2023 GW Epilepsy Board Review & Best Practices

Psychosocial Management

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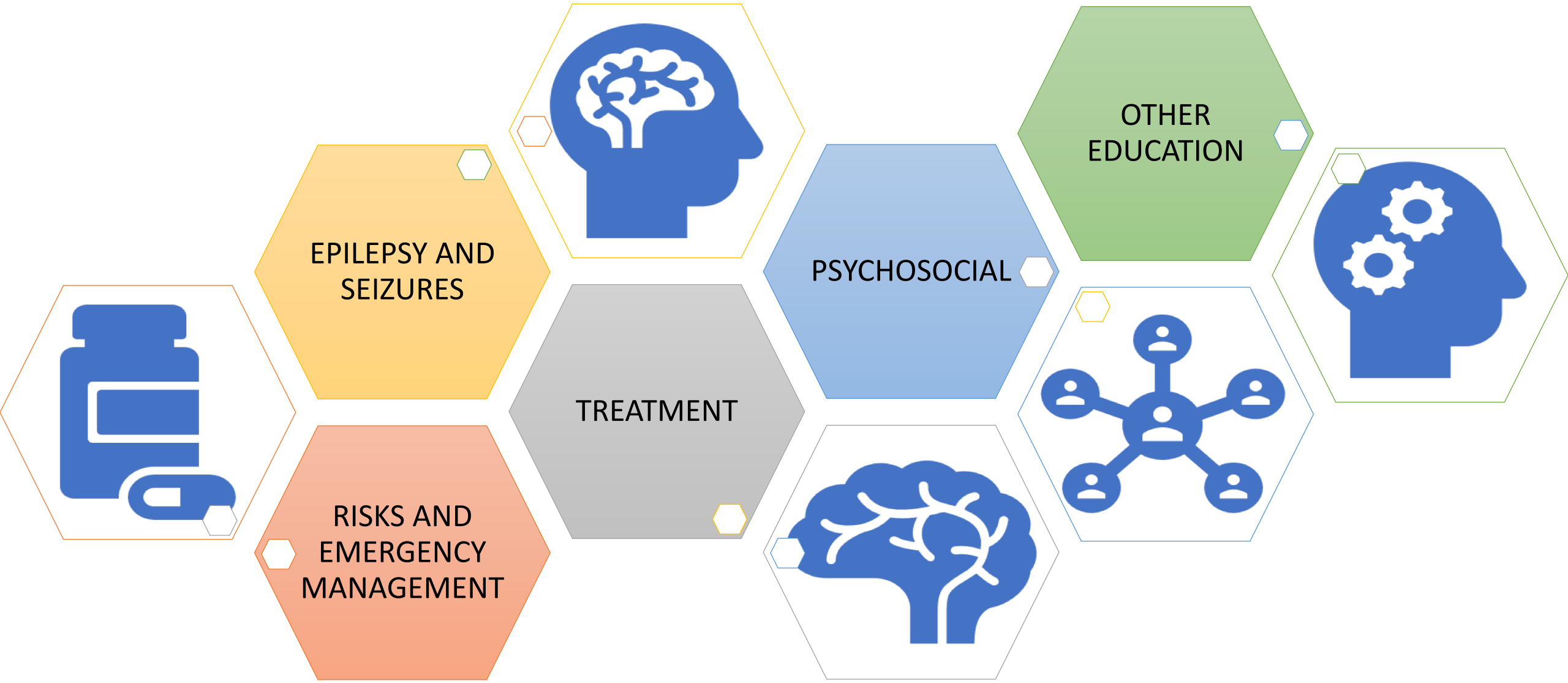
Outline

Patient and family education	Safety, precautions and restrictions	Education and Employment	Quality of life	Prognosis
• Specific age considerations • Seizure First Aid • Medication Compliance and affordability	• Sports • Driving • Piloting • Alcohol and drug use	• Education and IEPs • ADA • Disability and accommodations	• Major concerns • Dating • Marriage • Stigma	

Patient and Family Education


EPILEPSY AND SEIZURES
TREATMENT
PSYCHOSOCIAL
OTHER EDUCATION
RISKS AND EMERGENCY MANAGEMENT

EPILEPSY AND SEIZURES:

What is a seizure

Different types of seizures

Potential seizure triggers

What is epilepsy

Potential etiologies and syndromes

Familial vs. genetic etiologies

Diagnosis of epilepsy

TREATMENT:

Names and doses of medications

Medication adherence and refills

Medication affordability

Side effects and allergies

Interactions with other medications

Epilepsy Surgery

Neurostimulation Devices

Other therapies

RISKS AND EMERGENCY MANAGEMENT:

Seizure clusters
Status epilepticus

Accidents

SUDEP

Rescue medications

Seizure first aid

Seizure action plan

PSYCHOSOCIAL:

Stigma

Social withdrawal

Impact on relationships

Psychiatric comorbidities: ADHD, ASD, depression, anxiety

Cognitive problems

Participation in social activities

Dealing with fears

Lifestyle management

OTHER EDUCATION:

Seizure diaries

Precautions and restrictions

Use of alcohol and drugs

Epilepsy centers

Medically refractory epilepsy

Career and employment

Reproductive health

Specific Age Considerations

INFANT AND CHILD

- Focus on family education
- Seizure recognition
- Seizure action plan for school
- Seizure first aid for school
- IEP

TEENAGER

- Medication adherence
- Knowing names and doses of meds
- Career planning
- Alcohol and drug use
- Driving restrictions
- Puberty
- Sexuality

COLLEGE YEARS

- Medication adherence
- Sleep deprivation
- Alcohol and drug use

Education for Caregivers

- First aid for seizures
- Parenting matters:
  - Balance between overprotection and discipline
  - Discussing the diagnosis with a child
- Resources for caregivers:
  - Information
  - Support groups, DME, respite care
  - Healthcare
  - Accessing services (daycare, school, community,…)
  - Advocacy skills
- Typical cognitive and psychosocial development

Seizure First Aid

How to help someone having a seizure

1

STAY with the person until they are awake and alert after the seizure.

