
Q25: [If Q24 Yes] How long did you continue taking the opioid medicine (examples: morphine, Dilaudid, Norco, Vicodin, hydrocodone) after leaving the hospital? (Select 1)

Response	n (%)
responses / total surveyed	18 / 507
Yes - Less than 3 months	13~(~72~%)
Yes - More than 3 months	4 (22 %)
Not sure	1(6%)



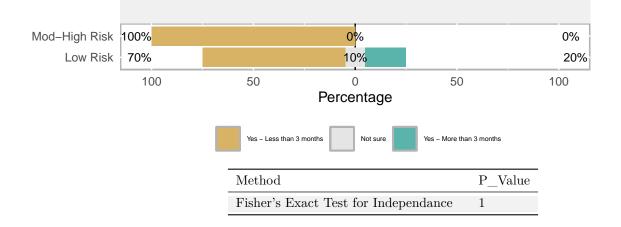
Very Few patients answered this question as they had had to answer Q14 and Q24 in the affirmative.

Contingency Table of Responses versus Risk Group			
	Low Risk	Moderate Risk	High Risk
Yes - Less than 3 months	7 (54%)	3 (23%)	3 (23%)
Not sure Yes - More than 3 months	1 (100%) 2 (100%)	$0 (0\%) \\ 0 (0\%)$	$\begin{array}{c} 0 \ (0\%) \\ 0 \ (0\%) \end{array}$



Method	P_Value
Fisher's Exact Test for Independence	1

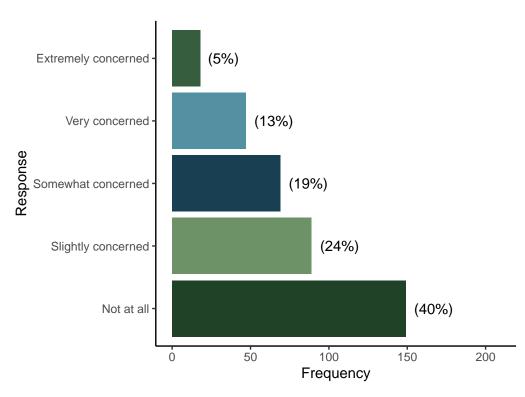
Contingency Table of Responses versus Risk Group			
	Low Risk	Mod-High Risk	
Yes - Less than 3 months	7 (54%)	6 (46%)	
Not sure	1 (100%)	0 (0%)	
Yes - More than 3 months	2 (100%)	0 (0%)	



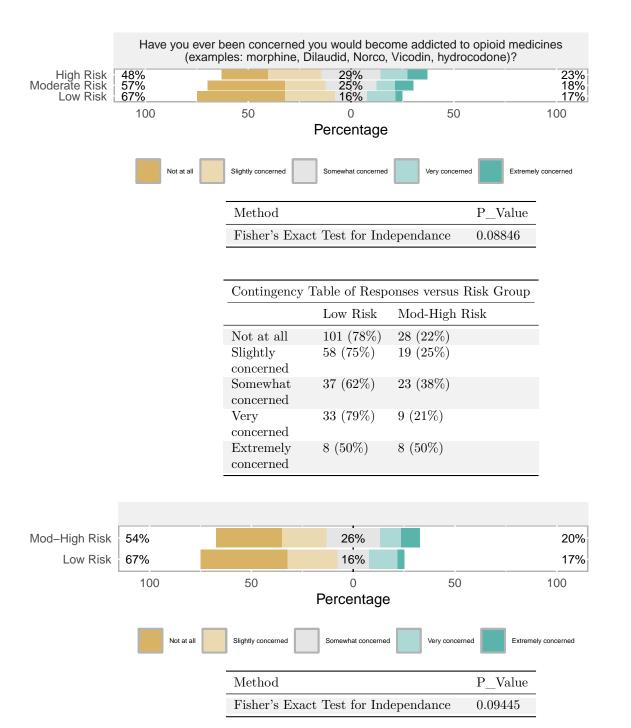
It is interesting to note that none of the patients in the high or moderate risk categories continued taking opioid medications for more than 3 months after leaving the hospital. However, our sample size is very small. All of these patients are those who received stem cell transplants, and had never taken opioids before this point. Questions 23 and 24 were required "yes"

