

# The Voice of the Patient

Helen Haskell

Mothers Against Medical Error

The Empowered Patient Coalition

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# The Empowered Patient Coalition

Informing Patients  
Building Partnerships



- Factsheets and Checklists
- Advocate Directory
- Patient Resources
- Report a Medical Event
- Publications & Videos
- Join Our Email List!

[www.empoweredpatientcoalition.org](http://www.empoweredpatientcoalition.org)

*"The Empowered Patient* throws light on the darkest corners of the medical bureaucracy and abounds in practical advice for keeping yourself safe in the face of its sometimes alarming inconsistencies. If you are a patient or plan on ever being one, you need to read this book!"

Helen Haskell, President,  
Mothers Against Medical Error

# The Empowered Patient



Hundreds of  
**LIFE-SAVING** facts,  
action steps and  
strategies you  
need to know

Dr. Julia A. Hallisy

# The Empowered Patient<sup>®</sup>

The Empowered Patient<sup>®</sup>  
**Guide to Hospital Care**  
For Patients and Families



The  
Complete  
Five-Part  
Guide

Dr. Julia A. Hallisy and Helen W. Haskell  
An Empowered Patient<sup>®</sup> Publication

*A GUIDE TO HOSPITAL CARE FOR  
PATIENTS AND FAMILIES*

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# What Patients Need to Know

- **The Basics: Documents, advocates, hierarchies, informed consent and medical records**
- **The Details: What to watch for from diagnosis to discharge**
  - The Diagnostic Process \* Surgery and Anesthesia \* Infection Control and Prevention \* Medical Error Reduction \* Discharge and Home Care
- **How to Navigate the System: Communicating concerns and complaints in and out of the hospital**
- **Knowing When You Might Have a Problem: Signs and symptoms of medical conditions requiring prompt attention**
- **How to Track the Patient's Condition: Keeping a patient journal**

# The Patient Journal

- 1) Personal Medical History
- 2) Healthcare Providers' Contact Information
- 3) Visits by Doctors and Other Healthcare Professionals
- 4) Record of Diagnostic Tests and Studies
- 5) Record of Medical Procedures
- 6) Patient's Condition & Care: Observations & Questions
- 7) Weekly Medication Record
- 8) 24-Hour Vital Signs Chart



# The Empowered Patient Coalition

Have you, or someone you love had an adverse medical experience with a product, procedure, or medication?

**Learn How Reporting Events Can Help Others**



[Click Here](#)

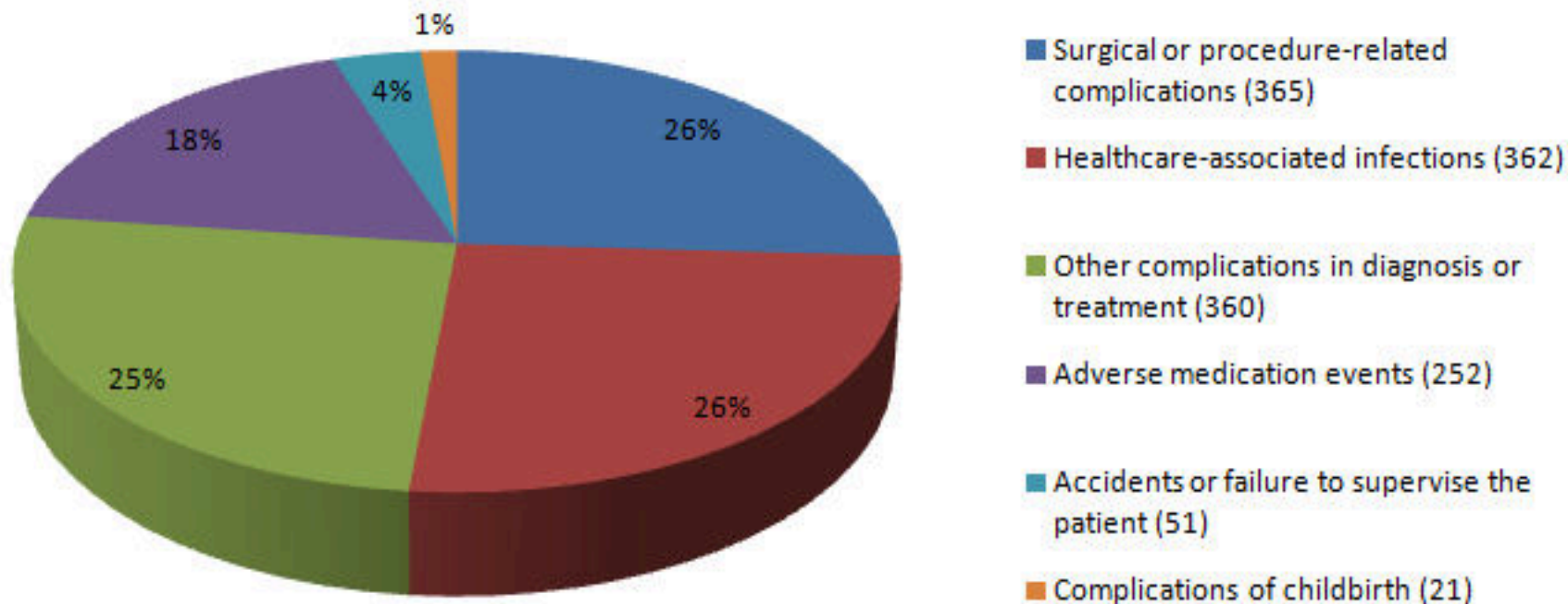
The goal of this joint effort by Empowered Patient Coalition and Consumers Union Safe Patient Project is to capture a snapshot of the impact of medical events from the patient's point of view.

This survey is designed to answer questions that are important to patients. We want the public to know that they can and must be the cornerstone to improving health care quality and safety and that their experiences are being counted...

# Why we created a survey

- Patient frustration with the reporting experience
- Need for a place where the patient's voice can be heard
- Desire to get a broad-brush picture of the patient's experience of medical harm, which is very different from the provider's
- Desire to ask questions not asked elsewhere

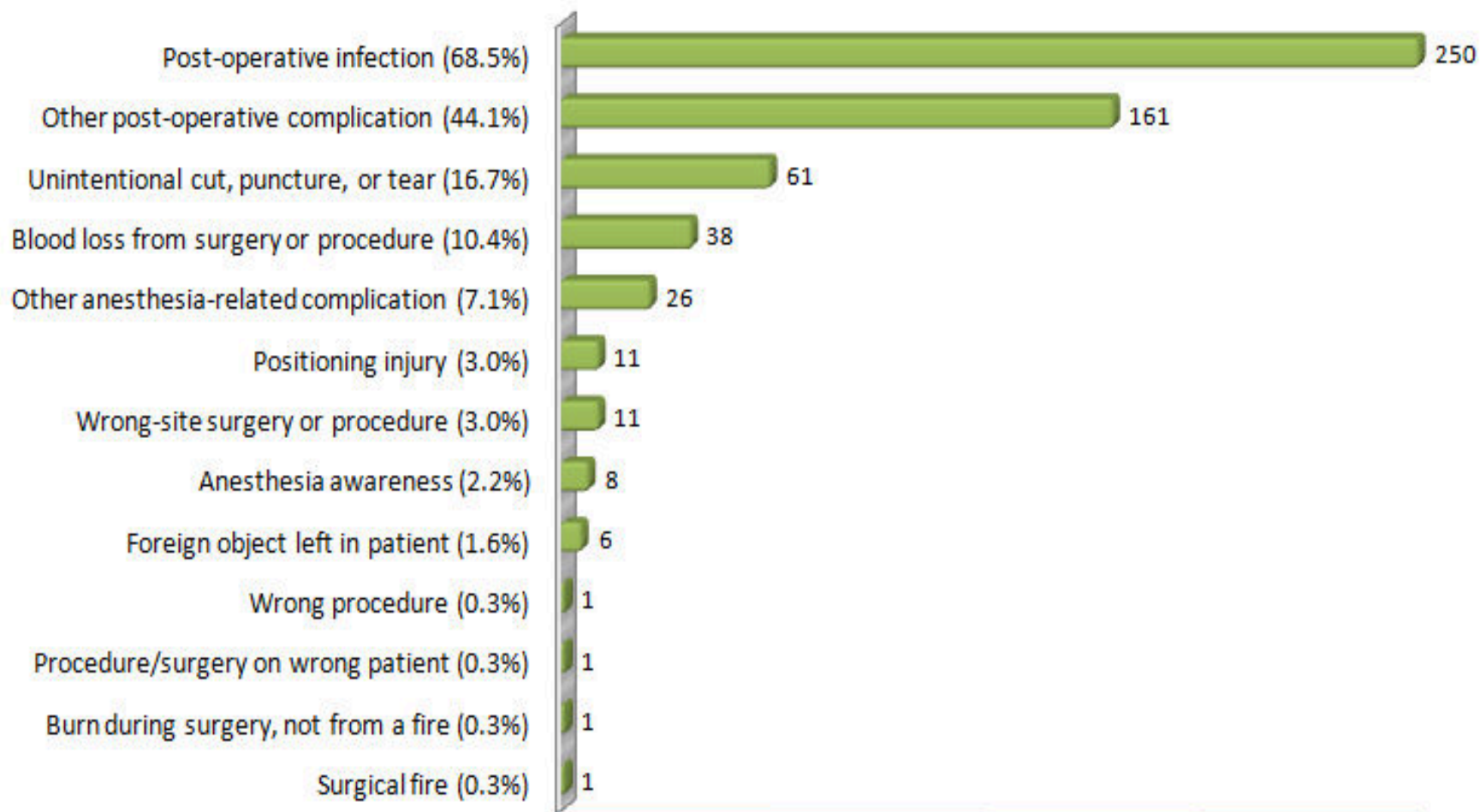
## Breakdown of Reported Adverse Events N=1411