✓**Time** the seizure ✓Remain **calm**
✓Check for **medical ID**

2

Keep the person **SAFE**.

✓Move or guide away from **harm**

3

Turn the person onto their **SIDE** if they are not awake and aware.

✓Keep **airway clear**
✓**Loosen tight clothes** around neck
✓Put **something small and soft** under the head

Call 911 if...

- Seizure lasts longer than 5 minutes
- Person does not return to their usual state
- Person is injured, pregnant, or sick
- Repeated seizures
- First time seizure
- Difficulty breathing
- Seizure occurs in water

Do NOT

✗ Do **NOT** restrain.

✗ Do **NOT** put any objects in their mouth.

✓**Rescue medicines can be given** if prescribed by a health care professional

Learn more: **epilepsy.com/firstaid**

EPILEPSY FOUNDATION | **epilepsy.com**

24/7 Helpline: 1-800-332-1000

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Medication Adherence

- Studies have shown variable non adherence rates – ranging from ~20% to ~60% depending on centers

Zafar, Azra et al. “Nonadherence to Antiepileptic Medications: Still a Major Issue to be Addressed in the Management of Epilepsy.” Journal of neurosciences in rural practice vol. 10,1 (2019): 106-112. doi:10.4103/jnrp.jnrp_136_18)

- Adherence needs to be assessed at each visit and the importance of it should be stressed
- Reasons for non-adherence should be evaluated with the goal to come up with solutions

FACTORS RELATED TO ADHERENCE	BELIEFS/ACTION RELATED TO NON-ADHERENCE	STRATEGIES TO IMPROVE ADHERENCE
Motivation	Do not need so much medication	Education and counseling
Degree of illness threat	Inconvenience of schedule	Facilitating schedule
Expectation of effectiveness	Unpleasant side effects	Adjusting doses, changing timing
Attitudes	Denial of need	Changing to cheaper options when able
Provider/patient interaction	Making the drug last longer because of cost	Using pill boxes, phone reminders, alarms
Social support	Physical limitations	Reinforcing need to contact physician for refills ahead of time
Experience with the regimen	Forgetfulness	Writing down medication schedule and reviewing it with the patient
Internal control	Run out of medication	Keep an emergency 1 week supply
Knowledge	Confusion about times, doses	
Afforability	Poor family support	
	Embarrassed to take medication in front of others	
	Inability to follow dosage instructions	

Epilepsy Foundation Greater Chicago
https://epilepsychicago.org/what-is-epilepsy/treatment/the-importance-of-treatment-compliance/

Medication Affordability

- Medications often too expensive for patients to afford
- Especially newer brand medications
- Some potential solutions:

Some pharmaceutical companies have discount cards for patients who cannot afford medications

Pharmacy assistance programs, especially for patient without insurance

rxAssist.org – comprehensive directory of Patient Assistance Programs

$4 programs offered by select pharmacies – only includes a very limited number of AEDs

RxOutreach – nonprofit pharmacy can help provide generic medications at cheaper prices

Safety, Precautions and Restrictions

Seizure Precautions

Avoid activities that could lead to injury in the event of a seizure	Driving (covered separately)	Water related: swimming in open water, taking baths
Fire related: cooking over open flame, using the oven unsupervised	Heights related: climbing ladders, going on roofs	Equipment/machinery related: use of heavy machinery, carrying firearms, heavy knives
Safety proofing environment	Ensuring safety of all other activities	Ensuring safety of children

Sports and Activities Participation

- Importance of balancing safety with quality of life

- Physical activity is an important component of physical and emotional well-being and quality of life (Epilepsy Foundation, n.d.; Howard et al., 2004)
  - Decreases anxiety and stress
  - Improves sleep
  - Encourage people with epilepsy to be as physically active as possible

- Individuals with epilepsy 1.4 times more likely to be physically inactive than the general population (Hinnell et al., 2010)

TABLE 6-3
Sporting and Recreational Activities Classified According to a Possible Risk for the Individual with Epilepsy

Low Risk	Moderate Risk	High Risk
Baseball	Basketball	Boxing
Bowling	Biking	Downhill skiing
Cross-country skiing	Boating or sailing	Gymnastics (equipment with height)
Golf	Football	Hang gliding
Ping-Pong	Gymnastics (floor)	Hockey
Track	Horseback riding	Motor sports
Walking	Karate	Rock climbing
Weight training (machines)	Skateboarding	Scuba diving
Yoga	Soccer	Swimming (long distance)
	Swimming	
	Waterskiing	

SOURCE: Adapted from Drazkowski and Sirven, 2011. Reprinted with permission from Lippincott Williams and Wilkins, http://www.lww.com.

SOURCE: Epilepsy Across the Spectrum: Promoting Health and Understanding (2012) – Chapter 6

Sports Precautions

- Protective equipment when appropriate
- Water sports require additional precautions
- Supervision recommended, especially for moderate and high risk sports
- Coaches, trainers, lifeguards… should be aware
- Seizure first aid should be taught/provided to the person supervising

Driving and Epilepsy

Only 0.2% of total fatal crashes in the US linked to seizures

Sheth et. al, 2004

Slightly, but not significantly higher than in other chronic diseases

Among car crashes in people with epilepsy, only 11% were attributed to seizures

Hansotia et al, 1987

Driving Regulations and Restrictions

- Restrictions vary per state
- Seizure freedom required – duration variable (between 3 and 12 months)
- Some exceptions based on physician evaluation:
  - Exclusively nocturnal seizures, exclusively focal aware seizures, seizure during a change in medication or medication tapering during EMU admission
- Physician reporting only mandated in some states:
  - California, Delaware, Nevada, New Jersey, Oregon, Pennsylvania
- In other states, patients are required to disclose to the DMV

