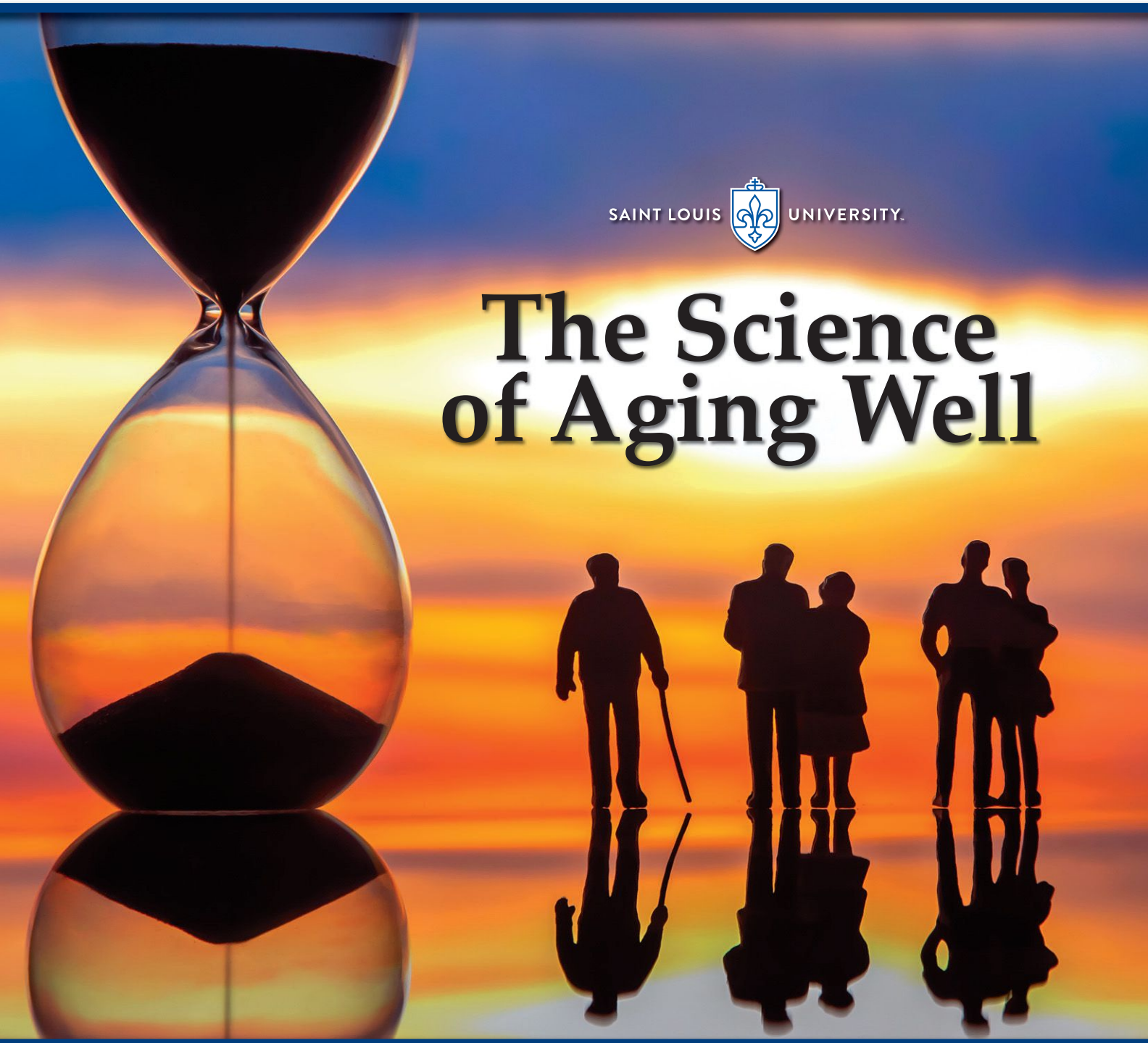
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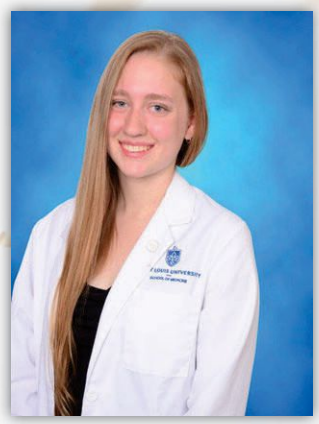
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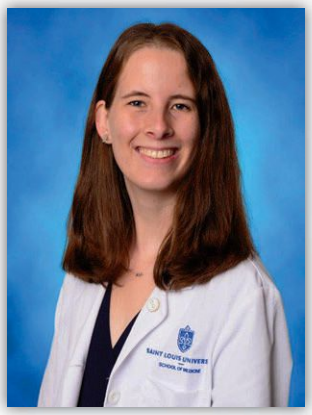
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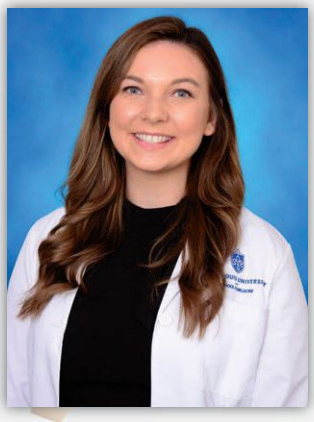
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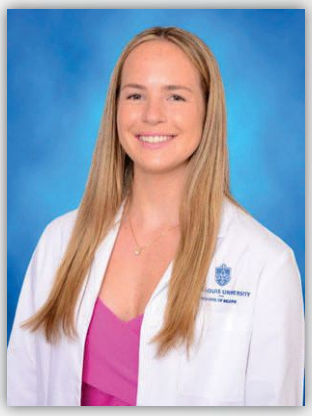
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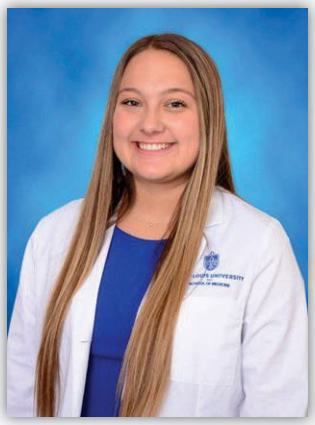
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Contact
Editor: John C. Hagan, III, MD / drjhagan3@gmail.com
Managing Editor: Lizabeth R.S. Fleenor / lfleenor@msma.org
Instructions for Authors: www.msma.org/Missouri–Medicine
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Mixing It Up: The Art and Science of Compounding Pharmacy

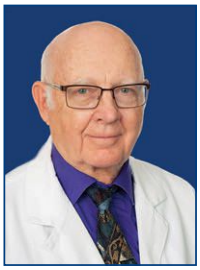
by John C. Hagan III, MD

Compounded drugs are not FDA approved. That doesn't mean that they don't work, just that safety and efficacy are not evaluated by the FDA.

If you had cataract removal and intraocular lens insertion in 1999-2001, there was a significant possibility that even after a technically perfect operation permanent double vision and/or ptosis would occur. Prior to 1999, these exceedingly troublesome complications were relatively unusual. What changed? How can a perfectly conducted surgery cause major ocular problems? What research was done in the period of 1999-2001 to identify and correct the complications? Curious? Read on.

Rather than keeping you hanging for about 1,000 more words, I'll tell you. There is a certain amount of immodesty and self-congratulation for which I apologize. Research conducted in 1999-2001 by myself and other physicians in Kansas City demonstrated to the world that the sudden increase of cataract surgery complications were due to the lack of the spreading enzyme hyaluronidase.[1-7]

How was the problem corrected? Compounding pharmacists (CPs) at O'Brien Pharmacy, also headquartered in The City of Fountains (and City of World's Best BBQ), produced a high-quality compounded drug that worked as well as the unavailable FDA-approved hyaluronidase.



John C. Hagan, III, MD, (pictured) is Past President of Kansas City Medical Society and KCMS Board member. He is Editor of *Missouri Medicine* and a Contributing Editor to Kansas City Medicine.

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Given how many cataract operations are done each year and the number of years it was before a synthetic hyaluronidase was developed, compounding pharmacists prevented perhaps 10,000 or more patients from permanently seeing double through droopy eyelids.

What do you know about compounding pharmacists and the unique drugs they create? Probably like me, prior to 1999, not much. Not something taught in medical school either. A thorough knowledge of the advantages and the drawbacks of compounded drugs can lead to better patient care, something to which we all aspire and is the basis for this editorial.

What is a Compounding Pharmacy and the Unique Drugs They Make?

First, a cardinal point: compounded drugs are not FDA-approved. That doesn't mean they don't work, just less manufacturing scrutiny and clinical testing. Conversely, compounded products may work better than a comparable FDA-approved drug or as well or better than an unavailable FDA drug (Figure 1).

A compounding pharmacy is a specialty pharmacy that creates custom medications for patients based on their specific needs. Compounding pharmacies use pure ingredients, combinations of meds, in variable forms e.g., pills, liquids, and powders to make unique medications that are not otherwise commercially available. In other cases, patients may not be able to take the FDA product. CPs can change pills into liquid form for those having trouble swallowing, and, for the sensitive, making the drug preservative, dye or gluten free. Compounding pharmacies are proving extraordinarily helpful during these troubling days of drug shortages, discontinued, or outrageously expensive FDA drugs. Their products are classified sterile or non-sterile depending on the technique used.

There are two types of compounding pharmacies:

1. 503A Compounding Pharmacies—These are regulated by the state(s) where they are located and sell retail.

2. 503B Compounding Pharmacies—These are wholesale drug manufacturers that are overseen by the FDA and dispense products nationally.

Other compound pharmacy rules, regulations, and laws are complex, as are those of FDA products. If you have further interest this is a good place to start: https://www.fda.gov/drugs/human-drug-compounding/human-drug-compounding-laws.

What Is a Compounding Pharmacist?

The compounding pharmacist is trained in an academic pathway that is identical to pharmacists dispensing FDA-approved drugs. The process for admission to pharmacy school is selective and rigorous. Compounding pharmacists pursue extra knowledge and training beyond the basics of pharmacy school after graduation to specialize in compounding. Their pharmacy degree program must be accredited. The national standards for compounding pharmacies, including their practices, facilities, equipment, and personnel are set by the United States Pharmacopeial (USP). This

Figure 1. Traditional pharmacists dispense FDA approved drugs, compounding pharmacists dispense uniquely formulated drugs that, while usually effective, are not FDA approved.



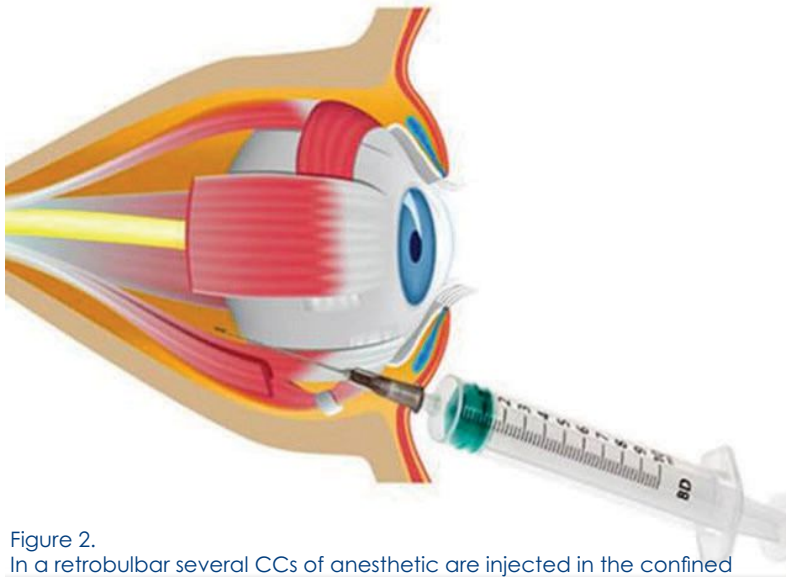


Figure 2.
In a retrobulbar several CCs of anesthetic are injected in the confined space of the orbit. This raises the hydrostatic pressure locally around the injection site. Hyaluronidase facilitates diffusing the anesthetic throughout the orbit lowering localized pressure. Without hyaluronidase the localized pressure can cause ischemic damage to nerves and extraocular muscles causing double vision and ptosis.

Source: PMFA Journal used with permission.

accreditation process helps patients and prescribers select compound pharmacies and CPs that meet high quality standards. The other agency is the National Association of Boards of Pharmacy (NABP) which offers a three-year accreditation for US licensed CPs. The NABP's accreditation process reduces risks, which may be considerable, in making medications for human use.

The compounding pharmacist must earn a Doctor of Pharmacy (PharmD) degree from an accredited program. This is four years specific to general and compounding pharmacology which follows variable years in college or university. Next, they must pass national tests, including the North American Pharmacist Licensure Examination (NAPLEX). The Multistate Pharmacy Jurisprudence Examination (MPJE) is a test that assesses a candidate's knowledge of these laws and regulations. Lastly, they must comply with appropriate state requirements.

A case can be made that CPs have a more difficult job than a standard pharmacist who dispenses FDA-approved medication made of pure chemicals in approved forms and amounts. The CPs essentially put a unique drug together that may contain variable amounts of the active ingredients in several forms (liquid, pills, powder, ointment, gels) and with unique excipients—lubricants, diluents, binders, flavorings, coating, and coloring agents for the formulation.

Given these variables and the often-complex formulations, the downside risks are considerable and exceed FDA-approved medicines. Perhaps the deadliest and most well know compounding disaster was the 2012 fungal meningitis outbreak which led to 64 deaths, 793 infections, and a prison sentence for the criminally negligent supervisory pharmacist. Additional information can be found at https://www.uspharmacist.com/article/pros-and-cons-of-pharmacy-compounding.