547 respondents / 1411 responses

## Breakdown of Surgical and Procedure-Related Events

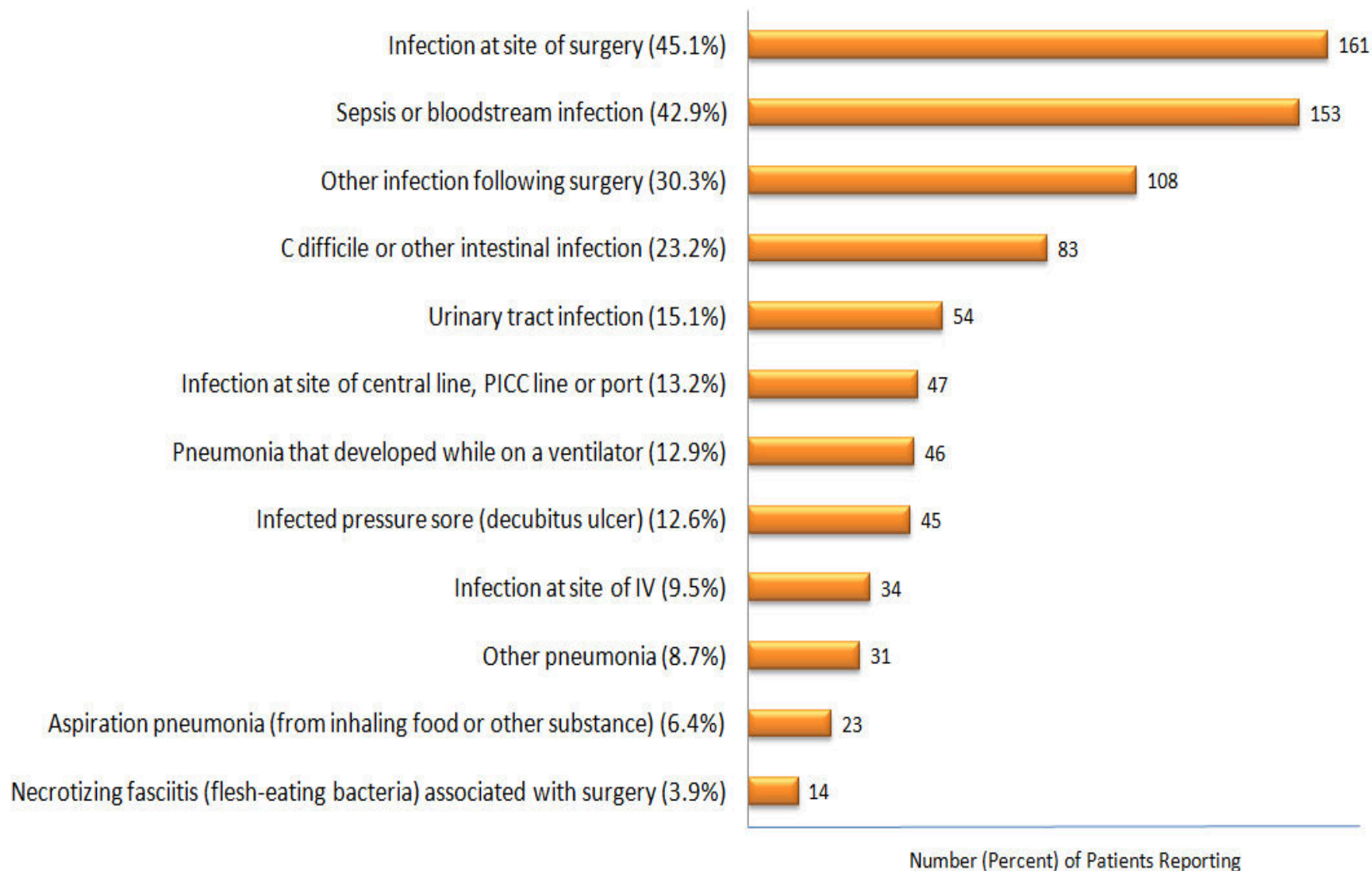
(365 respondents/576 responses)



Number (Percent) of Patients Reporting

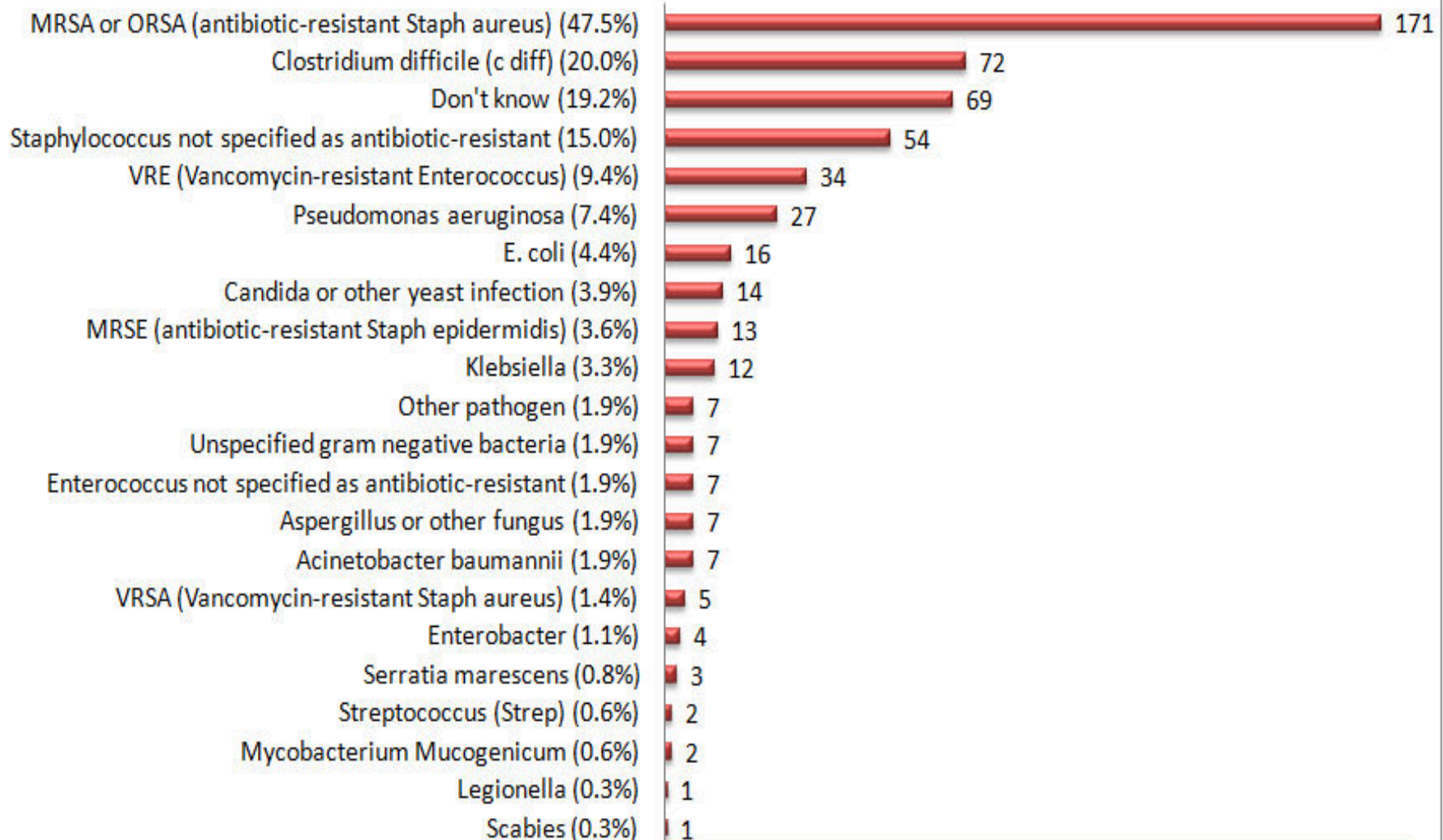
## Breakdown of Healthcare-Associated Infections and Pneumonia