Q26: Have you ever been concerned you would become addicted to opioid medicines (examples: morphine, Dilaudid, Norco, Vicodin, hydrocodone)? (Select 1)

Response	n (%)
responses / total surveyed	372 / 507
Not at all	149~(~40~%)
Slightly concerned	89 (24 %)
Somewhat concerned	69~(~19~%)
Very concerned	47 (13 %)
Extremely concerned	18 (5 %)



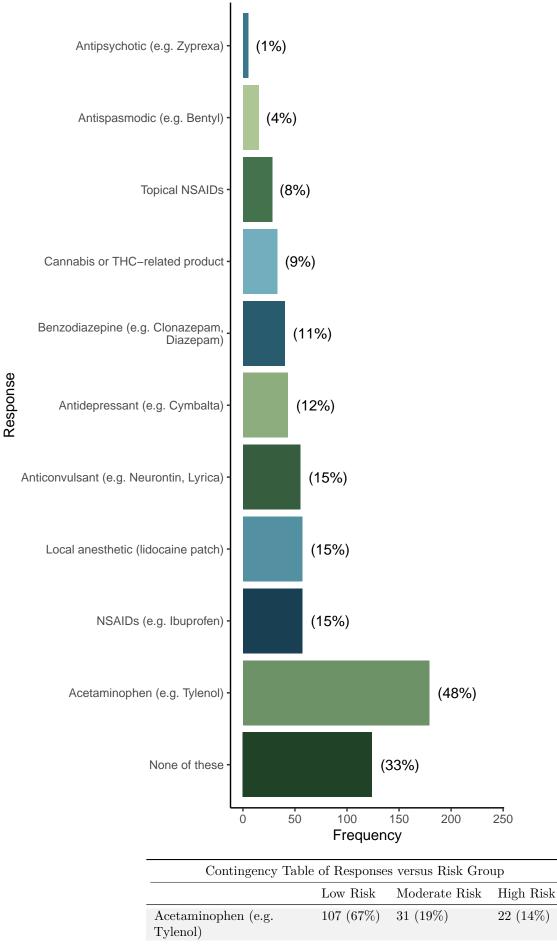
Contingency Table of Responses versus Risk Group			
	Low Risk	Moderate Risk	High Risk
Not at all	101 (78%)	21 (16%)	7(5%)
Slightly concerned	58 (75%)	11 (14%)	8 (10%)
Somewhat concerned	37 (62%)	14 (23%)	9 (15%)
Very concerned	33 (79%)	5(12%)	4 (10%)
Extremely concerned	8 (50%)	5 (31%)	3 (19%)



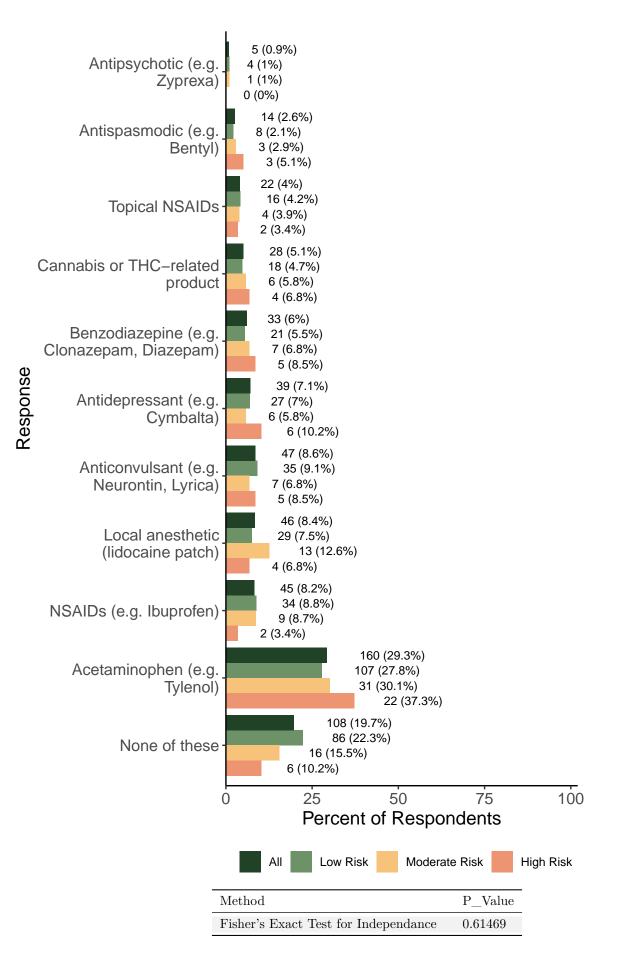
Even though the Likert plots are a suggestive of a difference between the Risk groups, our p value of our test for independence is still not small enough to conclude that.