AAN/AES/EF Consensus Statement – 1994

- *How should the driver licensing determination be made? What weight should be given to the treating physician's opinion?*

a. The licensing decision should be **made by the state DMV** rather than by the treating physician.

b. The **treating physician** should be responsible for **reporting the pertinent medical facts** on forms provided by the DMV.

c. Driver licensing medical forms should be detailed and precise.

d. The form should ask the treating physician's opinion about whether the patient should be licensed and should provide space for narrative commentary by the physician should the physician so desire. The **physician's opinion and explanatory statements should not be required**, however.

e. To the extent possible, the process should be structured so that licensing decisions in straightforward cases can be made independently by first level DMV staff on the basis of the information on the forms.

f. State statutes should establish the structure of the driver licensing process and appeal rights, give DMV its authority, and give proper protections from liability to those involved in the process.

g. The licensing criteria and the determinants for each medical condition should appear in regulations and guidelines rather than in the statute. Such criteria and determinants should be developed by a group with expertise in the particular medical condition.

h. The licensing process should **allow individual consideration**.

i. Licensing criteria should be fair, nondiscriminatory and based on comparable risks in other populations with similar attributes.

Should a specific seizure-free interval be required?

A seizure-free interval should be stated, and 3 months is preferred, starting from the date of the seizure. Both favorable and unfavorable modifiers could alter the interval.

Favorable	Unfavorable
Seizures during medically directed medication changes	Noncompliance with medication or medical visits and/or lack of credibility
Simple partial seizures that do not interfere with consciousness and/or motor control	Alcohol and/or drug abuse in the past 3 months
Seizures with consistent and prolonged auras	Increased number of seizures in the past year
Established pattern of pure nocturnal seizures	Prior bad driving record
Seizures secondary to acute metabolic or toxic states not likely to recur	Structural brain lesion
Sleep-deprived seizures	Non-correctable brain functional or metabolic condition
Seizures related to reversible acute illness	Frequent seizures after seizure-free interval
	Prior crashes due to seizures in the past 5 years

AAN/AES/EF Consensus Statement – 1994

Additional Questions Addressed

- Should a restricted license be available? If so, under what circumstances and with what restrictions?
- Reporting
- Case review
- Degree of immunity for physicians
- Should each state have a medical advisory board? What functions should it have?
- Should the law provide for voluntary surrender of licenses?
- What hearing and appeal rights should exist?

Commercial Driving Regulations

- "The Federal Motor Carrier Safety Regulations prohibits an individual with epilepsy or a seizure disorder from operating a commercial motor vehicle in interstate commerce."
- Exemptions can be considered if one of these conditions is met:

Seizure Disorder/Epilepsy diagnosis

- If seizure disorder/epilepsy diagnosis → seizure-free 8 years, on or off ASM
- If taking ASMs, plan should be stable for 2 years
- Annual recertification

Single unprovoked seizure

- If single unprovoked seizure → seizure-free 4 years, on or off ASM
- If taking ASMs, plan should be stable for 2 years.
- Recertification every 2 years

Single provoked seizure

- If single provoked seizure, Agency will consider specific criteria for recurrence

Low-risk factors:

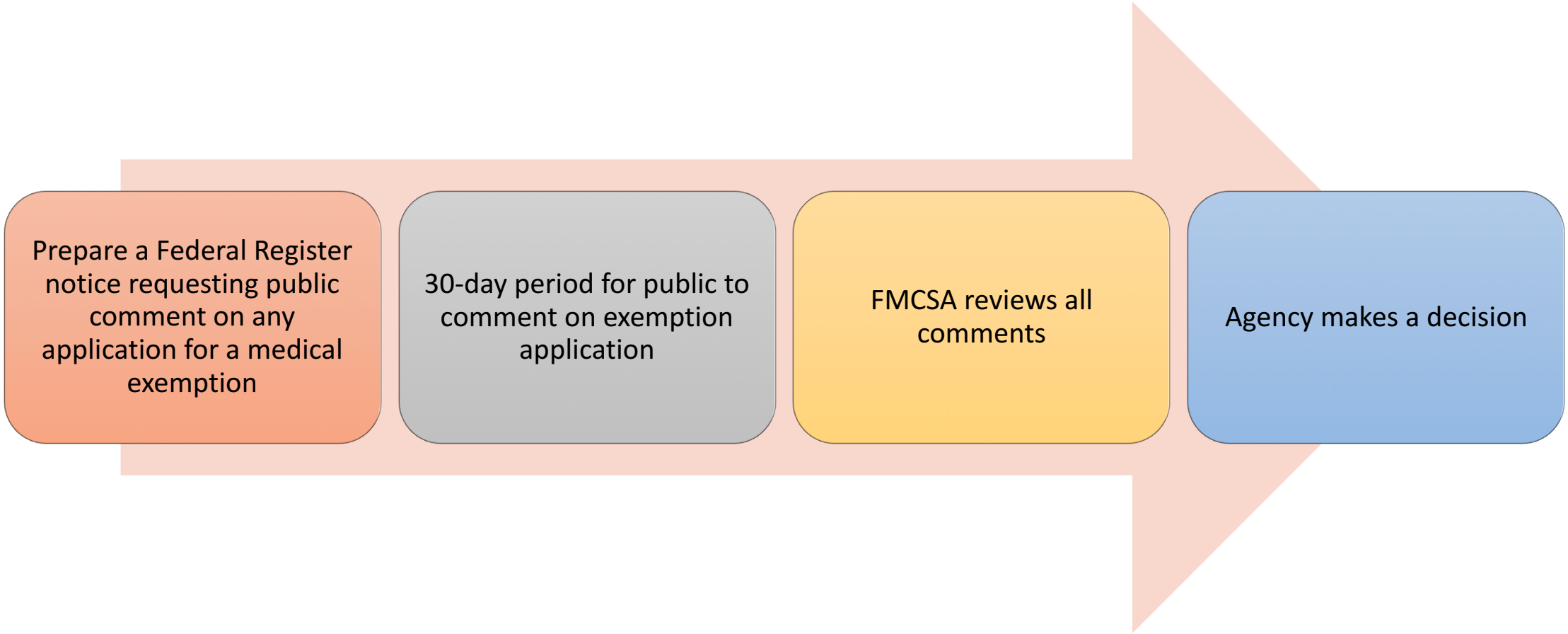
- Medication; non-penetrating TBI with LOC 30 min or less; brief LOC not likely to recur while driving; metabolic derangement not likely to recur; alcohol or illicit drug withdrawal