(357 respondents/799 responses)



## Pathogens Involved in Healthcare-Associated Infections/Infestations

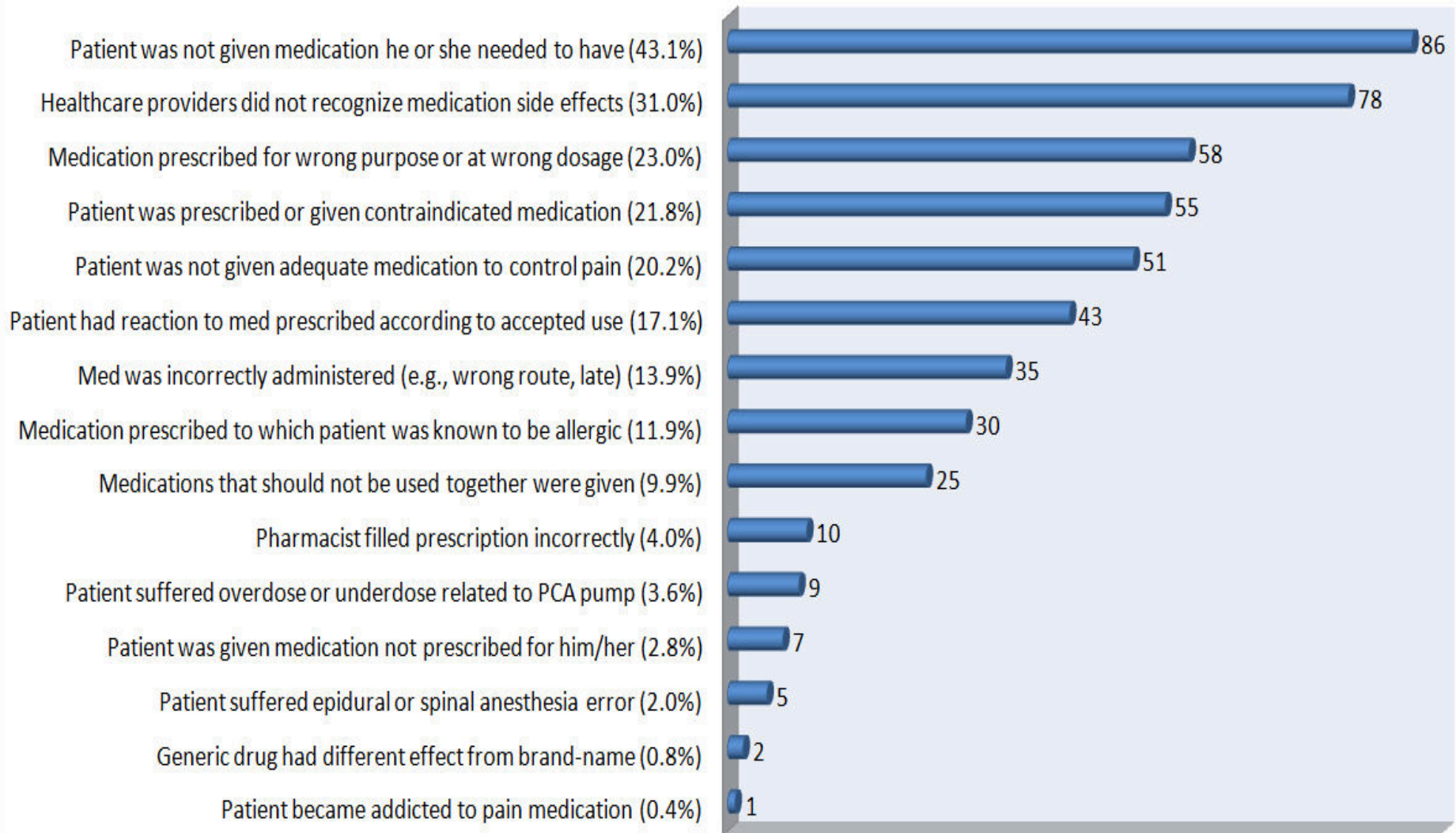
(360 respondents/535 responses)



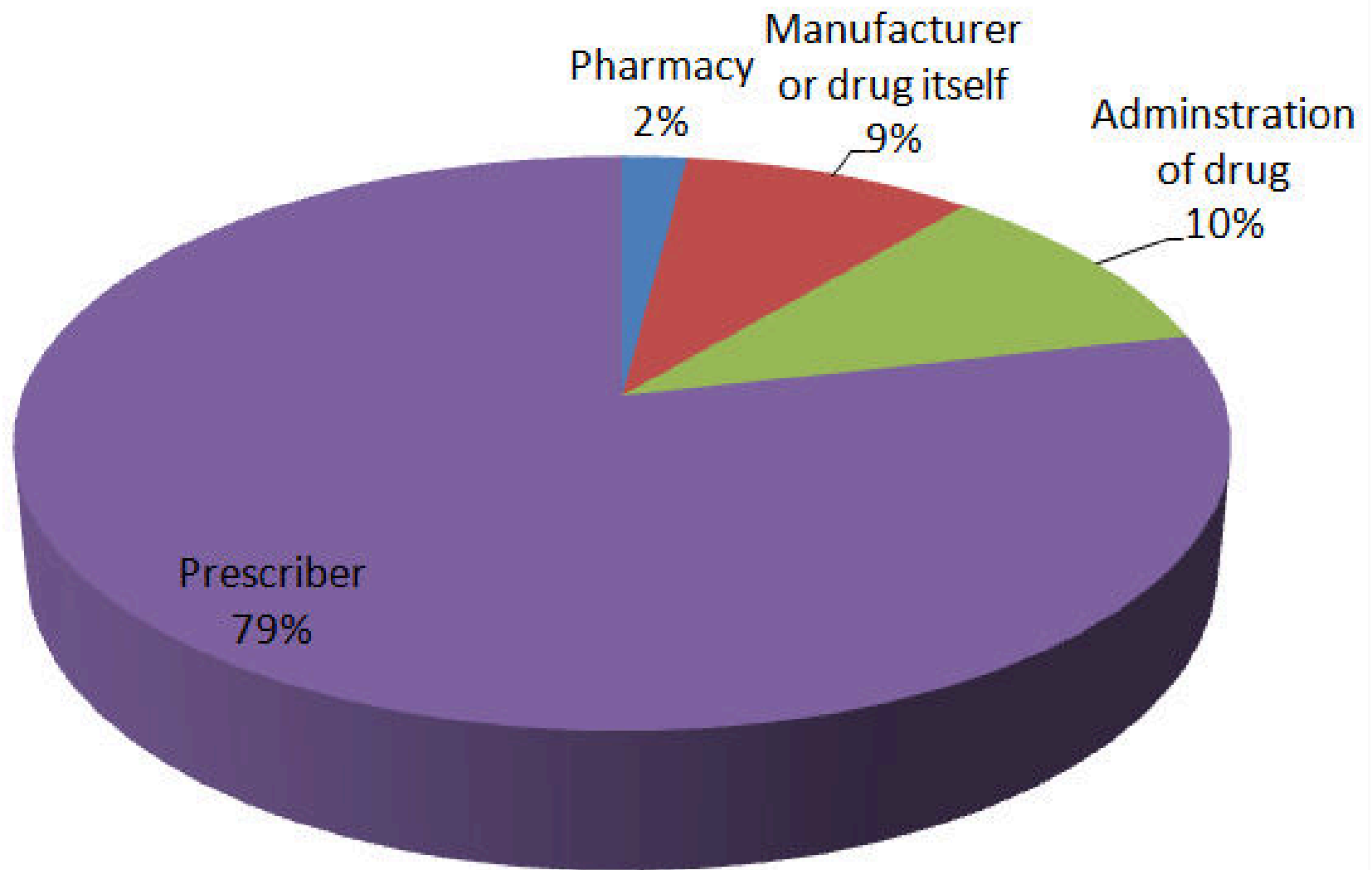
Number (Percent) of Patients Reporting

## Breakdown of Adverse Medication Events

(252 respondents/495 responses)