Most Important Indication: The Only Product Available

I'm going to elaborate my two major research experiences with a compounding pharmacy. Both were very successful collaborations and are having major beneficial nationwide consequences. These advances would not have happened if I and others had to rely on US Pharma and FDA-approved drugs.

Double Trouble

I mentioned this eye surgery epidemic in the opening of this discourse. Wyeth Drug was the only manufacturer of hyaluronidase (Wydase®); the drug was made out of extract from the testicles of cows. Collection and production were obviously no easy task. Allegedly Wyeth, who introduced the drug in 1950, bailed on production due to the large costs of FDA-mandated improvements in the older factory used to produce Wydase. In

1999, there was no other source of surgical grade hyaluronidase in the world. Yet to Wyeth it was "We are out of here; deal with it on your own."

Hyaluronidase is a spreading enzyme mixed with anesthetics that are injected retrobulbar immediately prior to cataract surgery (Figure 2). It makes the anesthetic more effective as it allows better and faster diffusion. The cause of the double vision and ptosis was liquid anesthetic-induced pressure damage to the extraocular muscles and nerves. In the closed confines of the orbit, into which a significant volume of anesthetic is injected, localized pressure induced by the liquid anesthetic was sufficient to cause ischemic damage. We first reported this[1-7] and it was later confirmed by many investigators.[8,9] In my own practice these complications occurred so often that I considered stopping cataract surgery completely; they vanished when I began using compounded hyaluronidase.

I serendipitously learned that compounding pharmacists had access to hyaluronidase and could make up a sterile liquid suitable for human injection in the same concentrations as Wydase. I also learned that O'Brien Pharmacy, a highly regarded compounding company, was located in Kansas City. I met with the owner, explained the problem and asked if his firm could make essentially a copy Wydase. He said they could. I was given a tour of the modern, ultra-clean facility, staffed with well trained and conscientious professionals. For my first several cataract surgery cases using this compounded hyaluronidase, I gave extended, ultra-thorough, well-documented informed consent. The results were dramatic. Double vision and ptosis stopped immediately. Happy patient! Happy surgeon! Happy malpractice lawyer? Not so much!

A prospective study[3] was begun and published in the leading national cataract surgery journal and presented at their 2001 American Cataract and Refractive Surgery Society annual meeting in San Diego. Word spread fast and for several years, compounded pharmacy-produced hyaluronidase was the only source worldwide. Eventually, an FDA-approved recombinant human hyaluronidase was created. In 2025, virtually no compounded hyaluronidase is used.

The Migraine Refrain: What is Wrong with Pharma?

This research, also done in Kansas City, has generated two first world literature reports.[10-14] Here I present a truncated summation. Several decades ago, KC glaucoma specialist Carl Migliazzo, MD, found timolol 0.5% eye drops applied to the eye for glaucoma treatment also relieved acute migraine. I began collaboration with him in 2014.

Our conclusions? Oral beta blockers, taken each day by mouth, maintain therapeutic blood levels. However, beta blockers in pill form taken PRN at first onset of an acute migraine headache do not work because therapeutic blood levels are not attained. The migraine outruns the pill. Liquid timolol topical to the eye, sublingual, or by nasal spray achieves therapeutic blood levels in 10-15 minutes.[10] The nimble liquid beta blocker outruns the migraine. Timolol and propranolol in pill form are FDA approved for migraine. So, clinicians use daily beta blockers for prevention in frequent migraine patients. Clinical research demonstrated the BB pills ineffective for acute migraine and thus are not prescribed by physicians.

Because liquid timolol works for acute migraine by traveling quickly down the tear duct into the nose where it is rapidly absorbed, we suggested a nasal spray.[10,11] Dr. Migliazzo and I made an enormous effort over a decade to interest pharma in the development of an FDA-approved nasal spray. Avaricious pharma executives revealed to us their most important goals—make money and more money and more money. Almost all pharma told us: "It's a brilliant and simple therapy, but it won't make enough money," and "We don't want an inexpensive and effective drug competing with our expensive and very profitable migraine products."

Once again, we turned to O'Brien Pharmacy. They produced a 0.25% timolol nasal spray but it was not concentrated enough.[12] After reading my editorial[13] calling for collaborators, Steve Kosa, MD, a KC headache neurologist, joined me for further study. With him on board, O'Brien Pharmacy produced a compounded 0.5% nasal spray. This was tested in his referral headache clinic and 10 of 16 (62.5%) refractory migraine patients responded favorably.[14] As of early 2025, compounding pharmacies are the only source of this new use of an old medicine which is

safe, effective, inexpensive, and available. Those of you that treat migraine patients, what is not to like about that? Many studies have confirmed our research.[15-18] The first placebo-controlled study (2018) to do so was conducted at University of Missouri-Kansas City, Department of Neurology by Drs. Gratton, Cossack and Nabrinsky.[17] They continue to be enthusiastic and use liquid timolol for their acute migraine patients as does Dr. Kosa.[14,18] Standard beta blocker contraindications and careful clinical monitoring are necessary. The spray will not work on patients already on a beta blocker for any indication. Patients that have failed daily oral beta blocker for migraine prevention and also not good candidates. The inexpensive timolol 0.5% nasal spray can be dispensed by O'Brien Pharmacy with a proper prescription and mailed to the patient. Presently a 15 ml nasal spray costs only about $75 and will treat many migraines. An acute migraine needs four drops for treatment; the cost to treat one migraine is about $5.70

I won't use the brand name so I don't get a call from the company's lawyers but a new FDA-approved migraine medication lists $1,200 for eight tablets. That is $150 per tablet. Got to pay for those yachts for pharma execs, you know.

Summary and Suggestions

So, what are my suggestions for use of compounding pharmacies and their unique products in your practice? First, if an FDA-approved product is available use it. In the instance that an FDA drug you prescribe is unavailable due to shortage or discontinued by pharma and an acceptable alternative FDA drug is not available, considering a high-quality compounding pharmacy is a good option. If an FDA drug is priced so expensive that your patient cannot afford it and a lower priced alternative not available, then consideration of a high quality (note how often I use those words—do your due diligence) compounding pharmacy product is a reasonable option. We are now seeing this play out big-time in relatively inexpensive compounded GLP-1 agonists for weight management.

I hope you are no longer 'mixed-up' about compounded medications.

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College Grades Have Become a Charade: It's Time to Abolish Them

by Yascha Mounk, PhD

When most students get A's, grading loses all meaning as a way to encourage exceptional work and recognize excellence.

Grade inflation at American universities is out of control. The statistics speak for themselves. In 1950, the average GPA at Harvard was estimated at 2.6 out of 4. By 2003, it had risen to 3.4. Today, it stands at 3.8.

The more elite the college, the more lenient the standards. At Yale, for example, 80% of grades awarded in 2023 were A's or A minuses. But the problem is also prevalent at less selective colleges. Across all four-year colleges in the US, the most commonly awarded grade is now an A.

Some professors and departments, especially in STEM disciplines, have managed to uphold more stringent criteria. A few advanced courses attract such a self-selecting cohort of students that virtually all of them deserve recognition for genuinely excellent work. But for the most part, the grading scheme at many institutions has effectively become useless. An A has stopped being a mark of special academic achievement.

If everyone outside hard-core engineering, math, or pre-med courses can easily get an A, the whole system loses meaning. It fails to make distinctions between different levels of achievement or to motivate students to work hard on their academic pursuits. All the while, it allows students to pretend—to themselves and to others—that they are performing exceptionally well.



Yascha Mounk is a professor of international affairs at Johns Hopkins University, the founder of the online magazine *Persuasion* and the author, most recently, of "The Identity Trap: A Story of Ideas and Power in Our Time." This essay is adapted from his Substack.

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Worse, this system creates perverse incentives. To name but one, it actively punishes those who take risks by enrolling in truly challenging courses.

All of this contributes to the strikingly poor record of American colleges in actually educating their students. As Richard Arum and Josipa Roksa showed in their 2011 book *Academically Adrift*, the time that the average full-time college student spent studying dropped by half in the five decades after 1960, falling to about a dozen hours a week. A clear majority of college students "showed no significant progress on tests of critical thinking, complex reasoning, and writing," with about half failing to make any improvements at all in their first two years of higher education.

In one of the oldest jokes about the Soviet Union, a worker says: "We pretend to work, and they pretend to pay us." To an uncomfortable degree, American universities now work in a similar fashion: students pretend to do their work, and academics pretend to grade them. It's high time for a radical reboot of a broken system.

Why Grades Matter

Grade Inflation Has Deep Roots

Tuition fees are higher than ever. And so universities have come to see students as prized customers whose demands—from lavish dorms and gyms to teachers who don't unduly interfere with their extracurricular commitments and busy social lives—better be heeded.

Another important reason why grade inflation has been able to take hold so easily is that many academics have lost faith in the utility of grades and grown uncomfortable with the authority entailed in their role as evaluators. That is in some ways understandable. In

the classroom, professors' primary preoccupation shouldn't be to assess students for their suitability for influential positions in society; it certainly isn't mine. Like many of my colleagues, I aspire to help students master complex ideas and develop the ability to think for themselves.

But as it happens, a good grading scheme can be useful in accomplishing our core purposes as teachers. Understanding this is key to understanding why a bad grading scheme does so much harm.

When people debate the utility of grades, they mostly tend to focus on their signaling function to outsiders. Selection committees need to pick who wins a prestigious fellowship. Employers need to pick which applicant to invite for a job interview. Grades give them access to the unvarnished judgment of multiple professionals who have closely observed the candidate's work.

This makes meaningful grades a key component of a meritocratic society. There will always be positions in society that are associated with greater prestige and material reward. In the absence of other compelling considerations, the fairest way to distribute these positions is to give them to those who are best suited to excel at them. This helps to make all of us better off. The main point isn't that the smartest student most deserves to become a doctor; it's that all of us deserve hospitals that employ the best possible doctors.

But grades don't just have an important signaling function to the outside world; they are, first and foremost, meant to give students a clear sense of how they're doing. When excellent, good and poor students get very similar grades, it is hard for students to know whether they are doing excellent, good, or poor work.

This is especially true in America because of a larger cultural emphasis on a certain kind of politeness and a greater fear of giving offense. One of the first things I was taught as a teaching assistant who had recently arrived from England, where feedback is traditionally much more blunt, was to present my assessment on student work in the form of a "poisoned Oreo cookie." Irrespective of the quality of a student's work, we were supposed to start and end our comments with chocolaty praise, smuggling the substance of a student's shortcomings into the creamy filling in the middle. Some students know how to read this code. Others focus on the faint praise and, taking comfort in their B+, fail to recognize their serious shortcomings.

The students I am lucky enough to teach are, for the most part, very smart. They find it easy to turn in competent work with relatively little effort. But when it's easy for them to earn an A or an A-, they fail to recognize how far they fall short of the true excellence to which they could aspire. Talented and hardworking though they may be, many of them never push themselves to live up to their true potential.

Punishing Ambition

One of the smartest and most inquisitive students I ever taught at Harvard came to me for advice for what to do after graduation. Since he was exceptionally talented, I assumed that he would have the grades to show for it, opening many doors to him. Sheepishly, he told me this was not the case.

How, I asked him, could that possibly have happened? The reason, he explained, is that he consistently took courses that challenged him. He would enroll in advanced classes across a range of STEM subjects, from astrophysics to engineering, even when they were far outside his area of specialization. In many, he excelled. But on two or three occasions, he struggled to catch up, and wound up with the Bs or Cs that hurt his GPA.

This student was far more gifted and intellectually ambitious than most of his classmates. But judging solely by his GPA, he was one of Harvard's worst students.

This predicament is a direct result of grade inflation. Back when the most commonly awarded grade at elite colleges was a B- or a C+, this lowered the stakes for any one course. If you messed up in one, you could compensate by doing very well on another for which you worked particularly hard or happened to have a special aptitude. As a result, a poor grade in one course had a relatively modest impact on a student's GPA.

Now that the most common grade at most four-year colleges is an A, the stakes for each individual course are much higher. A single negative

outlier takes on outsize weight. To get a stellar GPA, a student doesn't have to be exceptionally good at any one thing; they have to manage risk in every course they take over four years.

By the same logic, grade inflation also punishes students for uneven performance over time. If you are a middling student with few major life challenges and strong mental health, you will wind up with a high GPA. If you are a brilliant student who really struggles during one term because of a family crisis or some mental health problem, your GPA will tank, never to recover. The current grading system favors mediocre kids from stable homes over talented ones from less stable backgrounds.

Unpopular Solutions

Lenient grading practices are hard to contain once they take hold. When students have the expectation that minimally competent work will get them an A, professors risk upsetting them—and scaring future students away from their courses—if they insist on more demanding standards. And there is a simple problem of fairness: Why should any one professor give students worse grades than their colleagues would, effectively punishing them for taking his or her class? (I must confess that these considerations also shape my own grading.)

A few professors have reacted to this dilemma with a sort of private rebellion. Harvey Mansfield, a conservative political theorist who recently retired after teaching at Harvard for half a century, used to tell his students on the first day of class that they would receive two grades: their "real" grade and their "ironic" grade. The real grade had not been affected by grade inflation; even smart and hardworking students had to expect to receive an occasional B. The ironic grade, which would eventually make its way to the registrar, was in line with the university's inflated standards.

Mansfield's practice was a neat sendup of the university. And it did fix one pedagogically important problem with grade inflation: The "real" grade he gave to students gave them a meaningful sense of how they were doing, preserving some incentive to push themselves beyond the mediocre level required to earn an A on the official transcript.