Q27: Did your myeloma doctor ever prescribe you other medications for pain? (Select all that apply)

Response	n (%)
responses / total surveyed	372 / 507
None of these	124 (33 %)
Acetaminophen (e.g. Tylenol)	179 (48 %)
NSAIDs (e.g. Ibuprofen)	57 (15%)
Local anesthetic (lidocaine patch)	57 (15%)
Anticonvulsant (e.g. Neurontin, Lyrica)	55 (15%)
Antidepressant (e.g. Cymbalta)	43 (12%)
Benzodiazepine (e.g. Clonazepam,	40 (11%)
Diazepam)	· · · ·
Cannabis or THC-related product	33(9%)
Topical NSAIDs	28 (8 %)
Antispasmodic (e.g. Bentyl)	15 (4%)
Antipsychotic (e.g. Zyprexa)	5 (1%)

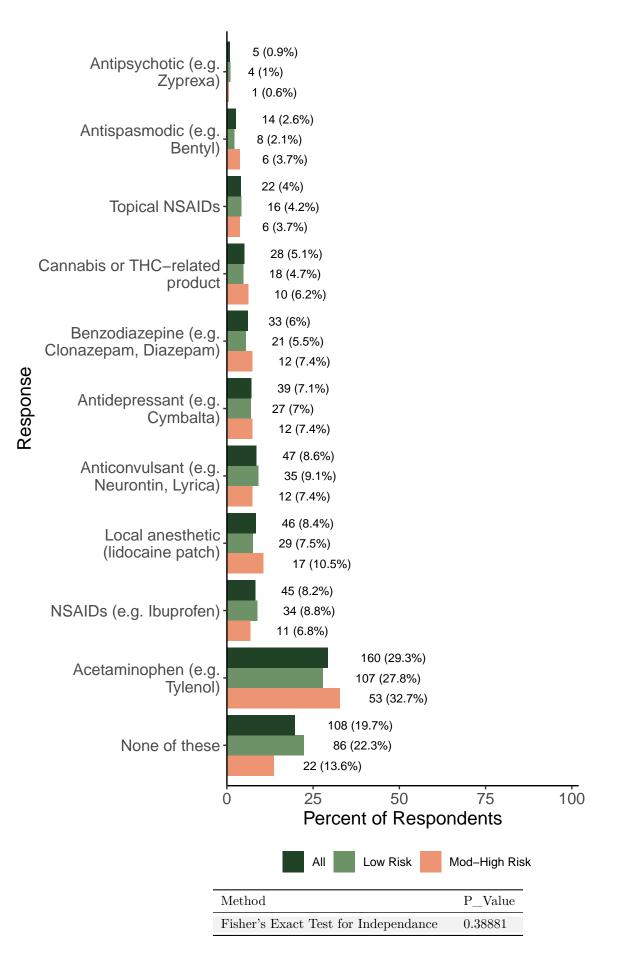


Anticonvulsant (e.g. Neurontin, Lyrica)	35~(74%)	7~(15%)	5 (11%)
Antidepressant (e.g. Cymbalta)	27 (69%)	6 (15%)	6 (15%)
Antipsychotic (e.g. Zyprexa)	4 (80%)	1 (20%)	0 (0%)
Antispasmodic (e.g. Bentyl)	8 (57%)	3 (21%)	3 (21%)
Benzodiazepine (e.g. Clonazepam, Diazepam)	21~(64%)	7 (21%)	5 (15%)
Cannabis or THC-related product	18 (64%)	6 (21%)	4 (14%)
Local anesthetic (lidocaine patch)	29 (63%)	13 (28%)	4 (9%)
None of these	86~(80%)	16~(15%)	6~(6%)
NSAIDs (e.g. Ibuprofen)	34~(76%)	9 (20%)	2(4%)
Topical NSAIDs	16~(73%)	4 (18%)	2 (9%)