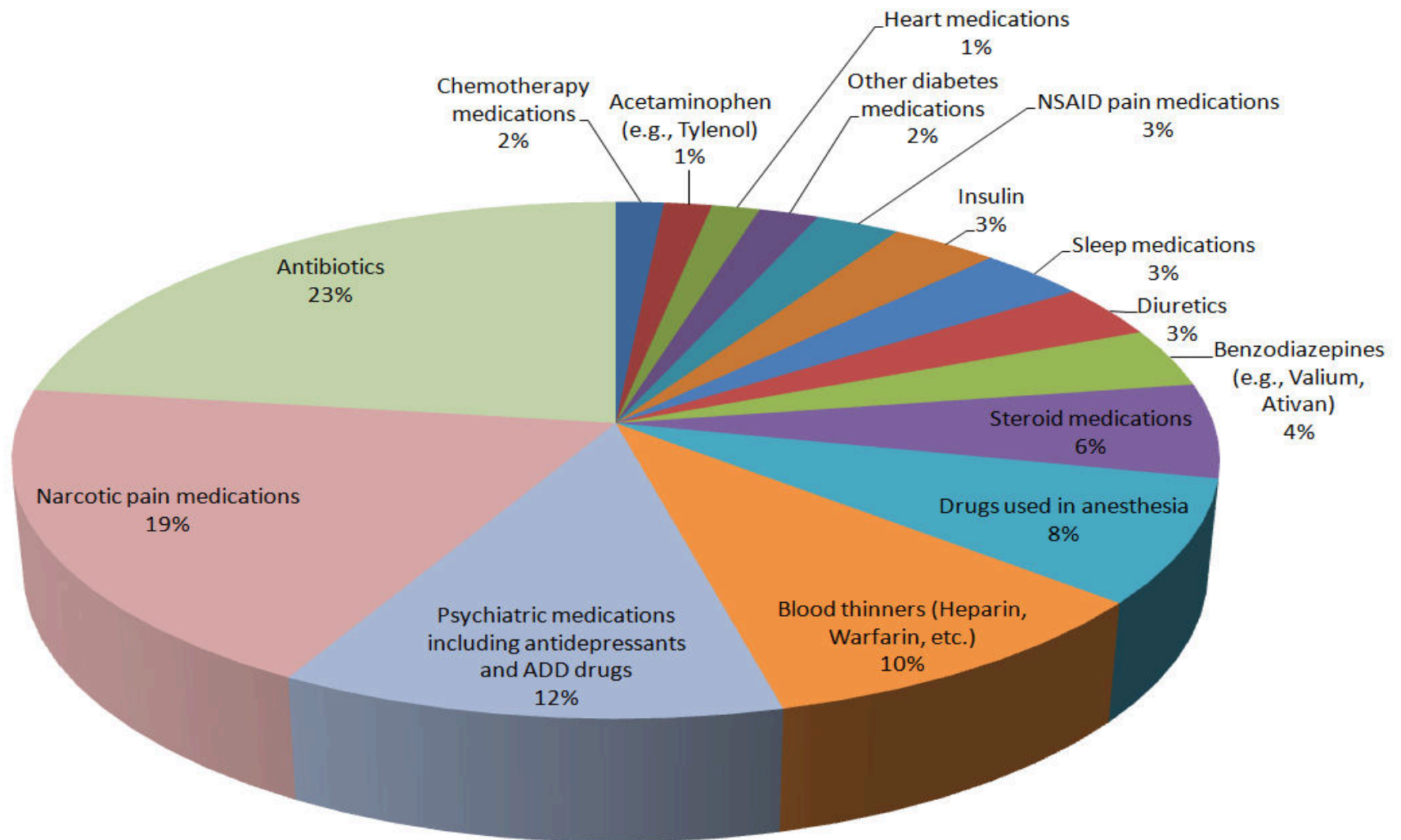
Number (Percent) of Patients Reporting



**Source of Medication Event (N=494)**

## Drugs Involved in Adverse Medication Events

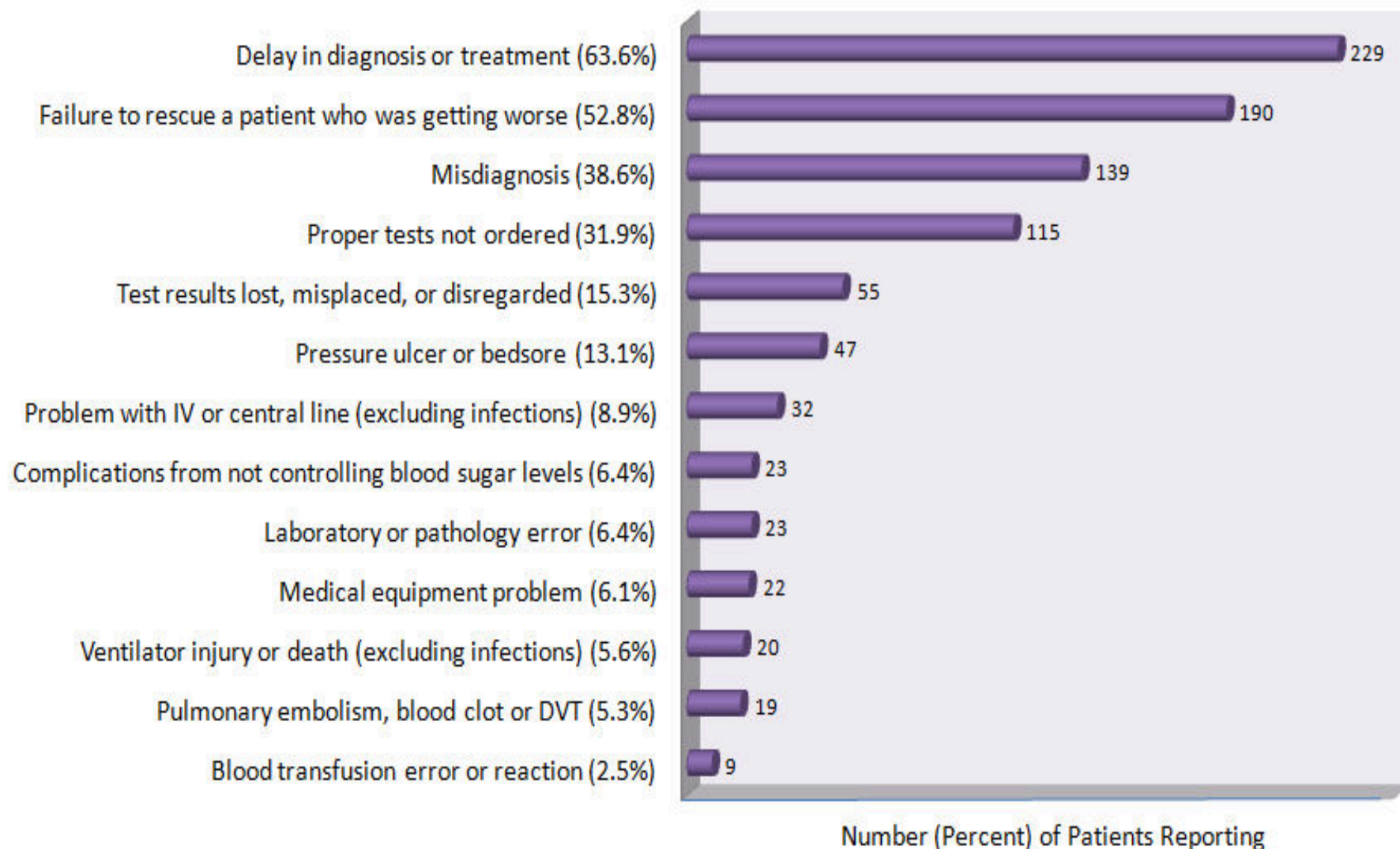
N=271