But his solution is insufficient. As Mansfield himself would readily admit, it maintained the charade that GPAs are a meaningful metric of performance to the outside world and didn't fix the pernicious incentive for students to avoid challenging courses.

The only true solution to the current malaise would be to reintroduce practices that make meaningful distinctions between students. Only when grades actually capture the full range of performance do they fulfill all of their useful functions.

The most straightforward way to accomplish this would be to grade students on a curve, something that makes grade inflation impossible. Another solution, already implemented by some departments at elite colleges, is to introduce limits on the number of high grades professors can award; this gives academics more flexibility than a strict curve but blocks them from awarding A's to most of their students.

It also might make it easier for colleges to get serious about kicking bad habits if they introduce a novel grading scheme. If students are used to receiving an A for mediocre effort, a system that places them on a 20-point or 100-point or 26-letter scale might make it easier to impose fine distinctions.

But here's the thing: I have pretty much given up hope that any of this is going to happen at scale. Grade inflation serves the short-term interests of the main stakeholders of American universities too well—and the first college president to wage a serious battle against grade inflation would have to navigate too many minefields.

Most university administrators are keen to keep their students happy, ever conscious that the first campus that takes on grade inflation could slide down the college rankings. Most students are perfectly happy with a system that ensures they get a high GPA and leaves them to focus on other aspects of student life.

And of course the flattening of grades also avoids the risk of all kinds of embarrassing revelations about actual gaps in performance. Awarding high grades to virtually all students allows elite colleges to hide their failure to improve the academic performance of students who were admitted with lower average SAT scores—whether recruited athletes, the children of rich donors or members of certain demographic groups.

So can anything be done?

A Modest Proposal

The best solution would be to take the simple, if somewhat brutal, step of ending grade inflation. But if that is not in the cards, then it's time for universities to admit that the emperor has no clothes. The second best option may be to put an end to the whole charade: universities could make all of their courses pass-fail.

This practice has already been adopted by some elite law and business schools. Students would still have to submit their assignments and meet the minimum standards that are now expected of them. But they would no longer be able to pretend that they had been recognized for exceptional achievements.

Abolishing grades is much worse than a grading system that makes real distinctions between students. But by the same token, it is much better than the status quo.

If universities no longer awarded grades to their students, they would:

- Stop misleading outside institutions, including prospective employers, into believing that GPAs are a meaningful metric of achievement.
- Stop communicating to students that mediocre performance deserves praise or constitutes the limit of what they can achieve.
- Stop creating a disincentive for students to take the most demanding courses or taking advantage of the full variety of course offerings.

Sometimes, a system becomes so irredeemably broken that the least bad option is to give up on it, at least for now. The grading system at American universities has now reached that stage. It's time to toss out the whole thing. And perhaps, in a few decades, we will be able to start again from scratch. **MM**

Medical Education Must Have Objective Metrics

Diminishing Objectivity in the Residency Application Process

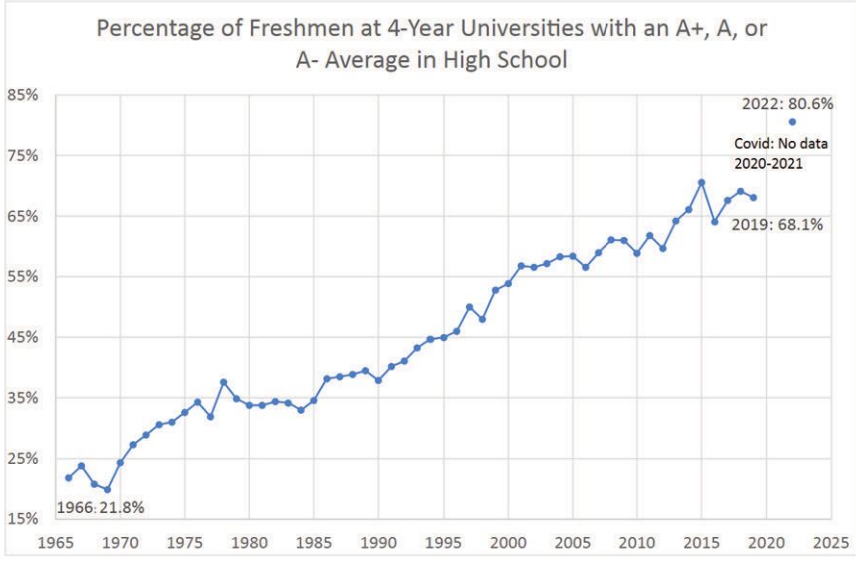
JAMA - published online February 6, 2025

Conclusions

The importance of qualitative evaluation metrics for a holistic application review process, such as letters of recommendation and personal statements, cannot be overstated. However, we believe that letting the pendulum swing too far away from objective metrics does a disservice to both applicants and programs. The challenge of evaluating a surging number of applications in the face of diminishing objective standards is real. Collectively, reinstituting USMLE Step 1 examination scores, retaining multicategory medical school grades, and capping the number of disclosed research experiences would foster a fairer and more consistent, transparent, and efficient application system for both programs and applicants.

James Agolia, MD1; Allen Green, BSc2; David A. Spain, MD1; et alJeff Choi, MD, MSc1, Department of Surgery, Stanford University JAMA. Published online February 6, 2025. doi:10.1001/jama.2024.28397

1 Picture = 1,000 Words



Source Summit Prep

Won't We Know If It's Toxic? A Review of the Impacts of Social Media on Public Health

by Jessica Williams, MD & Patricia Cavazos-Rehg, PhD

The question of whether social media is toxic with regards to public health is quite complex.

Social Media: Who are the Major Players?

The term "social media" encompasses websites and applications through which users create online communities to share ideas and information. Commonly used social media platforms include Meta (Facebook, formerly), Instagram, X (Twitter, formerly), TikTok, YouTube, Reddit, Snapchat, Pinterest, and LinkedIn, among others. Although most Americans utilize one or more of these platforms, socio-demographic variables play significant roles in which they are most likely to use.[1] For example, those who are 30-49 years old utilize Facebook, WhatsApp, and LinkedIn at higher rates than other groups of other ages; teenagers are more likely to use YouTube, TikTok, and Instagram.[2] Women report more usage of Pinterest and Instagram compared to men, who use Reddit and Twitter at higher rates.[1] Higher income correlates with X (Twitter) usage, while higher levels of formal education are correlated with use of LinkedIn and Instagram.[1]

With technological advancement and the rapid evolution of the internet, the target demographic of social media has changed drastically. Consider the lifespan of Facebook (now, Meta), which was originally only for college students (18 years and above).[3] Now, 95% of US teenagers are using social media, and nearly half of these teens report being online "almost constantly"[2] (doubling from 2015).[4] In children 8-12 years of age, 40% report using a social media platform,[5] despite 13 years being the minimum age for social media use, per the Children's Online Privacy Protection Act (COPPA).[6] Ultimately, social media continues to dominate more and more of our attention, with the average individual spending 151 minutes per day on social media in 2022.[7]



Jessica Williams, MD, (pictured), a PGY4 Resident, Department of Psychiatry, Washington University School of Medicine, St. Louis, Missouri. She is joining the WU Psychiatry faculty in 2025. Patricia Cavazos-Rehg, PhD, is Professor, Department of Psychiatry, Washington University School of Medicine, St. Louis, Missouri

Social Media Use & Mental Health

In the beginning of social media, opinions were primarily positive, espousing its novelty and utility in allowing for connectivity and rapid sharing of information at a distance.[8] Many publications before 2013 indicated that the use of social media had positive effects on self-esteem and perceptions of social support.[9,10] From then on, social media grew at an exponential rate, prompting increasing concerns that escalating time online may have a negative impact on mental health.

We are frequently told by news outlets that social media is bad for us,[11,12] though these claims are not entirely substantiated by scientific findings. To this point, two meta-analyses found minimal negative correlation (r = -0.07;[13] -0.079)[14] between time spent on social media platforms and psychological well-being.[13,14] When parsing out more specific parameters of social media use, multiple recent studies have found a significant relationship between time spent on social media and negative feelings of low self-esteem,[15] narcissism,[15,16] isolation,[17,18] and fear of missing out (FoMO).[19] As such, the "conventional wisdom" today

is that social media can be harmful, especially through its potential to provoke feelings of loneliness and social isolation.[20]

Given that social media, by its very nature, increases social connectivity, why does such loneliness prevail? Consider the Belongingness Hypothesis, which posits that we have powerful innate drives to connect with others and to resist dissolution of existing bonds.[21] Amid the inherent information overload brought to us by social media, primarily consisting of distorted, idealized portrayals of our peers' lives (i.e., the "highlight reel"), this drive to belong inevitably provokes comparisons with our own unfiltered behind-the-scenes experiences.[22,23] As Teddy Roosevelt said on jealousy, "Comparison is the thief of joy."



Rates of social media contagion and sociogenic illnesses are increasing.

The question has been raised of whether interpersonal comparison via social media differentially affects various age groups. In the impressionable pre-teen population, increased use of "other-oriented" social media use (interacting with others' posts) had negative associations with adolescents' self-esteem, which increased as participants progressed from ages 10 to 14 years, with this impact shown to be stronger in girls than boys.[24] In college students the concept of FoMO was found to spur compulsive use of social media by directly activating the drive for belonging.[25–27]

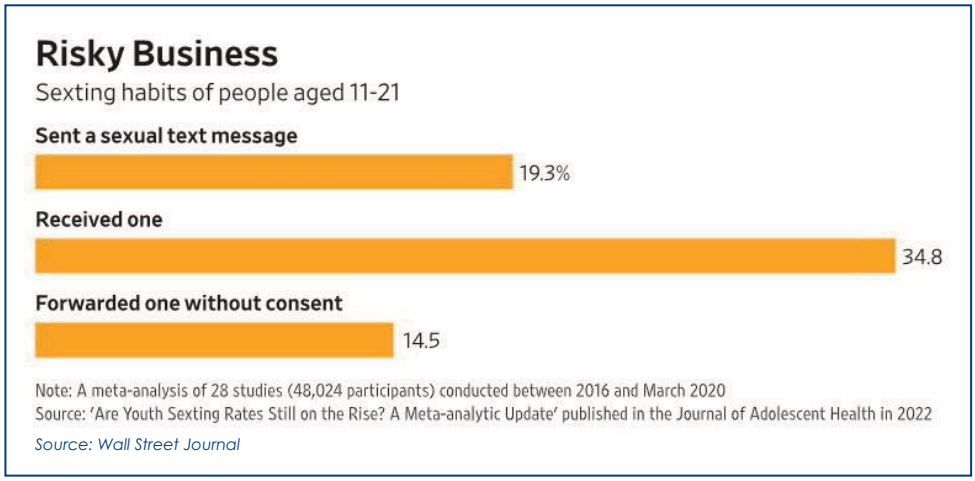
This compensatory overuse of social media use is modeled by theories of addiction, in which unfulfilled psychological needs trigger the urge to go online to relieve negative feelings.[26] Such compulsive use of social media, driven by FoMO, can ironically sour real-life connections via dominating attentional capacity (i.e., "phubbing," or being engrossed in social media, with the resultant ignoring of one's conversational partners or surroundings).[28]

When considering "problematic social media use," defined as addiction-like symptoms of preoccupation, loss of control, tolerance, and withdrawal,[7] a 2022 meta-analysis revealed statistically significant correlations with depression, anxiety, and stress.[29] Along a similar vein, there now exists a mainstream conceptualization of "social network use disorder," including Facebook and Instagram use disorders (of note, these are not officially recognized as disorders).[30,31] Physiologically, thinking of compulsive social media use as mediators of depressive and addictive/use disorders is reasonable, given demonstrated relationships between social media use and cortisol levels,[32,33] inflammatory markers,[34,35] and dopamine synthesis.[36,37]

Social Media Content and Mental Health

Another major concern regarding social media use is how the content itself can inform and directly impact mental health. Such content is reaching the 77% of Americans aged 18-34 who turn to social media to find information on mental health.[38] This behavior has been examined through the lens of "information foraging theory," which explains, from the evolutionary perspective, that humans have an innate drive to seek information, and will attempt to do so in the most efficient way (Rate of Gain = Information Value/Cost Associated with Obtaining Information).[39–41] As such, neatly packaged content in engaging posts or videos, often shared by social media influencers (SMIs), become the most enticing source for those seeking to learn more about mental health.