Moderate-to-high-risk factors:

- Non-penetrating TBI with LOC or amnesia > 30 min, or PBI; ICH with stroke or trauma; infections; ICH; post-op complications from brain surgery with significant hemorrhage; brain tumor; stroke

https://www.fmcsa.dot.gov/regulations/medical/seizure-exemption-application

Process to determine granting an exemption



https://www.fmcsa.dot.gov/regulations/medical/seizure-exemption-application

Piloting Regulations

Per the FAA guidelines:

- *"An established diagnosis of epilepsy, a transient loss of control of nervous system function(s), or a disturbance of consciousness is a basis for denial no matter how remote the history. Like all other conditions of aeromedical concern, the history surrounding the event is crucial. Certification is possible if a satisfactory explanation can be established."*

Potential exemptions that can be reviewed on a case-by-case basis:

- Single episode of febrile seizure:
  - Prior to age 5
  - Without recurrence
  - Off medications for 3 years
- Seizure-free without medication for 10 or more years
- Age-limited epilepsies (such as BECTS) seizure-free for 4 years and with a normal EEG
- Provoked seizures:
  - Due to electrolyte or severe metabolic imbalance, medication use, or convulsive syncope
  - With normal MRI and EEG

https://www.epilepsy.com/what-is-epilepsy/seizure-triggers/alcohol

Alcohol Risks

- Small amounts of alcohol (~1-2 drinks occasionally) do not cause seizures, BUT increase risk of seizures or change level of ASMs in the blood
  - Exception: JME → sensitive to even small amounts of alcohol
- Seizures usually related to binge drinking and alcohol withdrawal
- Combined with ASMs → increased sedation and more rapid intoxication
- Alcohol consumption often combined with poor sleep and missed medications
  → increased risk of seizures

https://www.epilepsy.com/what-is-epilepsy/seizure-triggers/alcohol

Drug Use Risks

Cocaine

- Can cause seizures as quickly as within seconds of consumption
- Can cause seizures in people without epilepsy

Amphetamines/stimulants:

- Generally safe under a doctor's supervision
- When abused → sleep deprivation, confusion, psychiatric disorders → missed ASMs → seizures
- Very high doses can cause severe GTCs

Marijuana:

- THC and CBD can help seizures but could also provoke them
- Stopping marijuana suddenly after using recreationally could increase risk of seizures

Heroin/narcotics:

- Do not directly affect likelihood of seizures in people with epilepsy
- Often lead to missed ASMs

https://www.epilepsy.com/what-is-epilepsy/seizure-triggers/alcohol

Common Seizure Triggers

- Alcohol and recreational drugs
- Medication non-compliance
- Sleep deprivation
- Menstruation
- Illness
- Some medications
- Flashing lights (in photosensitive epilepsies)
- Stress

Education and Employment

Education

- More likely than others to have learning problems that will affect school performance – despite average IQ
- Important to educate school staff about seizure first aid and seizure action plan
- 1973 Rehabilitation Act – Section 504:
  - *Provide to students with disabilities appropriate educational services designed to meet individual needs of such students to the same extent as needs of students without disabilities are met*
  - *An appropriate education could consist of education in regular classrooms, education in regular classes with supplementary services, and/or special education and related services*
- Section 504 Education Plan:
  - *Classroom accommodations, related services, testing accommodations, assistive technology, and/or behavior management plan determined necessary for the student to access the general education curriculum to the same extent as nondisabled students*

https://www2.ed.gov/about/offices/list/ocr/504faq.html

https://dcps.dc.gov/page/section-504-process#:~:text=504%20Plan%3A%20Within%20five%20(5,student%20to%20access%20the%20general

Individuals with Disabilities Act (IDEA)

- Federal law – free, appropriate education in least restrictive (most “normal”) setting possible for children with disabilities

- Ensures special education and related services:
  - Infants and toddlers with disabilities – birth through age 2 – and families receive early intervention services
  - Children and youth ages 3-21 receive special education and related services

- Requires appropriate health services to be provided when needed

https://sites.ed.gov/idea/about-idea/#Rehab-Act

Individualized Education Program

- Students with special education services must have an IEP
- Written plan that outlines needs and goals for the school year
- Parents, teachers, other school staff come together to look at student's unique needs
- Guides delivery of special education and services
- Progress toward annual goals measured and parents regularly informed of child's progress
- Goals reviewed yearly

https://www2.ed.gov/parents/needs/speced/iepguide/index.html#closer

SEIZURE ACTION PLAN (SAP)

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Name: _____ Birth Date: _____

Address: _____ Phone: _____

Emergency Contact/Relationship _____ Phone: _____

Seizure Information

Seizure Type	How Long It Lasts	How Often	What Happens

How to respond to a seizure (check all that apply) ☑

- ☐ First aid – **Stay. Safe. Side.**
- ☐ Give rescue therapy according to SAP
- ☐ Notify emergency contact
- ☐ Notify emergency contact at _____
- ☐ Call 911 for transport to _____
- ☐ Other _____