Contingency Table of Responses versus Risk Group		
	Low Risk	Mod-High Risk
Acetaminopher (e.g. Tylenol)	107 (67%)	53~(33%)
Anticonvulsant (e.g. Neurontin, Lyrica)	35 (74%)	12 (26%)
Antidepressant (e.g. Cymbalta)	27 (69%)	12 (31%)
Antipsychotic (e.g. Zyprexa)	4 (80%)	1 (20%)
Antispasmodic (e.g. Bentyl)	8 (57%)	6 (43%)
Benzodiazepine (e.g. Clonazepam, Diazepam)	e 21 (64%)	12 (36%)
Cannabis or THC-related product	18 (64%)	10 (36%)
Local anesthetic (lidocaine patch)	29 (63%)	17 (37%)
None of these	86 (80%)	22 (20%)
NSAIDs (e.g. Ibuprofen)	34 (76%)	11 (24%)
Topical NSAIDs	16 (73%)	6 (27%)

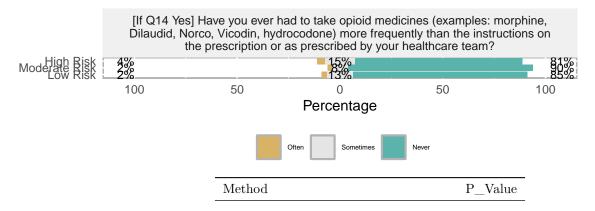
Contingency Table of Responses versus Risk Group



Q28: [If Q14 Yes] Have you ever had to take opioid medicines (examples: morphine, Dilaudid, Norco, Vicodin, hydrocodone) more frequently than the instructions on the prescription or as prescribed by your healthcare team? (Select 1)

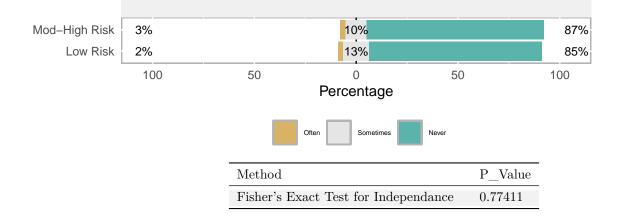
			Response	3	1	n (%)
				s / total surveyed		280 / 507
			Never	s / total surveyee		232(83%)
			Sometime	es		41 (15%)
			Often		,	7 (2%)
	Often -	(2%)				
esponse Somet	imes -		(15%)			
Ν	√ever -				(83%	6)
	L	0	100	Frequency	200	300
			Conting	ency Table of Re	esponses versus R	tisk Group
				Low Risk	Moderate Risk	

0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0				
	Low Risk	Moderate Risk	High Risk	
Often	4 (67%)	1(17%)	1 (17%)	
Sometimes	21 (72%)	4(14%)	4 (14%)	
Never	139~(67%)	45~(22%)	22~(11%)	



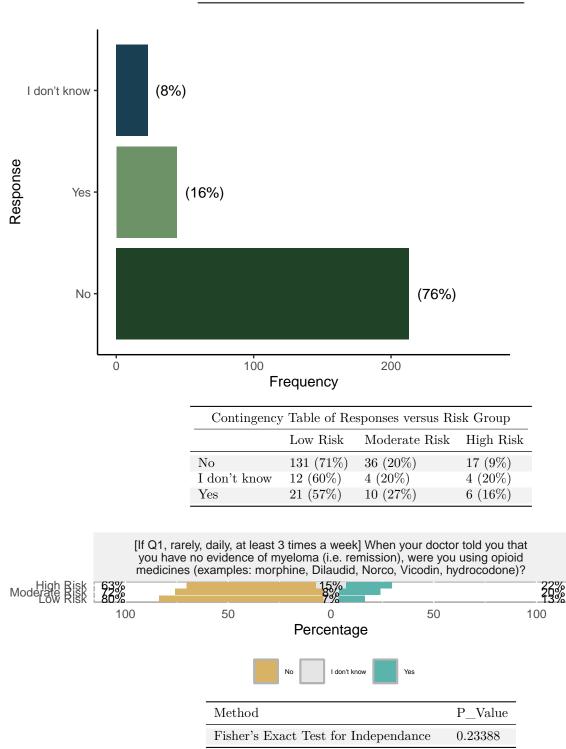
Fisher's Exact	Test for	Independance	0.76312
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Contingency Table of Responses versus Risk Group				
Low Risk	Mod-High Risk			
4 (67%)	2(33%)			
21 (72%)	8(28%)			
139~(67%)	67~(33%)			
	Low Risk 4 (67%) 21 (72%)			