Such SMIs are those who have amassed large followings on social media over which they exert significant influence via regular and engaging content.[42] SMIs can serve as well-intending and authentic role



models in that they can highlight the importance of critical topics such as nutrition or mental health, and they can disseminate such public health information to an adolescent and young adult population that may be difficult to reach through conventional channels.[43] For example, there is a small subset of SMIs who have educational backgrounds and expertise in providing mental healthcare.[44–47]

The lack of expertise of the vast majority of SMIs, and their potential commercial interests, can pose risk of harm to impressionable youth, especially when misinformation is conveyed or unhealthy practices are promoted.[42] And, in the midst of the world wide web, much of the content can be inaccurate, misleading, or lacking context,[48] a proportion that is only increasing with the rising tide of artificial intelligence.[49,50] An important distinction: disinformation is spread with intent to harm, whereas misinformation inadvertently perpetuates inaccurate narratives believed to be authentic.[51]

Such misinformed content is primarily created and disseminated by SMIs.[52–54] In this regard, we are seeing increasing rates of self-diagnosis of mental health conditions as users identify with their favorite SMIs.[55] While there are some benefits to normalizing mental health conditions (i.e., combating stigma, raising awareness), there is concern that many social media users may be over-pathologizing the normal range of human experience.[55] Clinicians are noticing contagion effects with dissociative disorders,[56] functional disorders,[57,58] and neurodivergence[58,59] being self-diagnosed by their patients. Ultimately, self-diagnosis can lead to additional harms, such as tension if the physician does not agree with the diagnosis, self-treating with recreational, illicit, or over-the-counter medications, delaying treatment due to misinformed reassurance, or even self-fulfilling prophecy of the prospective diagnosis.[60–62]

Concerns are rising for the pervasive glorification of dangerous behaviors, including disordered eating on pro-anorexia ("Pro-Ana") websites,[63–65] substance use like THC products and synthetics,[66] and even self-harm or suicidality.[67,68] Adolescents, one of our most impressionable population, are the primary group subject to all of this malignant messaging. Consider the viral challenges, such as "the black-out" and "choking" games,[69] or the Blue Whale Challenge,[70] that end up on adolescents' For You pages by way of the TikTok algorithm.[71,72] Fortunately (in a way), these challenges are not very widespread, though when they do directly harm a social media user, they inevitably leave profound ripples in their wake.[69]

Speaking from the field of psychiatry, rates of social media contagion and sociogenic illnesses are increasing.[73] We are asking complex questions of how we can combat such effects of the social media behemoth. Along with the rapid evolution of social media and its content, the psychiatric profession is adapting its approach to understanding and defining mental illness.[74] We are collaborating with vital stakeholders, including social media users, influencers, and large mental health organizations such as AACAP and NAMI,[75,76] in efforts to utilize the influence of such platforms to promote national mental health. Altogether, the question of whether social media is toxic with regards to public health is quite complex: there are many concerns about the influence that it may wield on the well-being of social media users, as we have discussed, though there is also significant potential to harness the power and reach of social media in order to ultimately promote public health.

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Preparing for the Next Deadly Pandemic: What Did COVID-19 Try to Teach Us?

by Farrin A. Manian, MD

The COVID-19 pandemic tried to teach us many lessons not only about a highly pathogenic virus but also about ourselves. Did we learn enough to pass the next test?

What do you remember about the pandemic flu of 1918?

I would often ask my "oldest-old"[1] patients years ago as an infectious disease physician, irrespective of the reason for my initial encounter. Aside from a keen interest in a historic pandemic that claimed the lives of 50 to 100 million people worldwide and 675,000 in the United States alone,[2,3] I was more than eager to listen to the first-hand accounts of the ever-dwindling number of survivors of "the deadliest pandemic of modern age."[4]

Admittedly, numerous books, articles and documentaries had already been written or produced about the 1918 influenza or the "Spanish Flu" pandemic, but none brought to life the lived experience of that period more vividly than the words and expressions of survivors with whom I shared a brief but precious moment in time and space.

An elderly woman readily recounted that she was only seven years old when the pandemic hit and life as she knew it came to a screeching halt. People of all ages were getting sick in droves, she recalled, and many places of gatherings such as churches and schools were forced to shut their doors. However, her most haunting memory revolved around not what she saw but what she heard in bed at night with her window cracked open: the sound of hammers nailing the covers of freshly loaded wooden coffins.

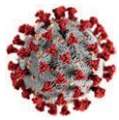
"You see, people would just be walking down the street and suddenly collapse because of the flu and they were young!" she recounted vividly, her raw emotions seemingly untouched by passage of time. Fear of contagion and dying was so high that no one dared getting near dead bodies except for the few good-hearted souls who came to remove the dead in the middle of night, she explained. Another oldest-old survivor recalled losing family members in the prime of their lives to the 1918 influenza leaving behind their orphaned children for relatives or others to raise.

My obsession with these and similar personal accounts of the "mother of all pandemics"[2] was in part sparked by my mother's account that my great grandmother often talked about how the pandemic killed so many people, including her only brother when he was only in his early 30s. It seemed that the influenza pandemic had taken everyone by surprise and inflicted its own shock and awe on the world in 1918. Although I had always expected one or more surprise pandemics during my lifetime as well, I was convinced that the extraordinary breakthroughs in science, medicine, infectious diseases, and vaccine development during the previous decades would be more than adequate to minimize their disruptive impact on our society and individual lives.

Of course, I was too naïve and a pandemic that virtually impacted every aspect of our lives



Farrin A. Manian, MD, MPH, received his MD degree from University of Missouri-Columbia and his Internal Medicine residency and Infectious Diseases fellowship at Vanderbilt University Medical School. He served on the faculty of Harvard Medical School as Associate Professor of Medicine. In 2020, Dr. Manian joined the Department of Medicine at Mercy Hospital St. Louis as Chairman and Academic Hospitalist.



did descend upon us with vengeance in 2020. And, despite an extraordinary global effort and unparalleled collaboration among countless scientists working around-the-clock to characterize a truly novel disease, determine its optimal treatment, and develop effective preventive vaccines, even the most advanced healthcare systems in the world were no match for a newly "crowned" virus, severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2), the agent of COVID-19. Indeed, at final count on April 13, 2023, COVID-19 had claimed the lives of at least 1.2 million Americans and seven million people worldwide.[5]

Admittedly, much has already been written about the COVID-19 pandemic. However, factual articles that critically examine the pandemic response by government and public health officials, the medical community, and society in general while offering ways to improve our readiness for the next one are few and far between. This is why the insightful two-part article (Part 1 November/December 2024 p 424-431; Part 2 January/February 2025 p 12-18) by McKinsey et al. in *Missouri Medicine* on optimizing preparedness for the next pandemic based on lessons learned from COVID-19 is timely and deserves a careful read.

The authors review several key aspects of COVID-19, including the origin of SARS-CoV-2 and its public health response and control measures, including mask mandates, shutdowns and closures, social distancing requirements and mass vaccination efforts. Undoubtedly, many of these countermeasures mitigated the impact of COVID-19 on our lives as discussed in the article. More specifically, the impact of vaccines on the pandemic trajectory cannot be overstated. In the US alone, COVID-19 vaccines prevented an estimated 3.2 million deaths, 18.5 million hospitalizations, and nearly 120 million infections during the first two years of their roll out alone.[6]

Unfortunately, implementation of time-honored or evidence-based interventions aimed at combatting the pandemic of our lifetime went far from smooth. Simply put, many people were not willing to abandon the routines of their everyday lives, irrespective of the potential societal toll of a poorly controlled pandemic. Not surprisingly, some countermeasures such as social distancing, shutdowns, and closures came with their own price tags, including their adverse impact on anxiety and stress at population level and their effects on our education system. More specifically, a switch to virtual classes or remote learning at the expense of in-person learning experience raised parental concern over children falling behind in their education.[7] In addition, many teachers reported challenges associated with remote classrooms, including "inactive students," lack of face-to-face student interactions, and difficulty in motivating students to engage in their lessons.[8] Ultimately, it seemed that any attempt to flatten the curve of the pandemic by switching to remote learning also carried the risk of flattening another curve: the learning curve of students.[9,10]

At the same time, a smoldering distrust of public health and medical authority came into full view by the "pandemic of misinformation" facilitated by social media.[11] Misinformation and disinformation were further fueled by frequently confusing, if not contradictory, public health messaging related to key aspects of the pandemic, including how to measure and report the COVID-19 community burden, indications for masking, the type of preferred mask, relative risks of various modes of transmission of COVID-19, period of infectivity, and indications for vaccine boosters.[12] Indeed, as an infectious disease physician practicing on the banks of one of the greatest rivers in the world, I often found the public health messaging as clear as the proverbial "Mississippi mud!"

Although the shortcomings in our public health response to the pandemic were manifest nationally, McKinsey et al. remind us that Missouri fared poorly in many of its rankings when compared to other states. Specifically, our rates of mortality, full vaccination, and interpersonal trust were in the bottom quartile of all the states. For example, we had no mask mandates when 39 other states had already adopted them. Similarly, the mean durations of our stay-at-home orders and closures of public places were several orders of magnitude lower than those of other states. A closer look at key factors in our state's underwhelming performance

revealed a fragmented public health system where the implementation of best evidence guidelines was often left in the hands of poorly resourced counties and local public health agencies. Undoubtedly, lack of a uniform public health policy and coordination of mitigating measures throughout the state fueled further mass confusion and contributed to the erosion of trust in our government and public health officials. After all, if the practice of science is based on evidence and facts, why should interventions to control a pandemic based on the best available science vary widely between adjoining counties and municipalities within the same state? Even the poor ranking of our state in interpersonal trust might have been emblematic of low levels of trust in our state government when dealing with a pandemic, given the positive correlation between interpersonal and institutional trust. [13,14]

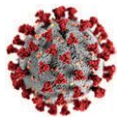
As suggested by McKinsey et al., the recent COVID-19 pandemic also offers the opportunity to learn lessons that can help us better prepare for the next pandemic. Notable among these is shoring up the entire public health system infrastructure throughout our state by improving our surveillance system for earlier detection of new pathogens with pandemic potential. Equally important is attracting and retaining highly qualified public health professionals dedicated to the prevention of infectious diseases. One potential barrier to achieving this goal is the existential threats to well-intentioned public health professionals solely due to the messages that they may carry.[15] To this end, as proposed by the authors, legislation that would criminalize harassment of public health workers as already done in most states is sorely needed.

McKinsey et al. also posit a best-case scenario in which the next catastrophic pandemic would not begin for at least another generation and that by then much of the negative sentiments and attitudes toward many of our public health professionals and scientists will have dissipated. I fear, however, that the unpredictability of pandemics may not afford us the luxury of a long interval between pandemics. Witness the rising concern over human infections by H5N1 avian influenza virus which may be only few mutations away from potentially causing a pandemic.[16] It goes without saying that we must reverse current trends in the distrust of the government, scientists, public health experts and members of the medical community with a sense of urgency.

Undoubtedly, the reversal of "pandemic of distrust" by the public[17] will require a herculean effort on the part of many stakeholders, including the government, public health officials and the medical profession, particularly physicians. As healthcare professionals whose very foundation of practice is firmly rooted in the scientific process, we are in an enviable position to leverage the hard-earned trust of our patients and members of our community and combat chaos and confusion with transparency and clarity, one person, one family, one community, and one region at a time. To this end, we would do well to adopt a "reasoned transparency" approach to our messages based on changing science instead of "fishbowl transparency" where changes in recommendations are not explained in the context of the old recommendations.[18]

We must also be cognizant of our own heuristics and avoid premature inferences when discussing incompletely characterized novel infectious agents and diseases that they cause. No one can claim expertise in a truly novel virus the likes of which mankind has never seen before. Even as a "seasoned" infectious disease physician, COVID-19 made an early learner out of me overnight.[19] Yet there seemed to be no shortage of "experts" opining on the modes of transmission and treatment of COVID-19 early in the pandemic, often without supportive evidence. Even as we began to learn more about the properties of SARS-CoV-2, confirmation bias (i.e., tendency in favoring information that confirms preexisting beliefs while ignoring evidence to the contrary)[20] reared its head. For example, some experts continued to insist that COVID-19 was not airborne or transmitted via aerosol (vs. droplets), despite increasing scientific evidence to the contrary.[21,22]

When writing this article, I came across a newly published perspective piece in the *New England Journal of Medicine* entitled "The Pediatrician's Lament."[23] As suggested



by its title, the author, a pediatrician, laid bare her frustration with parents who resist full vaccination of children against vaccine-preventable diseases of childhood. To remain worthy of trust by our patients, the author argues, physicians should "step into a public role" and collectively defend science, health, and vaccines. This is a sound advice for all physicians to consider not only in our daily practice but also in preparing for the next pandemic.

"History doesn't repeat itself, but it does rhyme" is a quote often attributed to Missouri's famous son, Mark Twain. The COVID-19 pandemic was not a repeat of the 1918 influenza pandemic a century earlier, but it seemed to rhyme with it in many ways, including the enormity of lives disrupted, if not lost, and a general distrust of government and public health officials. Such distrust, along with increasing popularity of anti-science movement, in turn contributed to disruption in many public health efforts to mitigate the impact of the pandemic on society and individual lives. Although I am grateful that I did not hear the nailing of coffins in the middle of night, I will never forget the inconsolable cries of anguished family members who lost their loved ones to a deadly but preventable disease. The COVID-19 pandemic tried to teach us many lessons not only about a highly pathogenic virus but also about ourselves. Did we learn enough to pass the next test?

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Disclosure

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Editor's Note

McKinsey et al. agree with Dr. Manian's critique and have no additional comments. **MM**

The Final Stretch

by David L. Pohl, MD

We are now entering the final stretch (of the legislative session).

It is difficult at this point to know what will catch fire and what will languish of the various bills being considered by the legislature (collectively known as "the good, the bad, and the ugly"). This is an on-going process, and any piece of legislation can change its status depending on what happens to it along the way.

By the time you are reading this, those bills which are most likely to pass are likely already out of committee (except for the ubiquitous "sleepers" which are going to pop up from the grave in the form of amendments to seemingly unrelated bills like burrs in a dog's coat after an Autumn walk in the woods).

We often consider the role of the MSMA to advocate for bills which we would like to pass. However, an equally important part of our approach is to also be on the lookout for those bills, actions, and endeavors which are detrimental to the practice of good medicine, or which can actively harm our patients or impede our ability to provide appropriate care. There have been times in the past that we have, near the end of the legislative session, worked to "kill a bill" that we initially supported and championed because of a "poison pill" amendment added late in the session.



David L. Pohl, MD, is a Radiologist from St. Louis, Missouri, and the 2024-2025 MSMA President.



This is your opportunity to shine. For those legislators who have not yet taken a firm stance on those items near and dear to us, your last-minute contacts may be what is needed to sway them in our direction. Additionally, your assistance in pointing out the foibles and unintended consequences of otherwise well-meaning attempts to help their constituents is invaluable. Remember those important words: "I am from your district." They have a magic of their own in the proper situation.