First aid for any seizure

- ☐ **STAY** calm, keep calm, **begin timing seizure**
- ☐ Keep me **SAFE** – remove harmful objects, don't restrain, protect head
- ☐ **SIDE** – turn on side if not awake, keep airway clear, don't put objects in mouth
- ☐ **STAY** until recovered from seizure
- ☐ Swipe magnet for VNS
- ☐ Write down what happens _____
- ☐ Other _____

When to call 911

- ☐ Seizure with loss of consciousness longer than 5 minutes, not responding to rescue med if available
- ☐ Repeated seizures longer than 10 minutes, no recovery between them, not responding to rescue med if available
- ☐ Difficulty breathing after seizure
- ☐ Serious injury occurs or suspected, seizure in water

When to call your provider first

- ☐ Change in seizure type, number or pattern
- ☐ Person does not return to usual behavior (i.e., confused for a long period)
- ☐ First time seizure that stops on its' own
- ☐ Other medical problems or pregnancy need to be checked

When **rescue therapy** may be needed:

WHEN AND WHAT TO DO

If seizure (cluster, # or length) _____

Name of Med/Rx _____ How much to give (dose) _____

How to give _____

If seizure (cluster, # or length) _____

Name of Med/Rx _____ How much to give (dose) _____

How to give _____

If seizure (cluster, # or length) _____

Name of Med/Rx _____ How much to give (dose) _____

How to give _____

Care after seizure

What type of help is needed? (describe) _____

When is person able to resume usual activity? _____

Special instructions

First Responders: _____

_____

Emergency Department: _____

_____

Daily seizure medicine

Medicine Name	Total Daily Amount	Amount of Tab/Liquid	How Taken (time of each dose and how much)

Other information

Triggers: _____

Important Medical History _____

Allergies _____

Epilepsy Surgery (type, date, side effects) _____

Device: ☐ VNS ☐ RNS ☐ DBS Date Implanted _____

Diet Therapy ☐ Ketogenic ☐ Low Glycemic ☐ Modified Atkins ☐ Other (describe) _____

Special Instructions: _____

_____

Health care contacts

Epilepsy Provider: _____ Phone: _____

Primary Care: _____ Phone: _____

Preferred Hospital: _____ Phone: _____

Pharmacy: _____ Phone: _____

My signature _____ Date _____

Provider signature _____ Date _____

Epilepsy.com

Revised 01/2020 130SRP/PAB1216

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Employment

- People with epilepsy have twice the unemployment rate of the general population
- Up to 50% of people with uncontrolled epilepsy are unemployed
- Due to limitations in certain occupations, as well as inequality in workplace policies and procedures

Americans with Disabilities Act

- Americans with Disabilities Act (ADA) passed by Congress in 1990
- “Law that protects the civil rights of people with disabilities in many aspects of public life”
- Amended by Congress in 2008 → “ADA Amendments Act of 2008 or ADAAA"
- Disability defined as:
  A. “A physical or mental impairment that substantially limits one or more major life activities of such individual;
  B. A record of such an impairment; or
  C. Being regarded as having such an impairment”

https://www.ada.gov/law-and-regs/

ADA and Job Applications

Before an offer is made:

- May not ask questions about medical condition or require a medical exam before making a conditional job offer
- Not required to voluntarily disclose they have epilepsy or another disability unless they need a reasonable accommodation for the application process
- May not ask applicant who has voluntarily disclosed they have epilepsy any questions about their epilepsy, its treatment, or its prognosis – but may ask whether they will need accommodations and what type

After an offer is made:

- May ask questions about health and epilepsy and may require a medical exam, as long as all applicants treated equally
- Provide reasonable accommodations unless doing so would be an undue hardship
- Choose voluntary disclosure to create an action plan in case of a seizure

https://www.ada.gov/law-and-regs/

Some Employment Accommodations

- Breaks to take medication
- Leave to seek or recuperate from treatment or adjust to medication
- Private area to rest after having a seizure
- Rubber mat or carpet to cushion a fall
- Checklist to help remember tasks
- Adjustments to work schedule, consistent start time or schedule change
- Permission to bring a service animal to work
- Someone to drive to meetings and other work-related events
- Permission to work at home
- Reassignment to a vacant position if no longer able to perform current job