185 respondents/271 responses

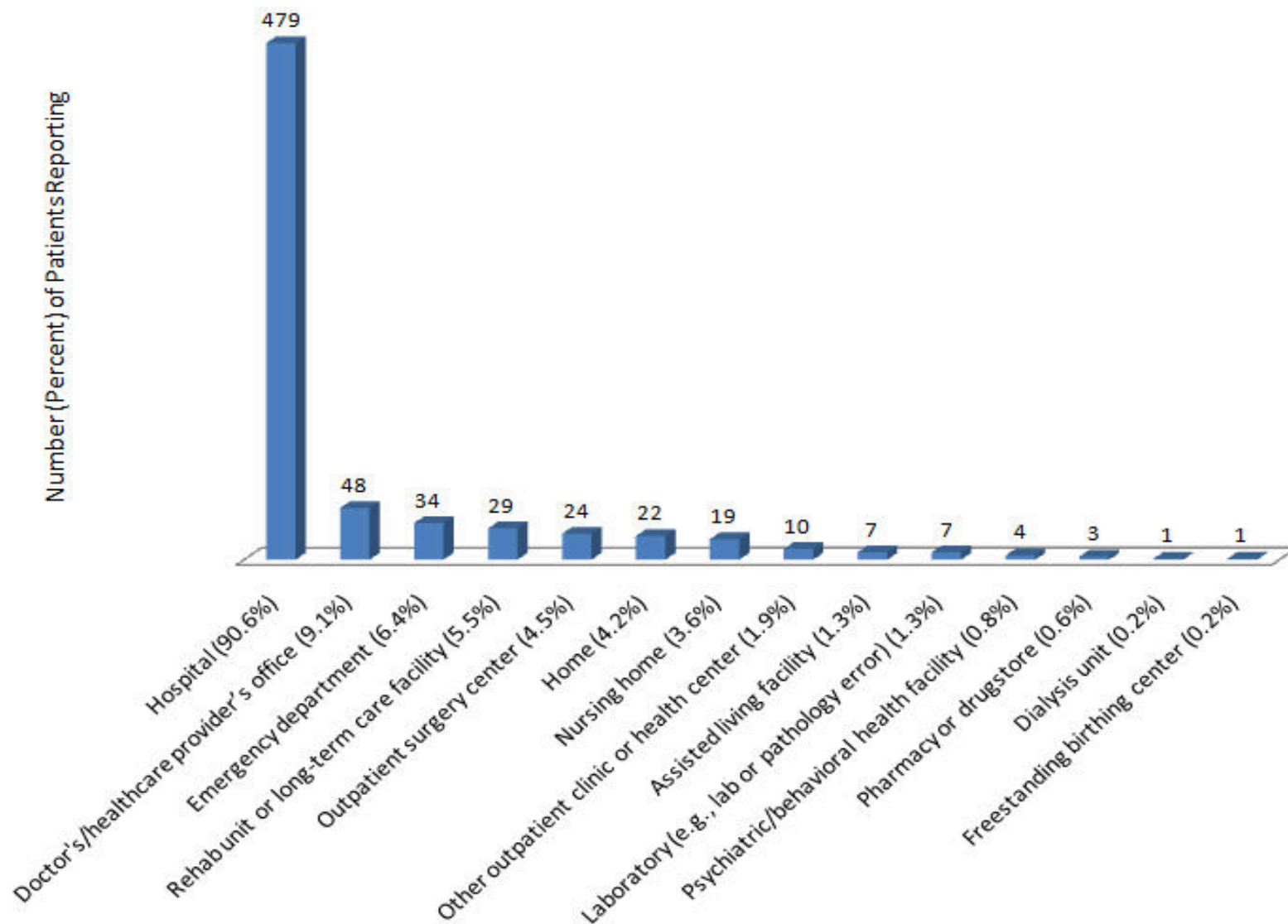
## Other Complications of Medical Treatment

(360 respondents, 923 responses)



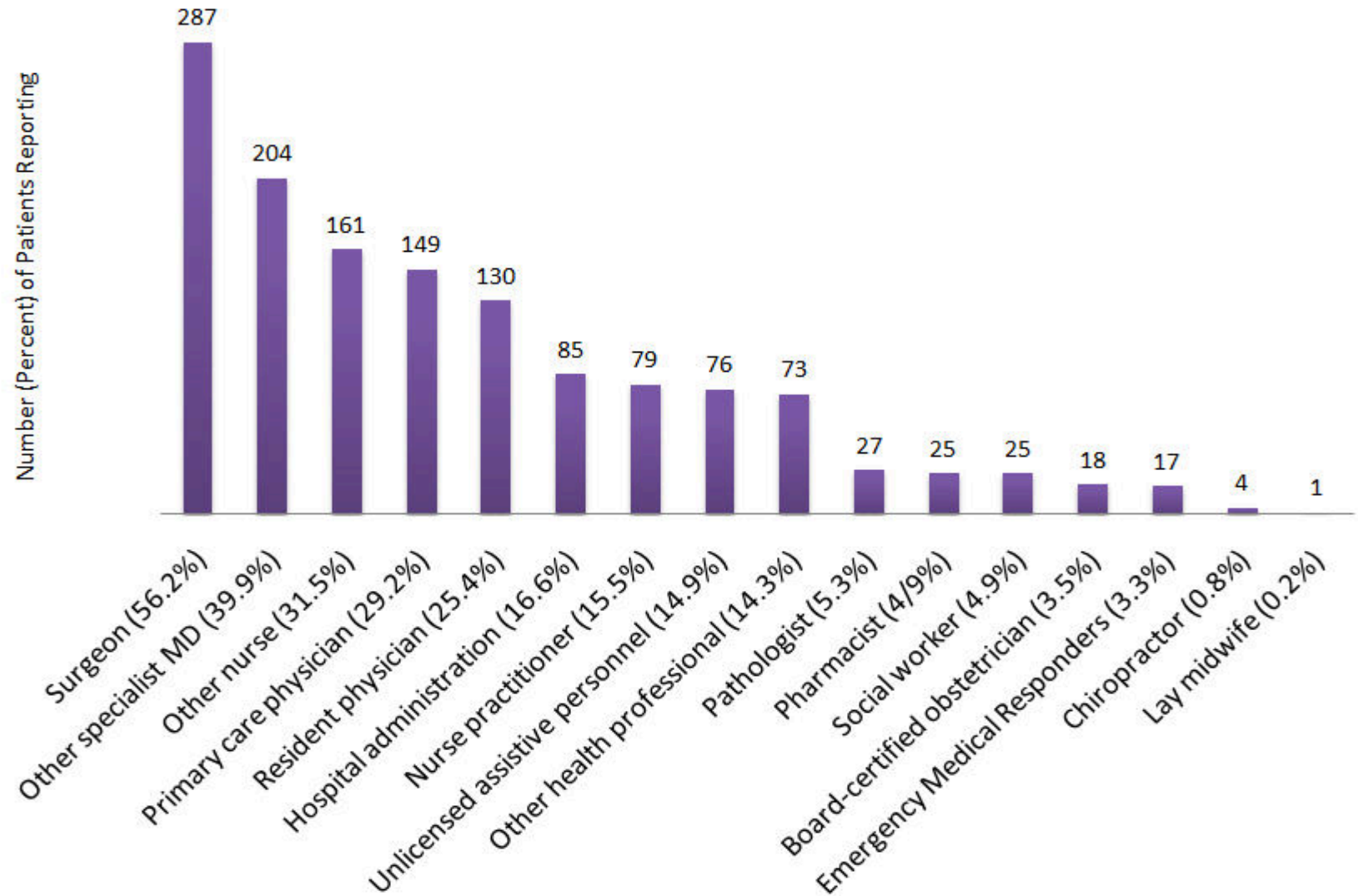
## Where Did the Event Happen?