If you have not already done so, sign up for MSMA's *Legislative Report* and *5 Things You Need to Know*. Also, reach out to your Component Society (or take steps to rejuvenate yours, if currently inactive) and to the Councilors for your District to see how you can effectively get involved at whatever level your time allows.

Talk to your non-MSMA colleagues about joining. If your local society is inactive, this is a fantastic opportunity to get it re-invigorated with small informal events that allow for those connections to develop and strengthen. Local input from our members helps assure that your MSMA represents you, and your concerns. Grassroots input is where some of the more important ideas come from since they may represent issues not yet apparent to your fellow members elsewhere in the state. Like so many things in life, what you "get out" of your MSMA membership is dependent on what you "put in" as an active member.

In conclusion, thanks to all our members, especially to those of you involved over the past year, who have worked diligently to contribute to the growth and success of our professional society, the Missouri State Medical Association. **MM**

How Do I Know Who You Are?

by Kathy Perryman, MD

It is an ethical principle that every patient has full knowledge of their healthcare professionals' education, training, and skills.

In 2021, the American Association of Nurse Anesthetists (AANA) decided to change the name of their organization to American Association of Nurse Anesthesiology. This name change comes at a time when many other nurse practitioners (APRNs) and physician assistants (PAs) are seeking new titles and more autonomy in medical decision-making. Title misappropriation is misleading, incorrect, and confusing to patients.

An anesthesiologist is a medical doctor, and a nurse anesthetist (CRNA) is an advanced practice nurse. The term "nurse anesthesiologist" is opposed by the American Medical Association (AMA), the American Board of Medical Specialties (ABMS), and the American Board of Anesthesiology (ABA). The New Hampshire Supreme Court upheld a ruling by the New Hampshire Board of Medicine to limit the use of the term "anesthesiologist" to only those licensed to practice medicine. A growing number of states require a medical license to use titles, such as anesthesiologist or other specialist designations. Truth and Transparency legislation has been adopted in several states.



Kathy Perryman, MD, is Associate Professor at the University of Missouri-Kansas City, and a retired Pediatric Anesthesiologist. She is also a longtime member of the Missouri Society of Anesthesiologists.

Why is this so important? It is an ethical principle that every patient has full knowledge of their healthcare professionals' education, training, and skills. In calling themselves "anesthesiologists," the AANA is not only falsifying their title but also violating that trust between patient and provider.

I bring a unique perspective to this ongoing debate over terminology: before I became a physician and specialized in anesthesiology, I was a CRNA. I always knew the differences between my knowledge base and skill set and that of my anesthesiologist colleagues. Therefore, after several years working as a nurse anesthetist, I knew that I wanted to fill that knowledge and training gap by going to medical school and completing an anesthesiology residency. The additional years of education and training were immensely valuable, providing me with a deeper understanding of complex physiology and disease processes, enabling me to identify and mitigate patient risks before surgery, prevent complications, respond to emergencies in the operating room, and enhance the patient postoperative recovery process. I understand firsthand the significant differences in education and training between the roles of anesthesiologist and CRNA. This distinction is crucial for patients' understanding and safety and should not be blurred by misleading terminology.

Unfortunately, the AANA has been pushing to be allowed to practice without physician supervision for many years and

now, for title misappropriation. Many states, including Missouri, have been fighting against independent practice bills repeatedly. The ASA has reached out to nurse anesthetist colleagues multiple times to remind them that it values them in the anesthesia care team and to express concern that the AANA leadership's name change will foster discord in their teams. The ASA is worried that this will undermine this relationship and that is what it wants to prevent as it is ultimately bad for patient care.

So, where do we go from here? Collaboration between our physician medical organizations is growing and will continue to be important to foster. The ASA has been working with the AMA and ABMS and participated in a summit with 30 national and state medical societies to begin a broad initiative to prevent some providers' deliberate efforts to mislead the public. The ASA has reached out to policymakers, the Council on Accreditation of Nurse Anesthesia Educational Programs, the National Board of Certification and Recertification for Nurse Anesthetists, and the National Council of State Boards of Nursing urging them to reject any requests to manipulate and misappropriate medical titles.

I am encouraged to see physicians from all specialties working together in organizations, such as AMA, MSMA, ABMS and others, to keep our patients safe and informed. We appreciate and value CRNAs, APRNs, and PAs, as we have worked well as a team for many years, and we hope for many more. I wish to see more physicians participating in advocacy for truth and transparency as we move forward together to stop current title misrepresentation and prevent future title manipulation and misappropriation. **MM**

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Getting to the Inner Circle: The Long, Hard Way

by Jo-Ellyn M. Ryall, MD

There are times that you want to clone yourself to accomplish all that is asked of you.

Born in Newark, New Jersey on May 25, 1949, I was the eldest daughter of Joseph and Tekla Ryall. Growing up in Irvington, NJ, I attended elementary and high school in my home parish. I went to Douglass College of Rutgers University and graduated in 1971 with a BA in chemistry. I was the first in my family to graduate college followed by my brothers, Paul, a civil engineer and Air Force Lt. Col., and Mark, a businessman with an MBA from Washington University (WU) in St. Louis.

I attended medical school at WU from 1971-75 and had no idea about organized medicine. Following graduation, I completed my residency in psychiatry, also at WU. After working at Malcolm Bliss Mental Health Center for two years and I eased into private practice in adult psychiatry in St. Louis County. In 1977, I joined the Eastern Missouri Psychiatric Society (EMPS) and started attending dinner meetings at the medical society building. Dinner was the same: steak, baked potato, salad, dessert, open bar, and no condiments. I brought a plastic lime for gin and tonics, and my friend, Pat Newton, brought the A-1 sauce for steak. We were immediately accepted in the fold. The members wanted to sit with us because we had condiments, but more importantly because we were young, interesting women.



As a medical student at Washington University, I participated in the Medical Education Community Orientation program in Washington, Missouri. Before I became a psychiatrist, I completed the medicine rotation and physically examined patients.

I joined the St. Louis Metropolitan Medical Society, the Missouri State Medical Association, and the American Medical Association when I attended the psychiatric portion of the MSMA Annual Convention in St. Louis in 1979. The following year, I went to MSMA Kansas City Convention for the psychiatric part and learned that the delegation from St. Louis had empty spaces, so I became a Delegate to the MSMA House of Delegates. I have remained a Delegate from St. Louis since that time—45 years.

I was elected President Elect of EMPS in 1982 which was followed by being President in1983-84. This is also when I learned to fly a private plane and was licensed as a private pilot in 1984. Three psychiatrists owned a Grumman Tiger, and we called our corporation Tri-Psych.

In the mid 1980s I was the EMPS Insurance Chair. This was the birth of managed care, and their goal was to cut patient benefits. This was a depressing time for me since I am and always will be a patient advocate, and they were the enemy. In 1986 I was appointed chair of the EMPS Public Affairs Committee, a position I held for 18 years. During that time, we started the Mental Illness Awareness Coalition, and presented programs to the public to decrease stigma. The coalition included the EMPS, the



Jo-Ellyn M. Ryall, MD, is a retired psychiatrist, St. Louis, Missouri. She has served as Delegate, Vice Speaker, and Speaker to the MSMA House of Delegates; on the Missouri Delegation to the AMA; and her local, state, and national Psychiatric societies and associations.

National Alliance for Mental Illness, the Mental Health Association, the Depressive/Manic Depressive Association, Recovery Inc., and several hospitals. During that time, I became a weekly guest on the KSDK-St. Louis Morning show with Jennifer Blome called "Your Mental Health."

Elected to the St. Louis Metropolitan Medical Society Council in 1986, I served for three years. In 1989, I was Vice President under Dan O'Sullivan, MD. In 1986 I was elected Vice Speaker of the MSMA House of Delegates then Speaker. I now have been MSMA Parliamentarian since that time.

That same year, I was asked by the American Psychiatric Association (APA) to replace Barbara Buchanan, MD, on the Section Council of the APA to the AMA. I went to my first AMA meeting in December 1986. A vacancy opened for an Alternate Delegate on the Missouri Delegation so I asked the MSMA to appoint me because I could go for half price since I was also representing psychiatry in the reference committees. I was appointed and then elected Alternate Delegate to a regular two-year term until I became a Delegate serving from for 10 years (1997-2007).

I attended 41 AMA meetings. In 1997, I ran for the Council on Constitution and Bylaws of the AMA and was appointed to the Bylaws Committee of the APA. I lost the first AMA race but ran again in 1998 and served eight years on the Council, serving as chair from 2004-2006. The Council undertook the immense task of rewriting the Bylaws, reducing the size by about one-third and making it more reader friendly. When Missouri reduced its Delegation by one spot in 2007, I stepped down so Bill Huffaker, MD, Chair of the Surgical Caucus could continue and therefore, help David Barbe, MD, win a seat on the AMA Board of Trustees.



I was elected Speaker of the MSMA House in 1989 and have been Parliamentarian since my term expired.



David Barbe, MD, helped me run for the AMA Board of Trustees in 2007 following our Heart of American Caucus theme of Route 66.



Senator Jill Schupp invited me and two medical students to stand on the podium of the Senate during Advocacy Day in 2022.

In 1993, I was elected as Deputy Representative from EMPS to the APA Assembly. I attended my first meeting in 1994. This was a different meeting than the AMA or MSMA. There were long discussions on the floor of the Assembly, and gradually, I got the rhythm of their procedures. In 1997 I was elected representative from EMPS when Roy Wilson, MD, became the Director of the Missouri Department of Mental Health and moved to Jefferson City. The Speaker of the Assembly, Dale Walker, MD, asked me to head an ad hoc committee to introduce the Assembly to reference committees so that the action papers could receive hearings and get edited before a major discussion on the Assembly floor. That process is still working well. In 2001, I was elected as the APA Deputy Representative for Area 4 (greater Midwest) and in May 2006, I became the Representative of Area 4. I also was appointed chair of the Procedures Committee of the Assembly. It fit well with my bylaws experience. I ran for APA Speaker Elect in 2003 and Recorder in 2004. These races were unsuccessful.

This is an example of a professional life dedicated to service in the medical political arena. I could not have done this work to the same extent if I had children. I was married and divorced and chose not to be a

single mother. I have had cats and dogs and now have two rescue miniature poodles.

I have always loved to travel, and when I was working I would do weekend visits to my brothers who at that time lived in Colorado (ski vacation) and Florida (beach vacation). I met a friend of my brother's and visited him in Alaska where I went fishing, (actually catching).

I started playing duplicate bridge in 1999, and started going to tournaments in different states. I met a bridge friend in 2010 and then started traveling on cruises. After I retired from medical practice in 2023, I took several cruises a year. I am making up for all the years that I did not go on long vacations. I did travel with AMA and APA so eventually I set foot in all 50 states.

When I started cruising on several Viking cruises —river and ocean—I added to my list of countries. I have seen most of the countries in Europe and hope to get to Australia and New Zealand this winter. In 2022 we toured Argentina, the Falkland Islands, and Chile. I took a land tour of Peru in August 2022.



I learned to ski in 1982 in Austria and spent many years skiing in Colorado with my brother's family.



Alaska gave me the chance to catch a 65 pound King Salmon. It was cut up, frozen, flown home, and shared with my bridge playing friends.

I am a sports fan and have season tickets to the Battlehawks, our UFL football team which replaced the Rams who moved to Las Angeles. I also go to spring training for the Cardinals. I enjoy water aerobics and volunteer at Opera Theatre of St. Louis on the transportation committee and the gardening committee.

I chose psychiatry when I was in medical school because it was fascinating. It was the only rotation that I read more than was required. I was very interested in psychopharmacology and what medicines could help my patients. Now that I am retired, I do miss several of my patients. I knew my chosen specialty would allow time to get involved in medical and also Missouri politics. I would make yearly trips to Jefferson City to talk to the legislators. When I retired, I got more involved with the SLMMS Alliance and now am Legislative Representative, so I am still going to MSMA's annual White Coat Day. I also became co-president of SLMMS Alliance.

I have learned that organized medicine helps us join forces to succeed against the forces that oppose medicine and try to come between our patients and us. Individual doctors do not have time to visit the legislators on a regular basis or even write every time some issue that affects us rears its head. We rely on the staffs of MSMA and the AMA to plead our cause. When I was called upon to travel to the legislature to testify in front of hearings in February 2007, I was fortunate to be in Washington DC during the introduction of the Mental Health Parity Bill. Immediately, I spoke to Senator Kit Bond (R-MO) and Senator Claire McCaskill (D-MO) about supporting that measure. I also spoke to several representatives about supporting it when it was introduced into the House.

There are times that you want to clone yourself to accomplish all that is asked of you. What I learned is that you start early and say yes to the volunteer opportunities that interest you. If you appear at meetings and are interested, you will be appointed and elected to positions. This can lead to a trail of opportunities that you have to weigh and see which you will choose. Choose wisely but choose to join and support with money if not with time and talent. Remember, you cannot do it alone and organized medicine provides support, educational opportunities, and a chance to change policies.

You must make choices. With dedication and persistence and skill, you will succeed. **MM**

CORRESPONDENCE

Praise for *Missouri Medicine*

I just finished reading the November-December 2024 *Missouri Medicine*. The journal just keeps getting better; this issue is terrific.

Your essential tremor case report was good; I especially appreciated your personal account of your military service.