https://www.eeoc.gov/laws/guidance/epilepsy-workplace-and-ada

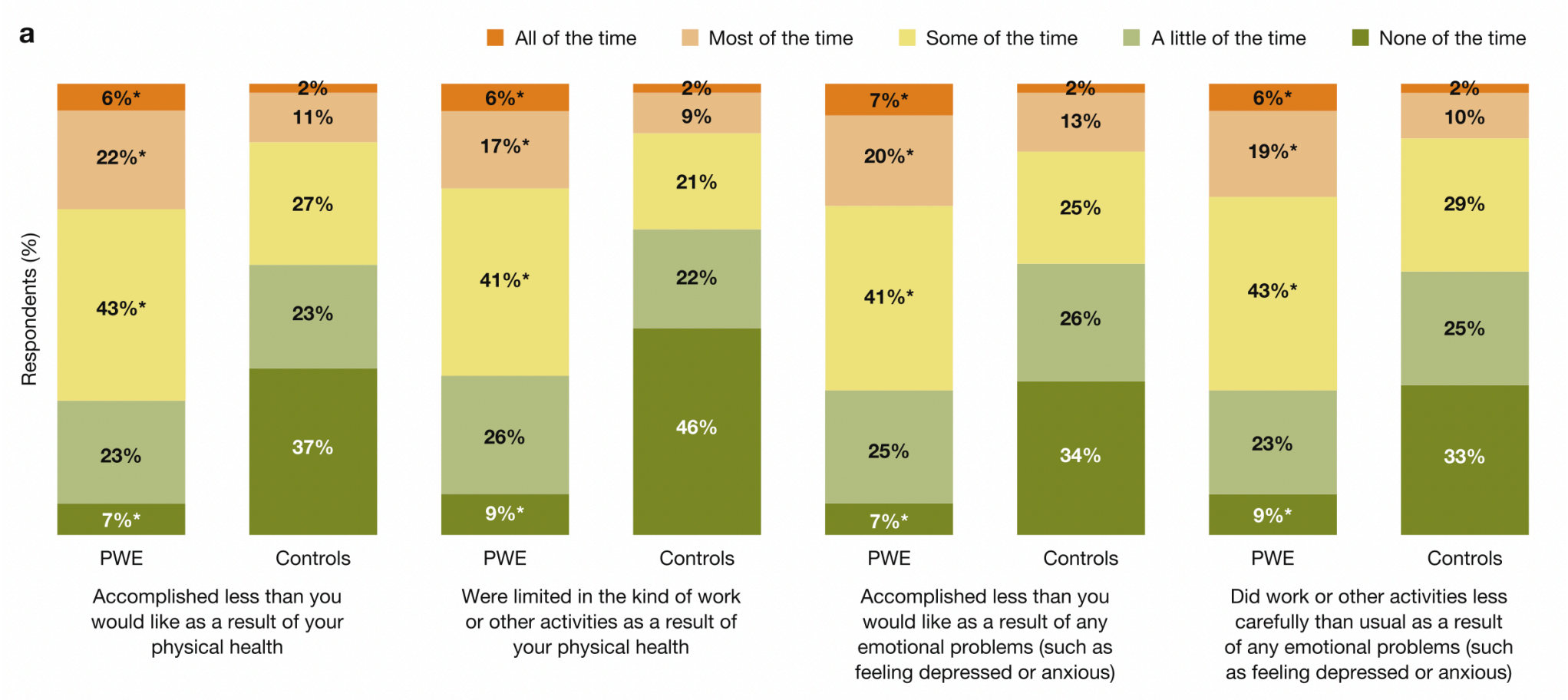
Disability Criteria for Epilepsy

- *"GTCs at least 1 per month for at least 3 consecutive months despite adherence to prescribed treatment*
- *Dyscognitive seizures at least 1 per week for at least 3 consecutive months despite adherence to prescribed treatment*
- *GTCs at least 1 every 2 months for at least 4 consecutive months or dyscognitive seizures at least 1 every 2 weeks for at least 3 consecutive months despite adherence to prescribed treatment and a marked limitation in one of the following:*
  - *Physical functioning*
  - *Understanding, remembering, or applying information*
  - *Interacting with others*
  - *Concentrating, persisting, or maintaining pace*
  - *Adapting or managing oneself"*

https://www.ssa.gov/disability/professionals/bluebook/11.00-Neurological-Adult.htm#11_02