(529 respondents/688 responses)



## Personnel Involved

(511 respondents/1361 responses)

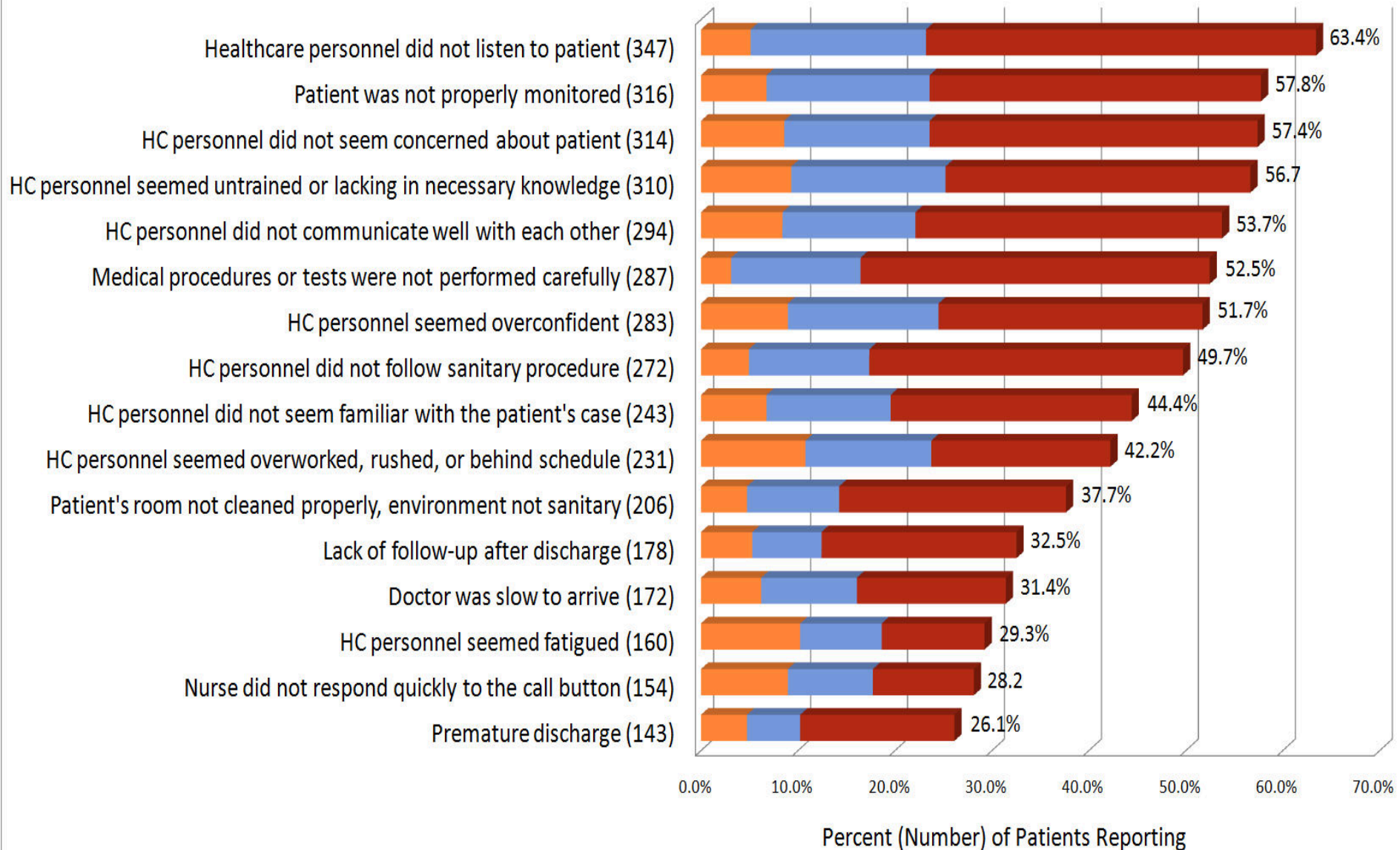


# Summary of Findings

- 90% of reported events were in hospitals.
- Most complications were postoperative.
- The most common complication was infection.
- Doctors were implicated in nearly every case; nurses in about half; other personnel much less frequently.
- The most common problem in medical treatment was delay:
  - Delay in diagnosis or treatment
  - Failure to rescue

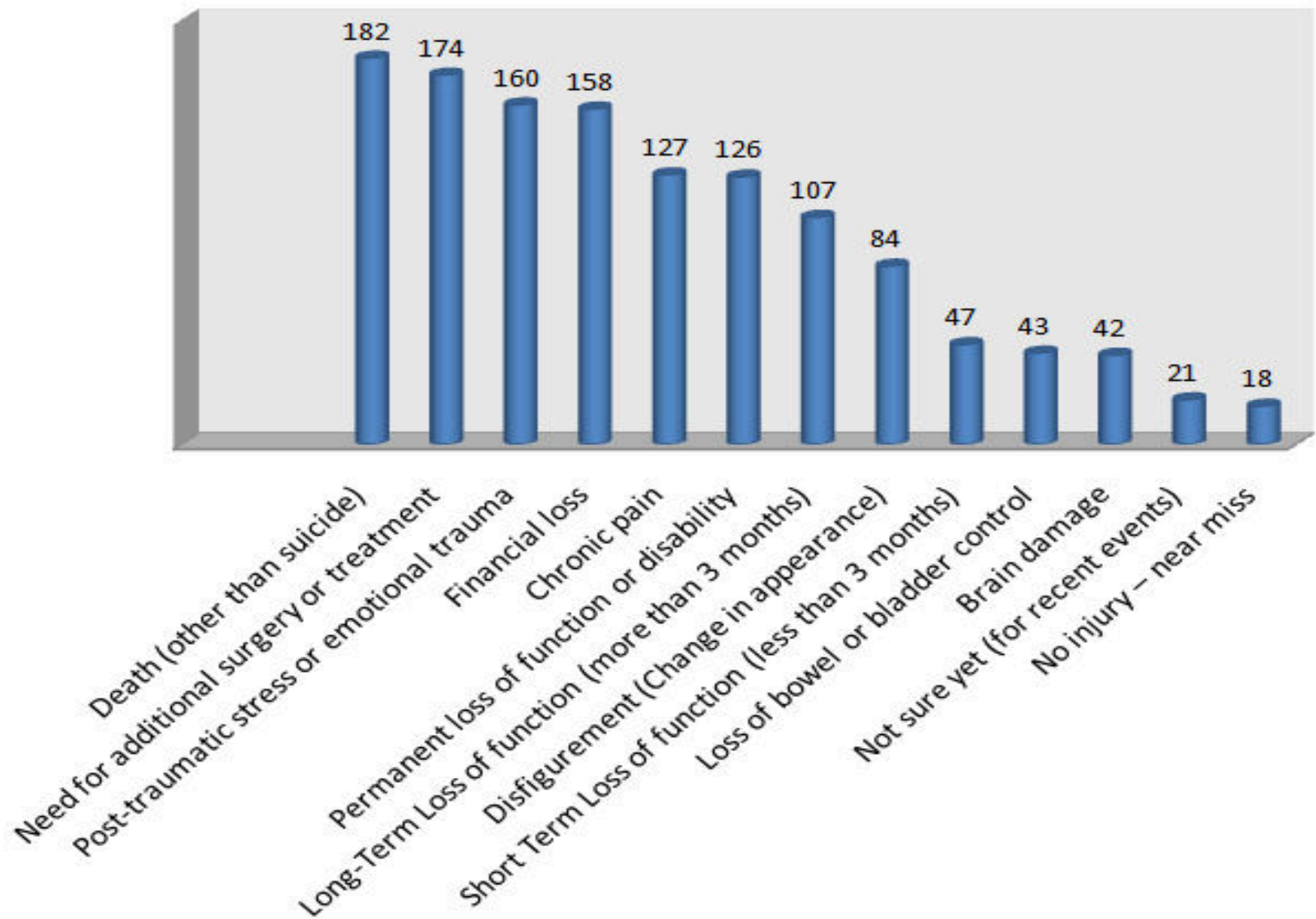
# Factors Contributing to Adverse Events (N=547)