Best wishes for your 2025,

Steven M. Shields, MD
Ophthalmology, St. Louis, Missouri

Medical Errors Should Not Be Criminalized

We read with interest the article from Todd and Carberry (November/December 2024 *Missouri Medicine*)on the implications of possible criminal acts committed by healthcare providers.[1] There are clear cases, such as some described in the article, where intentional harm was committed by healthcare providers and criminalization may be appropriate. However, the recent case of Radonda Vaught, a nurse who, through a series of errors, committed a medication error leading to a patient's death, has brought to light some of the negative implications of the criminalization of medical errors.[2]

A robust safety culture is one in which there is commitment to both psychological safety and organizational learning from medical errors, while acknowledging that the practice of medicine is high risk.[3] The criminalization of medical errors risks patient safety by impairing safety culture and impacting clinician well-being. Medical errors are "the failure of a planned action to be completed as intended (i.e. error of execution), or the use of a wrong plan to achieve an aim (i.e., error of planning)."[4] Unfortunately, medical errors remain pervasive in medicine, despite numerous advances in patient safety.[5] In general, medical errors are underreported, and one of the most frequent barriers to reporting medical errors is fear of consequences.[6] When healthcare providers are concerned about blame, punishment, or even criminal liability, they will be reluctant to report. This fear of blame and punishment, and the lack of the ability to be transparent about the need for systemic improvement, has profound impacts on both psychological safety and clinician well-being. Lack of support at work is well-known to be one of the most significant drivers for clinician burnout.[7,8] Additionally, failure to report medical errors impedes the ability to analyze and investigate the incidents and seek opportunities for future improvement and prevention of repeat errors.

Just Culture, an essential component of safety culture, emphasizes that while individuals should not be blamed for medical errors that result from poor system design, those who are reckless should be held accountable. A very small percentage of medical errors are due to reckless behavior. To determine whether a medical error is blameless or an intentional violation, several algorithms may be consulted, including James Reason's Decision Tree for Determining Culpability for Unsafe Acts,[9] the United Kingdom National Patient Safety Agency Incident Decision Tree,[10] or the Leonard and Frankel Model of Accountability.[11] At the heart of these algorithms, a reckless action is defined as an intentional violation of known best practices or standard of care. They may be summarized by asking: would someone, in the same situation and with the same level of training and expertise, have made the same error? If so, it might have been a blameless error (likely a result of poor system design, which should be rectified); if not, there may be a violation due to recklessness, and that person's actions may need to be sanctioned.

Multiple organizations, including the American Society of Anesthesiologists,[12] the Anesthesia Patient Safety Foundation,[13] the Institute for Healthcare Improvement, the Lucian Leape Institute,[14] and the American Academy of Emergency Medicine,[15] among many others, have affirmed that, while reckless individuals must be held accountable for their actions, healthcare professionals should not be criminally punished for medical errors. The criminalization of medical errors decreases psychological safety and clinician well-being and in so doing, leads to a dysfunctional safety culture, fear of the repercussions of reporting errors, a lack of awareness of and an inability to fix systems issues that led to the medical errors – and consequently, persistently flawed environments that inevitably may lead to further errors. This negative cycle clearly impairs patient safety.

As a result, we maintain that while individuals committing reckless actions or intentionally harming

IN THE NEWS

Missouri Medicine Announces New Board Members

Missouri Medicine announces new Editorial Board members. Board members are selected on the basis of exceptional professional accomplishment and expertise in their specialty.



Julie M. Marshall, MD, FASA, is a Professor of Anesthesiology, Vice Chair for Education and Faculty Development, and Interim Director of Research in the Department of Anesthesiology, University of Missouri Health Care in Columbia, Missouri.

She replaces **Kathy Perryman, MD**, who has served the Editorial Board since 2018. Dr. Perryman is Associate Professor at the University of Missouri-Kansas City, and a retired Pediatric Anesthesiologist. She is also a longtime member of the Missouri Society of Anesthesiologists. We thank Dr. Perryman for her service.



Mark R. Wakefield, MD, University of Missouri Healthcare, is Director of the Renal Transplant Program, Associate Director of Clinical Affairs, Ellis Fischel Cancer Center Program Director of Urology Residency Program, Chief Medical Officer for Ambulatory Services, Division Chief of Urologic Surgery, and Professor of Surgery.

He replaces **Elizabeth A. Piontek, MD**, Saint Luke's Health System, Kansas City, Missouri, who has served the Editorial Board for almost a decade. We thank Dr. Piontek for her service. **MM**

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patients must be held accountable, medical errors related to human error and that are a product of systemic flaws should not be criminalized. We as medical professionals need to continue to draw awareness to these issues, and we applaud the efforts of Todd and Carberry in doing so.

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Emily Methangkool, MD, MPH
Chair, American Society of Anesthesiologists
Committee on Patient Safety and Education

Karolina Brook, MD, FASA, CPPS
Vice Chair, American Society of Anesthesiologists
Committee on Patient Safety and Education

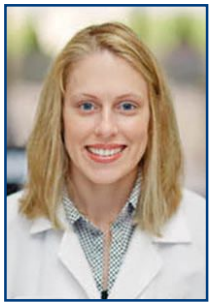
MM

Developing an Aging-Friendly Healthcare System

by Angela M. Sanford, MD & Susan J. Elliott, DNP, APRN, FNP-C

SAINT LOUIS UNIVERSITY

How can the healthcare culture be changed into one which is more aging-friendly?



Angela M. Sanford, MD, (pictured), is Associate Professor of Internal Medicine, Division of Geriatric Medicine at SSM Health/ Saint Louis University School of Medicine, St. Louis, Missouri. Susan J. Elliott, DNP, APRN, FNP-C, is at the SSM Health/Saint Louis University School of Medicine, St. Louis, Missouri.

Abstract

With the rapidly increasing population of older adults, there is a great need to develop Aging-Friendly Healthcare Systems (AFHS) equipped in providing comprehensive healthcare to a complex population across an expansive care continuum. While there are several important components in a successful AFHS, the pinnacle of the AFHS is quality of life for the patients it serves. The John A. Hartford Foundation has launched the 4Ms (What Matters, Mentation, Mobility, and Medication) initiative as a structured approach to assist in the development of AFHS. The AFHS is highly supported by the interdisciplinary team, geriatricians, and primary care physicians, all whom are facing serious workforce shortages, particularly in Missouri. Beginning in 2025, hospitals that participate in Medicare's Hospital Inpatient Quality Reporting (IQR) Program will be required to report on Aging-Friendly Hospital Measures based on the 4Ms framework or face possible reimbursement penalties.

Introduction

The year 2034 marks the transition point at which there will be more people over 65 years of age than under 18 years of age for the first time in history. [1,2,3,4] The "graying of America" will be inescapable with one in four older adults being 65 years of age or older, and the population of 85 years or older tripling.[4] It is foreseeable that there will potentially be more non-working adults than working adults and an astronomical shift in the numbers of older adults with unmet healthcare needs. Historically, healthcare systems were designed around the disease-based acute care model, which aims to treat singular acute disease episodes rather than addressing increasing numbers of chronic comorbidities intersecting with advancing life expectancies across a population.[5] With the rapidly increasing population of older adults, there is a great need to develop Aging-Friendly Healthcare Systems (AFHS) equipped in providing comprehensive care to a complex population.

What is an Aging-Friendly Healthcare System?

No all-encompassing definition exists on constructing an AFHS, but opinions exist on necessary components (Figure 1). Components of a robust AFHS include quality of life, successful transitions of care, reduction in hospitalizations, promotion of aging in place, identifying and supporting end-of-life care preferences, maximizing



Figure 1. Key components of an Aging-Friendly Healthcare System

functional and cognitive abilities, and the creation of individualized treatment plans. While all of these components are equally important for care delivery, the pinnacle of the AFHS is quality of life for the patients it serves. These AFHS components should be implemented in all locations of care delivery for older adults across the system, including the outpatient clinic, the hospital, and post-acute and long-term care facilities. Because healthcare for older adults occurs across the geriatric care continuum, the AFHS requires infrastructure in place to facilitate smooth transitions of care across the continuum. The implementation of successful transitions of care is critical to improving measurable outcomes such as morbidity, mortality, hospital/facility length of stay, and hospital/facility readmissions rates as well as reducing overall healthcare costs.[6] Financially, establishing an AFHS makes dollars and sense, as demonstrated in a study of two large health systems which found an increased monetary return on investment through improvement on federal survey quality scores and decreased hospital length of stay, admission frequency, and admission severity.[7] In this study, the AFHS demonstrated lower costs, primarily through the reduction in delirium which is a common complication in older adults in the inpatient hospital setting resulting in costly delays and barriers to care.[7] It also generated an extra revenue of $3.6 million dollars annually from Medicare Annual Wellness Visits (MAWV) via a focus on screening and prevention and generation of downstream referrals.[7, 8]

Accounting for Disparities

The AFHS must account for healthcare disparities and high levels of disability in the aging population. Health spans do not always match age spans resulting in a large proportion of older adults living with poor health and missed opportunities to improve health span by staying socially, mentally, or physically active.[9,10] Older adult single households 65 years and older increased from 9.4% in 2010 to 11.1% in 2020 and the poverty rate in this demographic increased by 0.3%.[11,12] The prevalence of those with the necessary financial resources to improve health, such as adequate social security and pensions, has decreased over time and is projected to continue to worsen.[13] Older adults often have high levels of disability with 39% of those over 65 having an ambulatory difficulty, 29% being hearing impaired, 21% being visually impaired, and 28% having cognitive impairment.[14] Additionally, more than one out of three older adults have one functional limitation, and nearly two out of three have problems ambulating or using stairs.[9] A large proportion of older adults (31.3%) have impairment in activities of instrumental daily living (IADLS), which are necessary to enable one to live safely alone and include the ability to manage money, medications, making telephone calls, preparing meals, shopping for groceries, and/or using a map when driving.[15] The AFHS requires resources and a support infrastructure in place to accommodate the common place functional, physical, and cognitive limitations in the population it is serving.

Who Should Lead the AFHS Initiative?

Geriatricians who specialize in the healthcare of older adults are uniquely poised to push aging-friendly initiatives and are experts in managing geriatric syndromes, facilitating transitions of care, differentiating pathologic versus physiologic aging, polypharmacy reduction, helping patients and families set realistic end-of-life care goals, managing multimorbidity, and having personal experience with each of the interdisciplinary team member roles.[16] According to the American Geriatric Society, in 2021, there were 7,454 board certified geriatricians nationwide, yet a predicted 30,000 geriatricians will be needed to serve the older adult population by

2030.[17,18] In 2022, Missouri only had 111 board certified geriatricians with the Missouri geriatric doctor to patient ratio being 19% lower compared to other states.[17,19] Too few geriatricians are present to change the healthcare system culture into a more aging-friendly mindset. Medical schools lack required geriatric rotations with only 10% requiring a geriatric rotation as of 2021, which is down from 23% in 2005, and internal medicine training programs no longer requiring geriatric medicine exposure as part of their curriculum.[20] Given that only 43% of geriatric medicine fellowship spots are filled each year, which is the lowest of all fellowship specialties, most of the work and policy change will need to be implemented by primary care providers and other members of the interdisciplinary team.[21] The goal, therefore, is for geriatricians to educate and train the workforce and interdisciplinary team on best management principles for healthcare delivery in older adults.



Figure 2. Members of the Interdisciplinary Team

In an aging-friendly healthcare system, adequate numbers of primary care providers, which include physicians and advanced practice providers (APPs), are needed across all socioeconomic levels. This may be challenging given the predicted shortage of 20,000-40,000 primary care physicians to adequately cover the population by the year 2036.[22] The Missouri primary care physician shortage is sobering with 32% of physicians now at retirement age. The state is hypothesized to be short by more than 3,000 physicians by 2030, ranking in the bottom half of all states for total numbers of active primary care physicians.[19] One hundred and eleven counties out of a total of 114 Missouri counties are designated as "Health Professional Shortage Areas," defined by the Health Resources and Services Administration as a specific geographic area or population group lacking adequate numbers of mental health, primary care, or dental healthcare providers to adequately serve the population.[23] Because much of the implementation of an AFHS is done by the primary care workforce, the shortage of primary care healthcare providers in Missouri will be an essential challenge for the state to tackle.

Importance of Interdisciplinary Team

Healthcare delivery in an AFHS is highly dependent on the interdisciplinary team (IDT) which is essential in providing comprehensive care to older adults and includes nurses, physical therapists, occupational therapists, speech therapists, social workers, dieticians, and behavioral health specialists—many of which are facing serious workforce shortages (Figure 2).[24] The interdisciplinary team has always been central in the field of geriatrics and has more recently been implemented in other specialties. The premise of the team approach allows each team member to contribute individual expertise through the lens of diverse specialties. With the expertise of multiple disciplines, care delivery can be comprehensive, additive, and encompassing of the physical, mental, and psychosocial needs of the individual which lies at the very heart of the AFHS. In addition to the interdisciplinary team, care delivery for older adults is also often implemented by family and caregivers. Recommendations to include family caregivers as part of the interdisciplinary team are important because caregivers are often patient advocates and aware of their loved ones' healthcare preferences and goals.[9] Of the family caregivers surveyed, 88% described wanting more support sharing the care burden, increased guidance and education, and additional financial resources in which to utilize to care for their loved one.[9] The AFHS will ideally work through the interdisciplinary team to support patients and their caregivers and utilize a team-based approach in healthcare delivery.