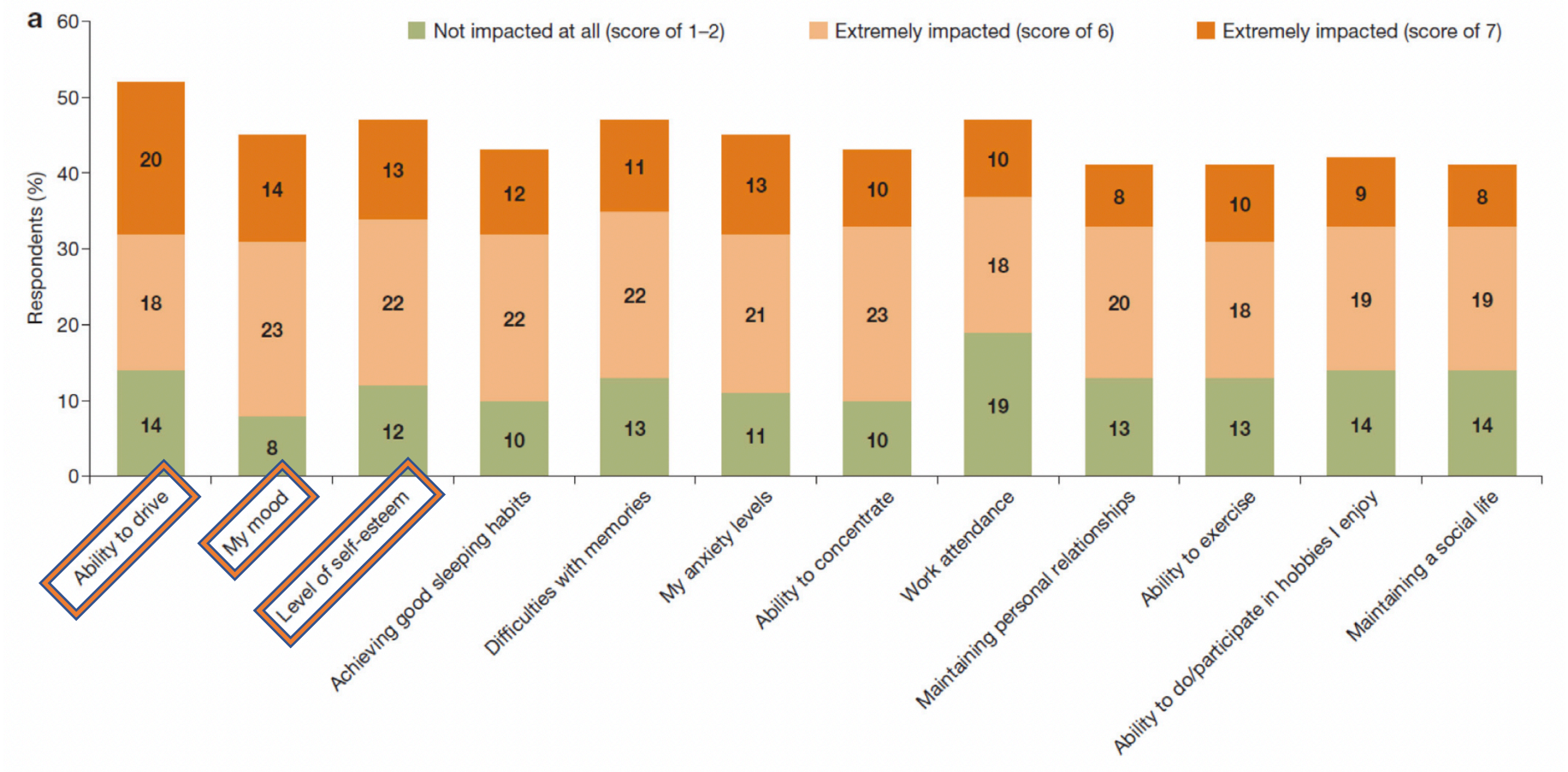
Quality of Life

How often respondents felt limited in their work and daily activities



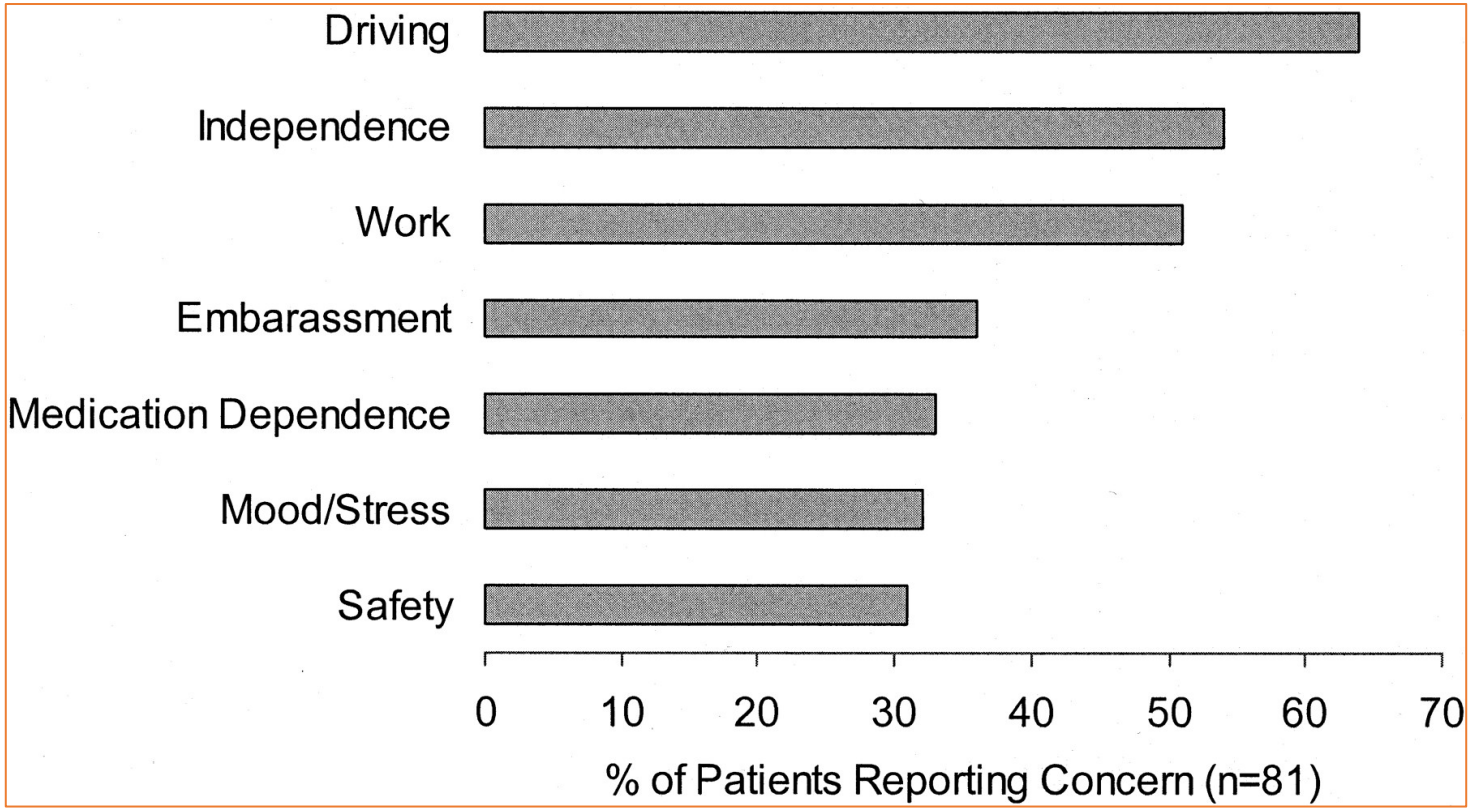
The impact of epilepsy on quality of life: Findings from a European survey. Strzelczyk et al. 2022

Aspect of daily life affected by epilepsy in the overall PWE population



The impact of epilepsy on quality of life: Findings from a European survey. Strzelczyk et al. 2022

Concerns listed by more than 1/3 of patients who have had 1+ seizures in the past 6 months



Optimizing health outcomes in active epilepsy. Gilliam. 2002

Predictors of HR-QOL in Epilepsy

- No “acceptable” seizure rate to patients
  - ⇒ Goal is **<u>seizure freedom</u>**
- Adverse medication effects and depression → big influence on subjective health status
- Epilepsy surgery → important treatment option for many patients
  - → Increase likelihood in patients with refractory epilepsy to become seizure free
    - ⮡ More likely to drive
    - ⮡ More likely to be able to decrease ASMs