■ Occurred, but not seen as contributing to outcome   ■ Seen as serious problem in patient's care   ■ Seen as major factor in patient's outcome



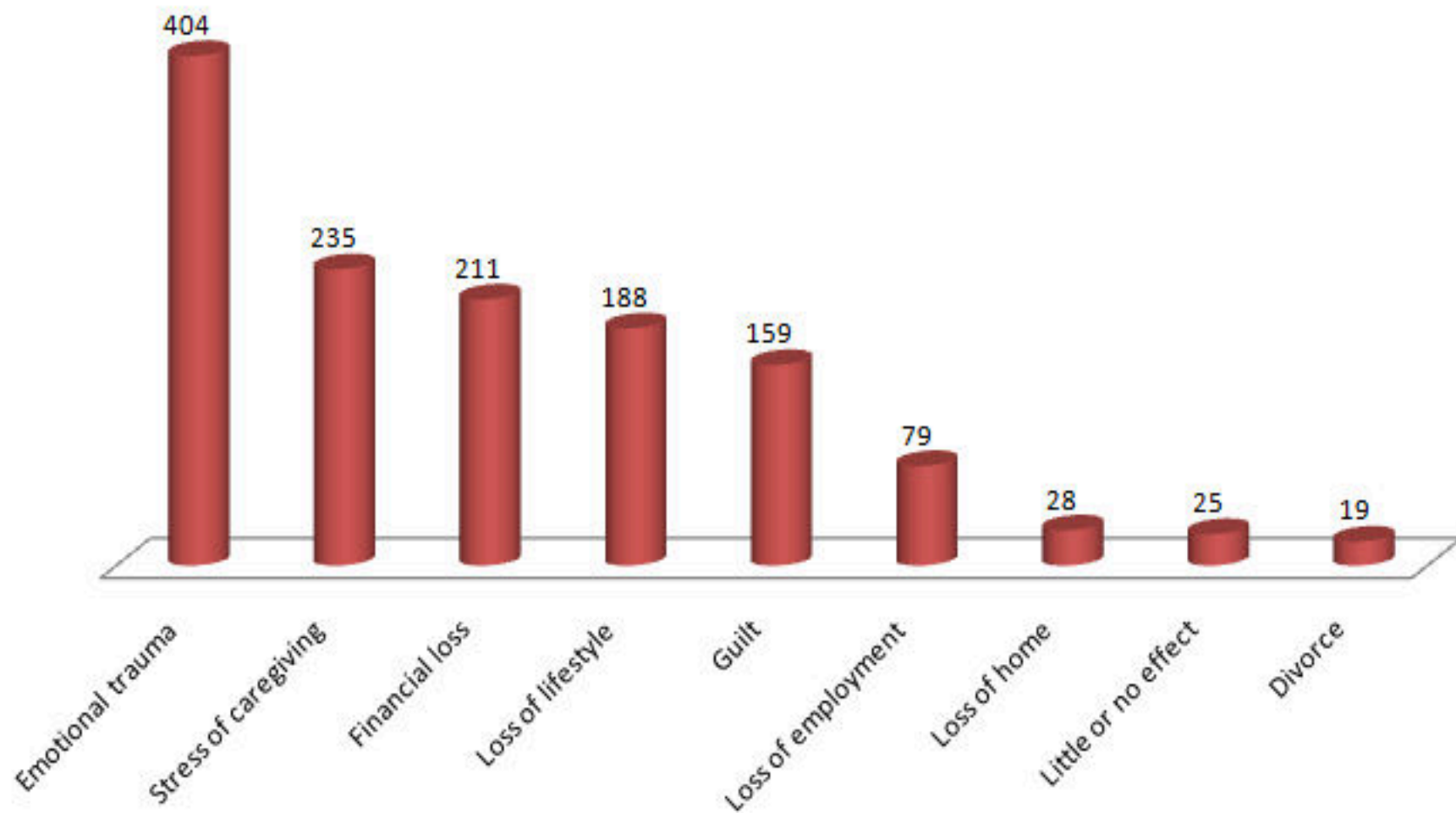
## Patient Outcome from Event

(511 respondents, 1307 responses)



## Effect of Event on Patient's Family and Significant Others

(469 respondents/1348 responses)



# Patient-reported outcomes from adverse medical events

- Patient slipped into a coma
- Loss of income
- Patient required long-term treatment
- Face paralyzed
- Anemia, chronic kidney failure
- Still living in severe pain
- Unable to return to full-time duty
- I lost many days of work
- Lost my ability to live in my home
- ...was blind for two years before death
- Died after nine weeks of isolation in a nursing home

# Patient-reported outcomes from adverse medical events

- Kidney failure, diabetes problems
- Loss of function and ultimately death
- Excruciating post-surgical pain
- Multiple surgeries to correct problem
- Multiple ED admissions
- Had to leave the ED to summon help
- The event precipitated other events that led to death
- Two suicide attempts
- Loss of insurance
- Not able to live independently

# Effect of adverse event on patient's family

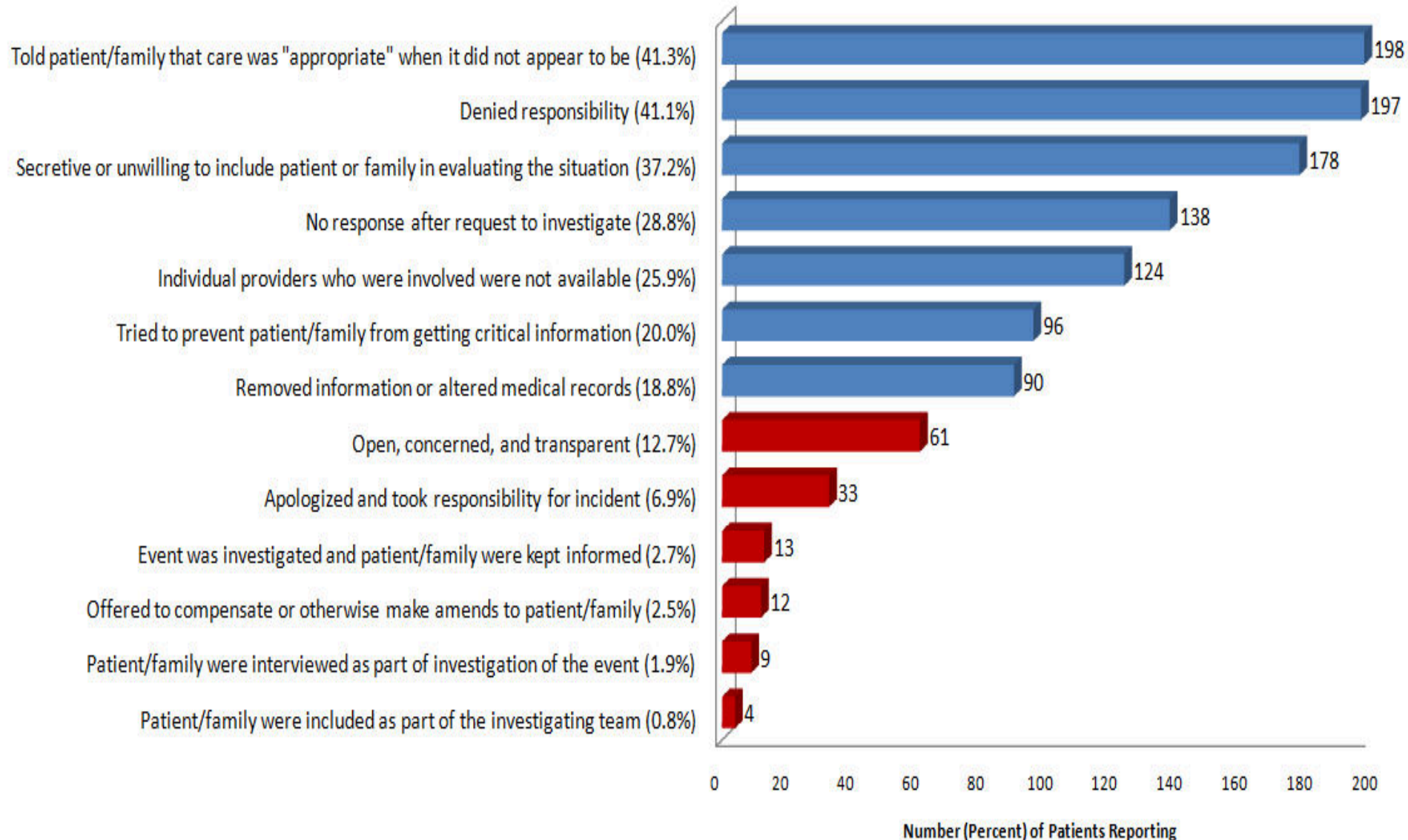
- Trauma, financial loss, depression
- Tremendous emotional stress
- Chronic pain and total lifestyle change
- Very troubled. I can't describe the anxiety
- Financial, physical and emotional disaster
- Loss of insurance
- Horrible fear, upset, confused
- I have been made to feel like I wasn't of concern
- I tried my best to shield my loved ones from the trauma
- Tragic. It tore my family completely apart