4Ms Framework of an Aging-Friendly Health System

What is the 4Ms Framework of an Aging-Friendly Health System? In 2016, the John A. Hartford

Foundation, a private philanthropic group dedicated to improving the healthcare of older adults, launched the 4Ms initiative in collaboration with the Institute for Healthcare Improvement.[25] The 4Ms include What Matters, which places emphasis on aligning care delivery with one's personal healthcare goals and preferences; Mobility, which focuses on maintaining physical function so that one can maintain independence; Mentation, which includes identifying and managing dementia, depression and delirium; and Medications, which should be routinely assessed for risk versus benefit and which should not interfere with the other Ms (Figure 3).[25]

The 4Ms can be implemented across the care continuum by assessing for each of the Ms, and acting on them by aligning care plans with What Matters most.[25] Structuring an AFHS around the 4Ms framework is achievable and facilitates improved outcomes during all levels of care delivery and points of transitions of care. Prioritizing individualized healthcare plans by What Matters is person-centered and leads to improved physical and psychological responses and increased treatment compliance.[26]

What do older adults want? Older adults value listening skills in their healthcare provider as highly as knowledge and competence—each at 67%, and nearly half of older adults want their provider to collaborate with them as partners.[9] Not surprisingly, 94% of older adults feel it is more important to maintain quality of life than quantity of life.[9] Demographic factors such as socioeconomic class, race, and ethnicity influence how older adults feel their healthcare provider interactions could be more age friendly. For example, more African American older adults wish for discussions on What Matters and decreasing polypharmacy (i.e., the 4M focused on Medication) as compared to other race/ethnic groups.[9] A recent study revealed that 90% of clinicians agree older adults require a different approach to care than younger patients, yet only 50% of clinicians feel that they "always" take patient age into consideration when determining care. [27] Only one in five providers are routinely addressing all four 4M categories with only about 50% asking about What Matters regarding well-being.[9] The majority of older adults (77%) also prefer to age in place rather than be moved from their home to a care facility such as an assisted living or nursing home, indicating infrastructure in an AFHS is needed to support this

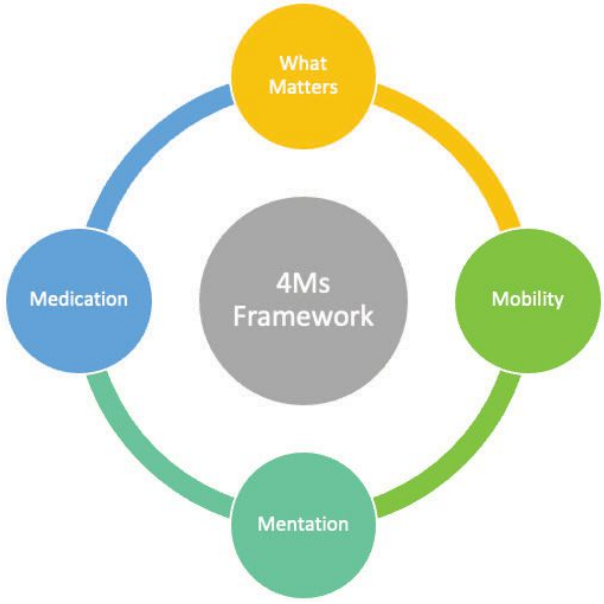


Figure 3. 4Ms Framework of an Aging-Friendly Healthcare System.[25]

preference whenever possible.[1,28] After surveying a large health system, only half of family members thought a care facility was the safest place for their loved one with more than 60% citing fear of poor quality of care and loss of dignity with institutionalization.[9] To promote successful aging in place, which is What Matters to many older adults, a focus on maximizing functional and cognitive abilities so that one can age in place should be prioritized.

Patient-Centered Care

Another important component of What Matters is patient-centered care.[25] Many best practice guidelines and research studies do not include older adult populations in the supporting evidence leading to ambiguous recommendations and difficulty applying study findings to older, frailer and sicker populations. The creation of individualized treatment plans is essential because much heterogeneity exists in the older adult population and there are limited evidence-based guidelines including those over 75 years of age. One 90-year-old may be robust, active, and living in the community while another 65-year-old may be wheelchair bound, frail, and living in a nursing home. The preventative healthcare goals of the two individuals are likely to be completely different requiring an individualized treatment plan accounting for the unique bio-psycho-social and physical needs

of each. Advanced care planning, or end of life care, is an essential part of What Matters and guides treatment plans for older adults.[9] Yet, only 13% of older adults have discussed end of life wishes with their primary care provider with one in three older adults in the United States having completed an advance directive.[9,29] Missouri data gathered from more than 11,000 older adults demonstrated 56% of people aged 65-74 reported completing advanced directives and 84% of those aged 85 and older reported completing advanced directives.[30] However, despite a positive cultural shift in the past several years that prioritizes end of life care goals, only one in eight adults receive care in their last months of life that is consistent with their wishes.[31] An AFHS must prioritize addressing end of life care preferences which align with the pinnacle component of "What Matters" and promotion of quality of life, which is central to a successful AFHS.

Medication

The epidemic of exceedingly long and increasingly inappropriate medication lists can diminish quality of life in older adults and through side effects and drug-drug interactions, adversely affect What Matters, Mentation, and Mobility. Prescribing cascades, where one medication is started to fix side effects from another medication is an important reason why Medication is included in the 4Ms framework. The CDC's National Ambulatory Medical Care Survey from 2009-2016 analyzed two billion healthcare visits of adults 65 years and older and found 36.8% were prescribed ≥ 5 meds and of those, 70% had one potentially inappropriate medication.[32] One study found that when using the Beers Criteria and STOP-START Toolkit, the percentage of potentially inappropriate medication prevalence by setting was 19.1% at primary care visits, 29.7% in the nursing homes, and 44.6% in the hospitals setting.[33] Medications can be addressed by performing a thorough medication reconciliation, deprescribing, ordering a pharmacy consult when pharmacy services are available, and avoiding high risk medications such as benzodiazepines, opioids, highly anticholinergic medications, sedatives, muscle relaxants, tricyclic antidepressants, and antipsychotics.[25] However, just 70% of providers ask about medications, limiting the management of polypharmacy and potentially inappropriate medications.[9]

Mentation

Mentation, another component of the 4Ms framework, can be addressed by screening for dementia, depression, and delirium. Data gathered from over 11,000 older adults in Missouri revealed that nearly 42% screened positive for dementia in the oldest age group (85 years of age and above).[30] Dementia, particularly that caused by Alzheimer's Disease, is one of the most feared health conditions by older adults with 69% citing that losing the ability to think clearly is the biggest worry of living a long life, yet only 40% of older adults report having a cognitive evaluation.[9] Screening for mentation/cognitive impairment should occur in both inpatient and outpatient healthcare settings and can be accomplished by any member of the interdisciplinary team. There are many validated screening tools, but the authors of this article recommend using the Saint Louis University Mental Status Examination (SLUMS) or Rapid Cognitive Screen (RCS).[34,35] Both are non-copyrighted, brief to administer, and have been validated internationally and across the geriatric care continuum. The SLUMS screening tool is particularly useful in that the score is adjusted for education level, making it more applicable in populations with lower education levels. In certain care settings, ensuring being orally hydrated, reoriented, having adaptation equipment on (i.e. hearing aides, glasses) and preventing sleep interruptions can improve acute mentation deficits and should be incorporated into best care practices.[25] Given the high prevalence of cognitive impairment in the aging population, the AFHS should routinely screen for cognition deficits and work to provide older adults and families with resources to preserve cognition and promote the best Mentation possible.

Mobility

The 4Ms framework component of Mobility can be addressed in the outpatient setting by performing gait evaluations, referring to physical/occupation therapy to improve deficits, screening for falls and fear of falls, and encouraging ambulation.[25] In the inpatient setting, getting patients out of bed for meals, ordering physical and occupational therapy, avoiding chemical and physical restraints, and removing catheters or other tethering devices may improve and/or maintain previous levels of mobility.[25] Older adults have a much higher risk of becoming immobile during prolonged hospital stays, which often results in institutionalization

and inhibits quality of life and one's ability to successfully age in place. System-wide implementation of the 4Ms, including Mobility assessments in all care settings, drives quality and safety, coordinates healthcare efforts across the care continuum, and improves outcomes during transitions in care.[26]

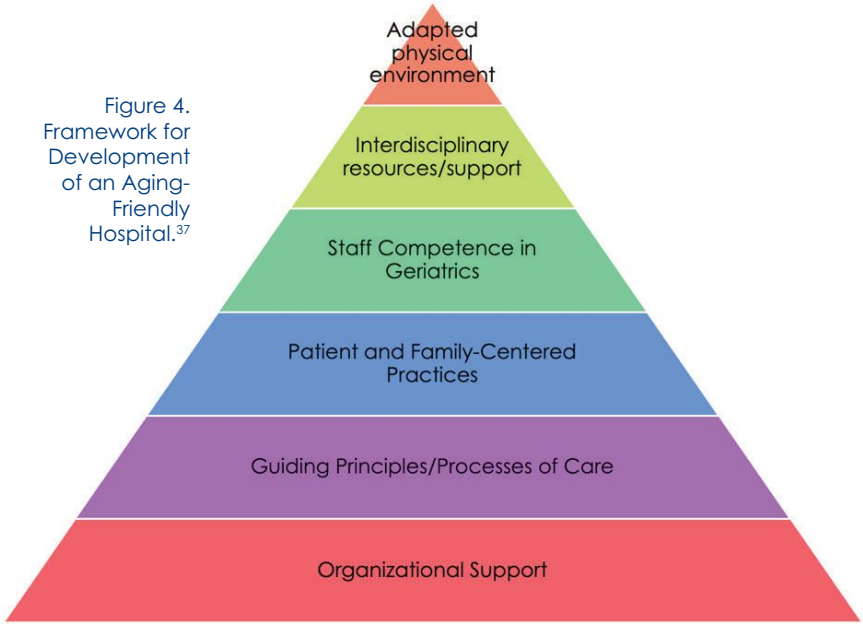


Figure 4. Framework for Development of an Aging-Friendly Hospital.[37]

Aging-Friendly Hospitals

Few hospitals truly meet the needs of older adults but evidenced-based aging-friendly approaches to better care in hospitalized older adults is emerging. Historically, hospitals were designed to provide rapid diagnoses and treatments of single episodes of acute illnesses. Older adults are more susceptible to hospital-associated complications such as falls, delirium, pressure ulcers, and functional decline which can prolong stays, increase readmissions, make higher costs and result in nursing home placement at discharge.[36] The framework for an aging-friendly hospital includes leadership/organization support, guiding principles, patient and family-centered care practices, staff competence in geriatrics, interdisciplinary team resources/support, and an adapted physical environment (Figure 4).[37] Leadership and organizational support is the highest priority and sets the stage for allocation of resources, development of aging-friendly policies and procedures, and adaptation of the physical space and healthcare team care delivery processes which are sensitive to the needs of older adults.[38] The guiding principles should be founded on evidence and best practices which account for the physiology and pathology of aging and encourages care delivery which promotes continuity through transitions of care and fosters the goal of maintaining physical and cognitive function throughout the hospital stay. Patient and family-centered practices ideally are devoid of ageism and respect the individualized bio-psycho-social care needs of older adults and their caregivers, maximizing patient/family satisfaction in the care received. Staff competence in geriatrics is achieved by continuous training and emphasis on managing common geriatric conditions such as falls, dementia, delirium, and incontinence. Interdisciplinary support highlights the important role of each member of the healthcare team and allocates additional financial resources to accomplish best practices even if they don't always appear to result in financial gain (i.e. allowing physical therapy to work with the older adult for longer sessions in the hospital to decrease functional decline even when health insurance may not reimburse fully for additional time). An adapted physical environment in the hospital promotes safety, independence and reduces functional decline and minimizes the vulnerabilities of often severely frail older adults. Examples of environmental adaptations include hallways with railings to promote ambulation, contrasting paint tones for the visually impaired, large clocks and calendars for orientation, bright lighting—ideally natural light to reduce delirium, common areas for families and visitors, chairs in rooms so patients can get out of bed for meals and throughout the day, elevated toilet seats and grab bars in bathrooms, walk-in showers for bathing ease, geri-chairs and accessible ambulatory devices to promote movement, availability of pocket talkers/hearing devices for those who don't have their hearing aids, and otoscopes for ear evaluations.[39]

Acute Care for the Elderly

Another important element of the Aging-Friendly Hospital is the availability of an Acute Care for the

Table 1. CMS Aging-Friendly Hospital Measures

Domain	Requirements
Eliciting Patient Healthcare Goals	• Use protocols to obtain and document treatment goals, living wills, healthcare proxies, and advance care planning
Responsible Medication Management	• Use evidence-based guidelines to review and reduce potentially inappropriate medications (PIMs)
Frailty Screening and Intervention	• Use validated instruments to screen mentation, mobility, and malnutrition • Care plan positive screens to minimize risk of delirium, promote early mobility, and develop nutrition plans • Collect and demographically stratify data on fall rates, pressure ulcers, and 30-day readmission rates • Use protocols to reduce delirium by shortening length of stay in the emergency department for admissions and discharges
Social Vulnerability	• Screen on admission and discharge for social isolation, economic insecurity, limited access to healthcare, caregiver stress, and elder abuse • Care plan positive social vulnerability screens for interventions, referrals, and resources
Age-Friendly Care Leadership	• Designate a champion and/or interprofessional committee to oversee, educate, report, and prioritize efforts on age friendly care initiatives • Use demographically stratified and compiled Age-Friendly Hospital Measures to drive quality improvement cycles

Elderly (ACE) unit/team.[39] The ACE unit/team philosophy was first developed around 1990 and is structured around a care model that focuses on the "big picture" and accounts for life expectancy, quality of life, and comorbidities while acute medical interventions are carried out.[40] It can be implemented as a physical place in the hospital (i.e. a geriatric floor/unit) or as a healthcare team that delivers care based upon this model. The ACE unit/team is driven by established guidelines and protocols based on published evidence for patient-centered care delivery in the geriatric population.[41] It recognizes the prevalence of geriatric syndromes, consistently screens all patients and utilizes evidence-based strategies to reduce the incidence of inpatient falls, delirium, length of stay, pressure ulcers and physical and cognitive decline.[39]

During each hospital stay, the ACE unit/team engages in dedicated discussions on patients' healthcare preferences and end of life care goals. A dedicated delirium unit may be part of the ACE unit/team and typically consists of a multi-bed room with specially trained staff who provide more individualized care and added assistance with activities of daily living.[42] The staff should be trained in managing behaviors

associated with dementia and delirium utilizing primarily non-pharmacologic strategies.[43] Delirium rooms tend to have a higher staff to patient ratio, but without such a structured multi-bed room the patients would likely require one to one bedside sitters, making a delirium room more economically beneficial. Both ACE units/teams and delirium rooms are highly supported by the interdisciplinary team. True patient-centered care dictates no physical restraint utilization and low chemical restraint utilization and to achieve this goal, added support from staff and the interdisciplinary healthcare team is essential.[44] Early mobilization, attention to visual and hearing aids, attention to and assistance with nutritional intake and maintenance of sleep/wake cycle are all focuses of the delirium room and good principles of managing/preventing delirium.[45] The prevention and quick management of delirium is economical for a healthcare system, as delirium is an independent predictor of adverse hospital outcomes such as morbidity, mortality, length of stay, nursing home placement, functional decline and higher costs.