Q29: [If Q14 Yes] Have you ever taken opioid medicines at the same time as medications like Ativan (lorazepam) or Klonopin (clonazepam)? (Select 1)

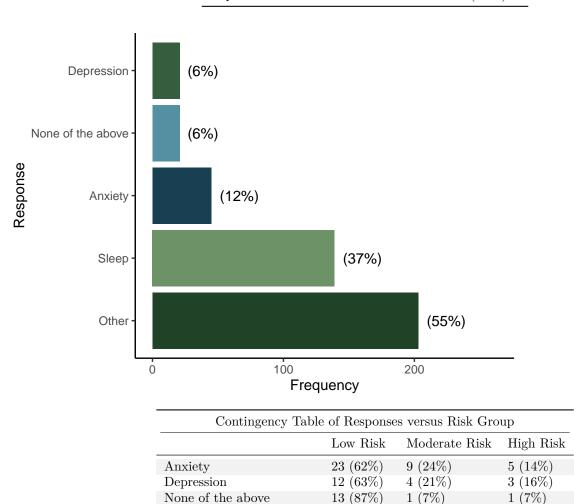
Response	n (%)
responses / total surveyed	280 / 507
No	213~(~76~%)
Yes	44 (16%)
I don't know	23~(~8~%)



		Contingency 7	Contingency Table of Responses versus Risk Group			
			Low Risk	Mod-High R	lisk	
		No	131 (71%)	53~(29%)		
		I don't know	12~(60%)	8 (40%)		
		Yes	21~(57%)	16~(43%)		
Mod–High Risk	69%		10%			21%
Low Risk	80%		7%			13%
	100	50	0	50		100
			Percentage			
		No	l don't know	Yes		
		Method			P_Value	
		Fisher's Exact	t Test for Ind	ependance	0.22839	

Q30: [If Q14 Yes] 30. Other than pain, did opioids ever help with improving any of the following: (Select all that apply)

Response	n (%)
responses / total surveyed	371 / 507
Other	203~(~55~%)
Sleep	139~(~37~%)
Anxiety	45 (12%)
None of the above	21~(~6~%)
Depression	21 (6%)



Other

Sleep

133 (73%)

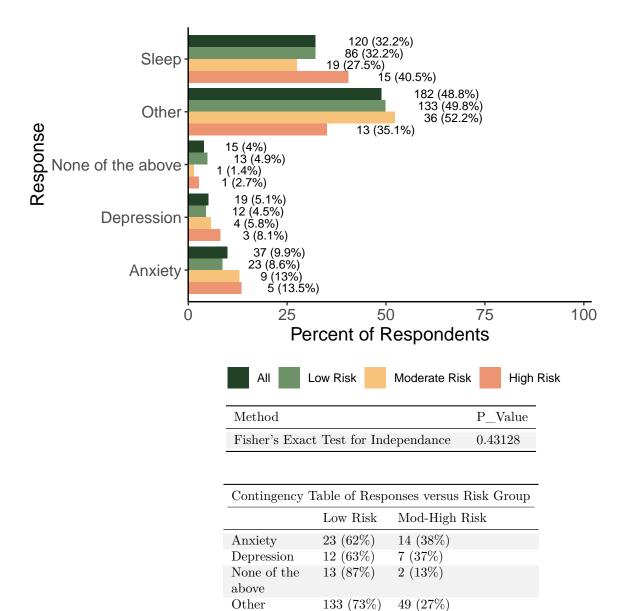
86 (72%)