# Effect of adverse event on patient's family

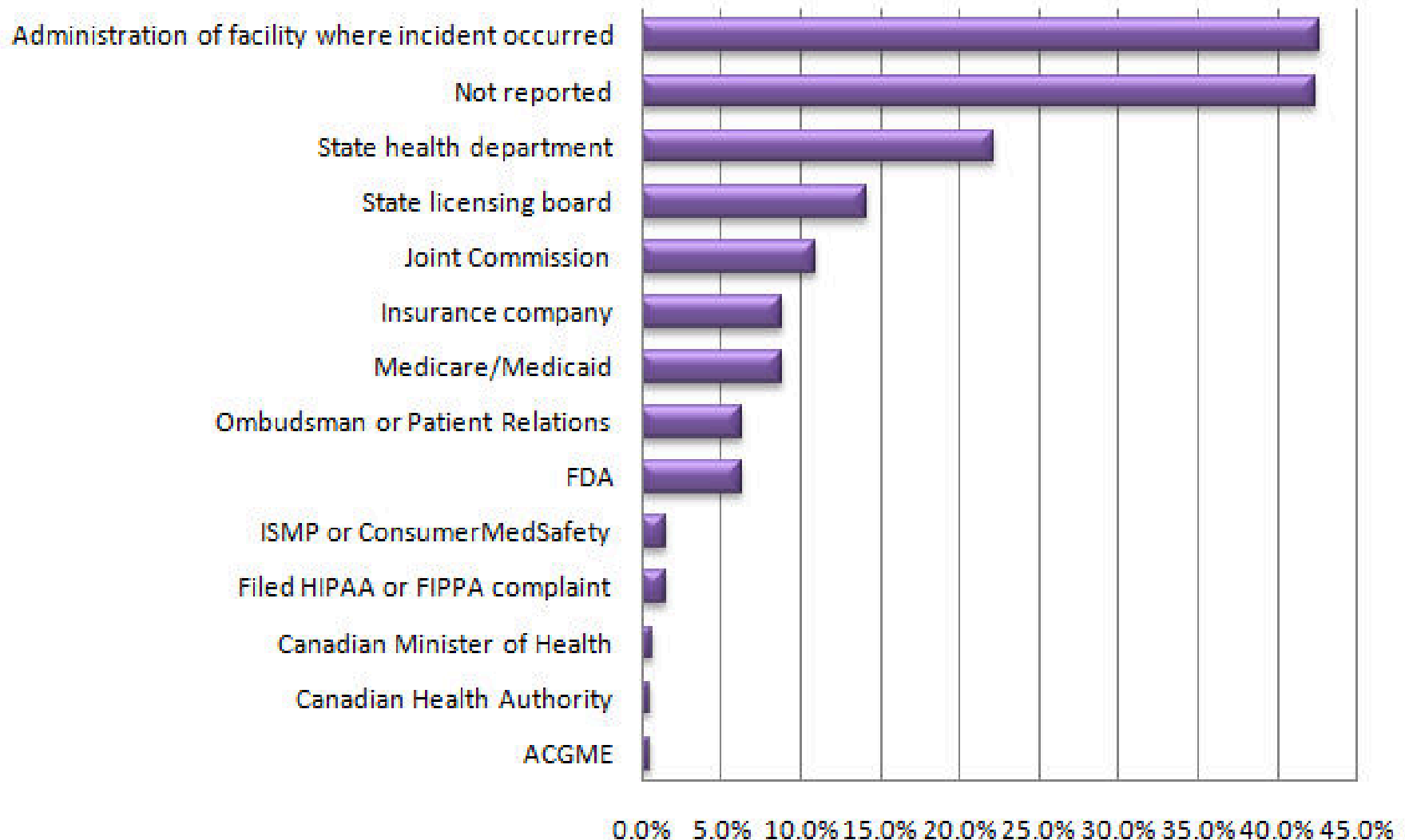
- We will never be the same
- She had three small children at the time of her death
- It is difficult to capture the degree of emotional trauma
- Great emotional toll
- Extensive cost – loss of relationship and communication – isolation
- The pain and agony of seeing a wife/mother unable to care for her own needs
- It was devastating to watch him die a slow death
- It destroyed our lives
- Ended up my wife divorced me
- Devastation

## How Did the Provider or Facility Respond?

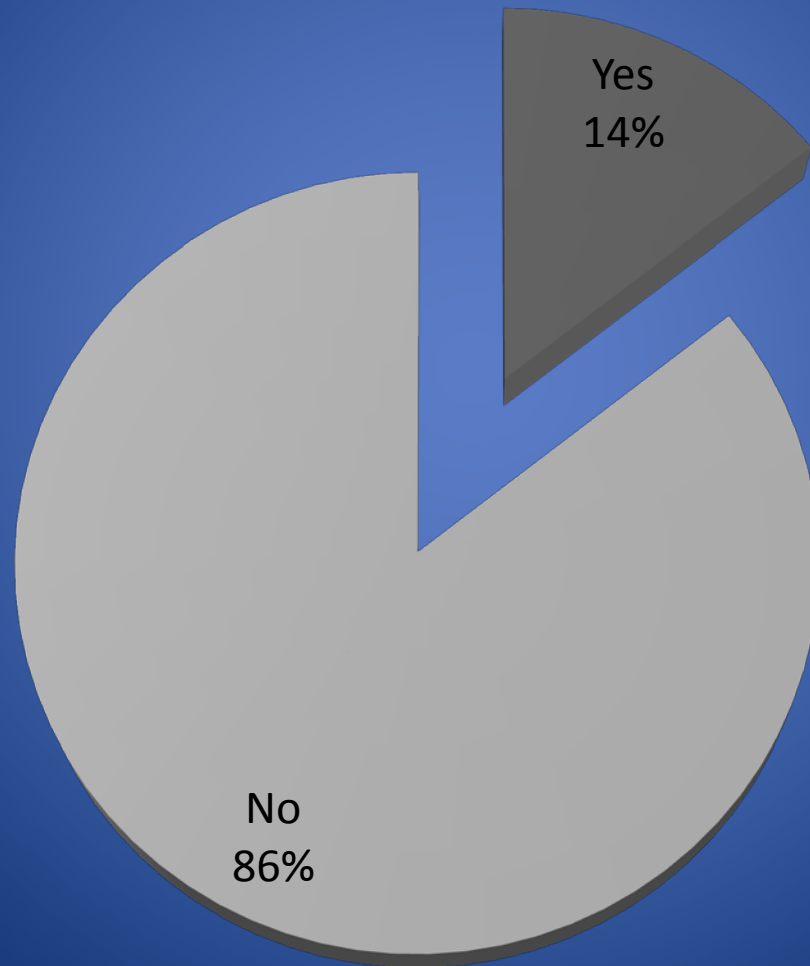
(479 respondents, 1153 responses)



## To what agencies or institutions did you report the event?



**Were you satisfied with the response of the  
institutions or agencies to which you  
reported? (N=270)**



# Patient experiences reporting medical events

- Medical board allowed me to read my statement, but did not consider action.
- I never heard from them, other than it would be looked into, and the standard "Thank you, we will look into the matter, etc., etc., etc."
- All said that they could not prove that the doctor or hospital did anything wrong.
- Although there were two autopsy reports submitted, a significant amount of investigative data, and arrest records for the surgeon, the state medical board did not deem the case worthy of investigation.
- Received only letters stating "Investigation ongoing."
- No one replied.
- Inconclusive and secretive.



Thank you

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