Optimizing health outcomes in active epilepsy. Gilliam. 2002

Dating/Social interactions

- Adds a layer of challenges → increased fear of rejection, fear of embarrassment, ignorance of others about epilepsy, stigma
- Increased depression/anxiety → more challenges when building relationships
- Increased risk of social isolation
- Different people feel differently about their epilepsy → more or less comfortable discussing it
  - Usually good to discuss diagnosis early on if seizures are not well controlled and need for first aid may come up
  - Usually good to discuss diagnosis if a relationship is becoming more serious
- Some ASMs may cause sexual dysfunction

Marriage/Family Planning

- More likely to never be married or have poor marital outcomes and worse quality of married life
- Very few studies looking at numbers
- Concerns with family planning and childcare
- Potential for missed work, frequent doctor visits, increase risk of mood or anxiety disorders, restrictions in leisure activities

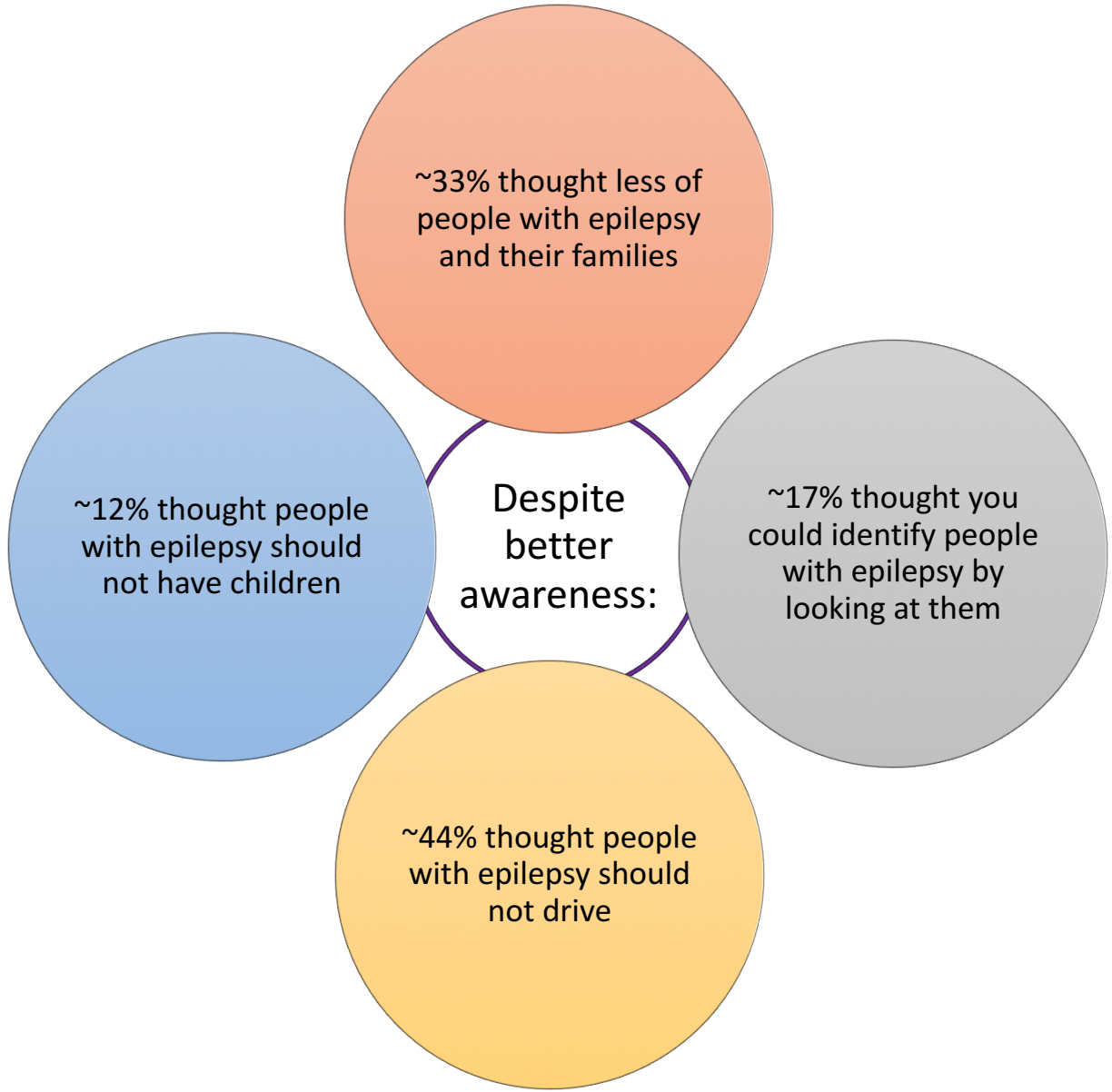
Stigma

- Lack of basic knowledge among general public
  → misperceptions about epilepsy → stigma → substantial burden on employment, educational opportunities, interpersonal relationships, QOL
- Over the years: improvement in awareness

	1949	1979
Answered no to: objecting to your children playing with epileptics?	57%	89%
Answered no to: is epilepsy a form of insanity?	59%	92%
Answered yes to: should epileptics be employed?	45%	79%

- Most favorable opinion among: better educated, better employed, younger, urban members of the population

A Survey of Public Attitudes Toward Epilepsy in 1979 with an Indication of Trends over the Past Thirty Years, Caveness & Gallup, 1980, Epilepsia



Uncovering public misconceptions about epilepsy. LaMartina, 1989, J Epilepsy

Prognosis

Prognosis

- Remission
- Seizure control vs. refractoriness
- Comorbidities
- Consideration of epilepsy surgery
- Mortality/morbidity:
  - SUDEP
  - Status epilepticus
  - Seizure-related injuries and accidents
  - Suicide

THANK YOU!