36 (20%)

19 (16%)

13(7%)

15(12%)

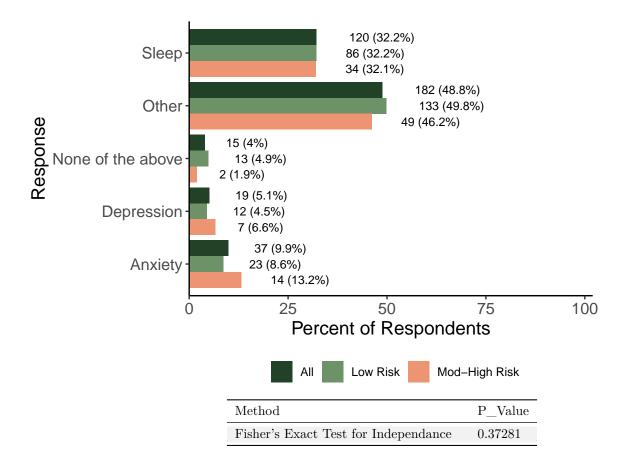


86 (72%)

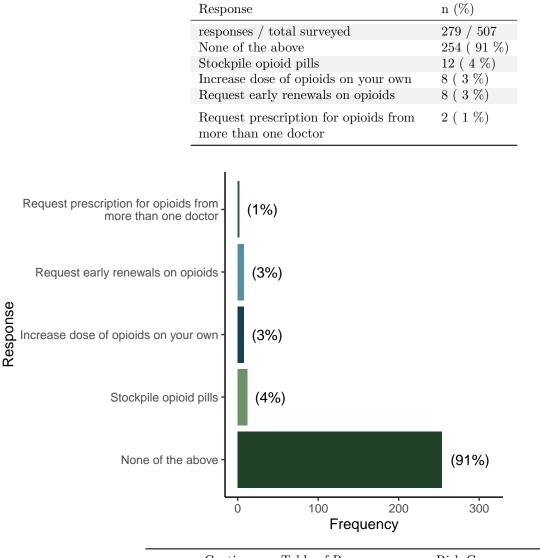
34(28%)

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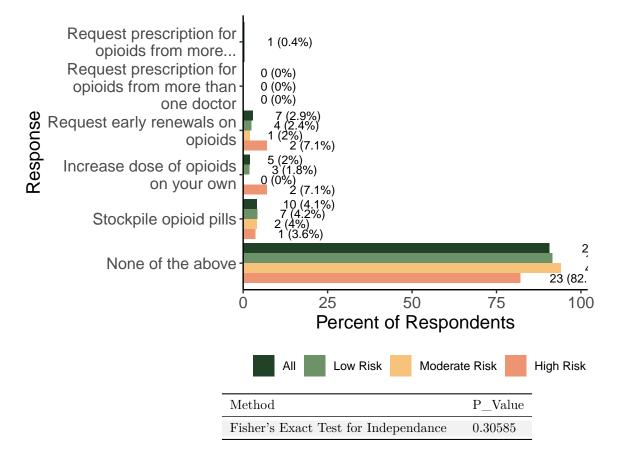
Sleep



Q31. [If Q14 Yes] Did you ever find yourself needing to do any of the following? (Select all that apply)



Contingency Table of Responses versus Risk Group				
	Low Risk	Moderate Risk	High Risk	
Increase dose of opioids on your own	3~(60%)	0 (0%)	2(40%)	
None of the above	152 (68%)	47 (21%)	23 (10%)	
Request early renewals on opioids	4(57%)	1 (14%)	2(29%)	
Stockpile opioid pills	7~(70%)	2(20%)	1 (10%)	



Contingency Table of Responses versus Risk Group			
	Low Risk	Mod-High Risk	
Increase dose of opioids on your own	3 (60%)	2 (40%)	
None of the above	152~(68%)	70 (32%)	
Request early renewals on opioids	4 (57%)	3 (43%)	
Stockpile opioid pills	7 (70%)	3 (30%)	