Beginning in 2025, hospitals that participate in Medicare's Hospital Inpatient Quality Reporting (IQR) Program will be required to report on Aging-Friendly Hospital Measures (Table 1) based on the 4Ms framework.[46] These measures apply to the care of adults over 65 years of age in the inpatient setting, emergency department, and other hospital departments. Hospitals must have policies and procedures that 1) elicit patient health care goals; 2) responsibly manage medications; 3) implement frailty screening and interventions (includes cognition and mobility); 4) assess social vulnerability (i.e. social isolation, caregiver stress, elder abuse); and 5) establish Age-Friendly Care Leadership.[46] The five domains focus on 10 requirements, and failure to comply with these requirements can result in reimbursement penalties.[46]

Conclusion

With the increasing aging population, an essential focus is the development of Aging-Friendly Healthcare Systems that can meet the unique healthcare needs of this complex population. The pinnacle of an AFHS is focus on What Matters, and quality of life and this should be the driving force for policy and procedure development. The 4Ms framework (i.e., What Matters, Mentation, Medication, and Mobility) developed by the John Harford Foundation offers a structured approach to prioritizing the components of an AFHS. Some questions to consider include asking if your healthcare system is ready to encounter the increasing older adult population? What elements are in place and what is still needed? How can the healthcare culture be changed into one which is more aging-friendly?

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Aging in Missouri 2025

by Mona Dagher, MD, Julie K. Gammack, MD & Charles Bradford, FNP-C

The graying of America….the silver tsunami….the age wave. Ready or not, here we come!

As Missouri's population ages, we must be ready for the health care and financial impact of this demographic change.



Mona Dagher, MD, (pictured), is a Geriatric Medicine Fellow, Division of Geriatric Medicine at SSM Health/Saint Louis University School of Medicine, St. Louis, Missouri. Julie K. Gammack, MD, CMD, FACP, is Professor of Medicine DIO, Sr. Associate Dean for Graduate Medical Education at SSM Health/ Saint Louis University School of Medicine, St. Louis, Missouri. Charles Bradford, FNP-C, is at SSM Health/St. Louis University School of Medicine, St. Louis, Missouri.

Abstract

In 1950, the US population stood at 152 million and was considered relatively "young" due to historically higher fertility rates, declining infant and childhood mortality, and a greater influx of young immigrant workers.[1] Between 1946 and 1964, the Baby Boom era saw an accelerated number of births, further shaping the country's demographics. However, in the decades that followed, birth rates declined while advances in healthcare led to improved survival rates and reduced mortality at older ages.[2] This demographic shift has contributed to a significant aging of the population.

US Aging Trends

By the year 2000, adults over age 65 had risen to 35.1 million, making up 12.4% of the total US population, compared to just 8.1% in 1950. Currently, seniors account for about 17% of the population (Figure 1).[3] By 2035, the entire baby boomer generation will be older than 65 and there will be more adults over age 65 than children younger than 18. By 2050, the older population will reach 88.5 million, representing 20% of the US census.[1,2] In 2060, nearly 25% will be over age 65. Historically women greatly outnumbered men in the population over age 65. With the improvements in health care, this gender gap is narrowing.

The US will also see an increase in the oldest-old age groups. Currently 12% of older women and 9% of older men are over age 85 (Figure 2).[4] By 2050, it is projected that 1 in 5 older women and 1 in 7 older men will be over age 85. This shift is significant as the oldest old will experience the highest rates of disability, chronic disease, and dependency, adding pressure to the health care system at both state and federal levels.[2]

Missouri's Aging Population

Missouri's aging population projections are nearly identical to national trends. In 2000, the older adult population in Missouri numbered 756,000 (13%) and was predicted to surpass one million by 2020.[5] We exceeded that number, and currently 1.3 million (19%) of the 6.8 million Missouri residents are 65 or older. About 2% are over age 85.

Life expectancy as of 2023 is 74.6 years in Missouri, compared to 76.3 nationally. This is the lowest in over 40 years and is attributed to COVID-19-related deaths and record high opioid overdose

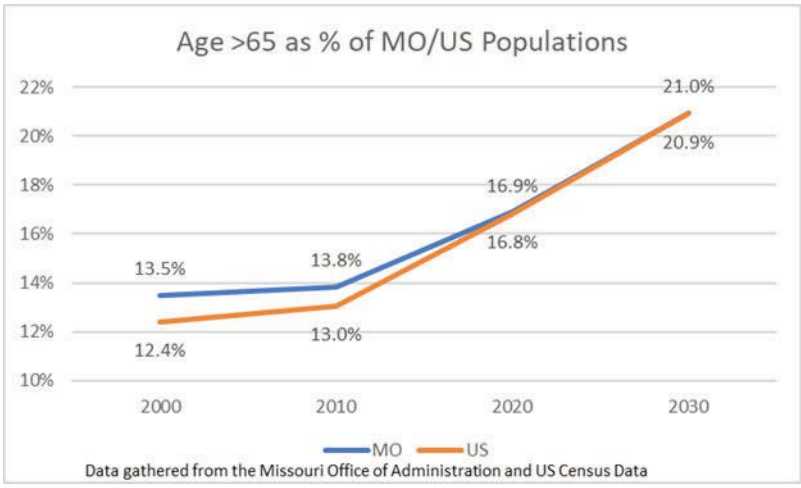


Figure 1. Age >65 as % of MO/US Population

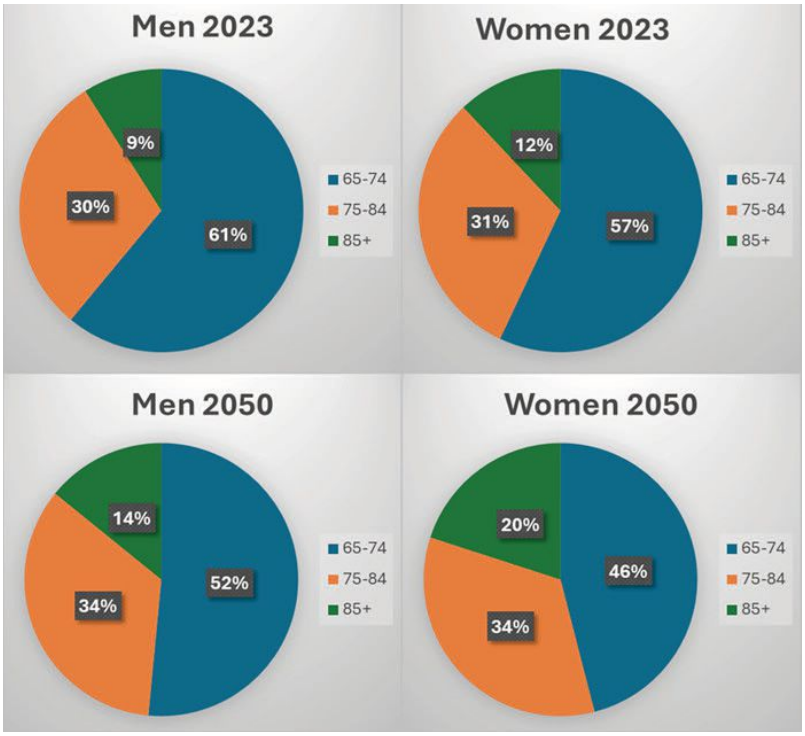


Figure 2. US Population over age 65 yrs: % by age category

deaths.[6] Due to declining birth rates, for the past three years the death rate of 1.16% is higher than the birth rate.

Heart disease and cancer contribute to about 40% of Missouri deaths over age 65 with Alzheimers disease being the third highest cause of death in those over age 95. Approximately 130,000 Missouri residents have the diagnosis of Alzheimer's dementia and 17% of those are enrolled in hospice care.[7,8]

Economic Impacts of an Aging Population

The financial impact of an aging society is in part driven by greater healthcare utilization and the rising complexity of care among older adults. Research indicates that individuals aged 65 and older visit physicians 20% more frequently than younger adults and have hospitalization rates nearly three times higher. A 2019 Kaiser Family Foundation study found that Medicare spending per beneficiary averages $7,566 for those aged 65 to 74 but nearly doubles to $16,145 for individuals aged 85 and older.[9]

The demographic shift will impact the healthcare infrastructure and long-term care resources for Missouri's aging residents.[5] For sustainability, our healthcare system will require adaptations in service delivery, workforce expansion, and policy reform to accommodate the needs of our older adults. Government spending on Social Security and Medicare is projected to rise, and state and local governments will need to allocate more resources toward healthcare and pensions for retirees. According to the Congressional Budget Office, federal expenditures on major health programs for older adults, including Medicare and Medicaid, are expected to increase from 6.6% of the gross domestic product (GDP) in 2020 to 9.2% by 2050.[10]

About 30% of the Missouri population lives in rural areas. Rural Missourians face higher health disparities than their urban counterparts.[11] These disparities include higher rates of chronic diseases including arthritis, asthma, cardiovascular disease, and diabetes. Since 2005, Missouri has lost eight rural hospitals with a total loss of 351 beds.[12] According to a review by the Chartis Group, 42% or 26 of Missouri's remaining rural hospitals are at risk of closing.[13] Missouri has recently approved the expansion of Medicaid eligibility which should significantly increase the need for rural hospitals.

In 2023, Missouri had a per capita personal income of $61,302 (compared with the national per capita of $68,531), ranking it thirty-fourth in the nation. The average retirement income in Missouri is $51,254, with $28,204 from retirement and $23,050 from Social Security income.[14] Housing costs for older Missourians consume around 29% of monthly income compared to the national average of 34%. Although Missouri ranked the sixth lowest state in cost of living, 9% of residents over age 65 live in poverty.[8]

Health care costs contribute to the financial burden faced by older adults. Overall, 31% of Missourians have over $1,000 and 10% have more than $5,000 in medical debt. About three-quarters report that debt was due to a single or recent medical expense. Almost 46% of the elderly reported that dental care contributed to their medical debt.[15] About 3% of Missourians reported an inability to see a doctor due to financial limitations.[16]

Aging Vulnerabilities

Cost of care is a major concern for older adults. More than 75 percent of health care costs are due to chronic conditions.[17] We know that poverty is associated with increased exposure to environmental risks, poorer health related behaviors, increased risk of chronic disease and mortality, poor health outcomes, disabilities, homelessness, and physical and cognitive decline.

An increased life expectancy has resulted in a higher prevalence of chronic and degenerative diseases.[9] The CDC reports that 80% of older adults nationwide have at least one chronic condition and 50% have at least two.[18] In a survey of older Missourians, 95% were found to have one chronic condition, more than 80% had at least two, and about 65% had at least three.[17] Among chronic comorbidities, obesity is a coexisting risk factor to many other health conditions. Missouri has an obesity rate of 37% in adults and continues to outpace the national average of 34%. According to the United Health Foundation's Senior Report, Missouri ranks thirty-third overall on measures of health determinants and outcomes.[19]

The number of Missourians over 65 with Alzheimer's disease will increase between 2010 and 2025, from 110,000 to 130,000.[19] Cognitive impairment can heighten financial vulnerabilities. Older adults may face difficulties in managing money and making investment decisions, increasing the risk of financial exploitation. Conversely, many older individuals provide care and financial support for younger generations, creating a complex dynamic within multigenerational households.

Despite more family involvement in elderly caregiving, older adults remain at high risk for abuse. As physical and cognitive abilities decline and dependence increases, the risk of elder abuse rises. In 2011, there were 17,571 reports of elder abuse in Missouri. Ten years later there were 29,000 reports and in 2025 DHSS predicts 33,000 reports.[20] Of these reports, nearly 75% were substantiated after investigation.[19]

Aging Workforce Challenges

Adults over age 65 account for 6% of the Missouri labor force with roughly 14% in this age group being employed.[21] Employers will need to adapt to an aging workforce by addressing increased labor costs, which include salaries, health benefits, and retirement contributions. Additionally, as older workers retire, labor shortages in key industries may emerge, requiring workforce development strategies to ensure economic stability.

As older adults become too ill, frail, or cognitively impaired to care for themselves, the need for direct caregiving grows. As the population of Missouri ages, so do our caregivers. Currently about 60% of Missouri caregivers are over 60 years old. Predominantly, these caregivers are family members who may also be managing their own health care needs.[11]

Unpaid family caregivers are an essential and often unrecognized workforce. The demands of caregiving can take a serious toll on physical and mental health, as well as financial stability. In the United States, many working-age caregivers, especially women, reduce their paid work hours, leading to diminished earnings and retirement benefits. According to the American Association of Retired Persons, caregivers in the US lose an average of $5,000 in income annually, with women disproportionately affected.[18] Additionally, caregivers bear direct costs such as home modifications, food, cleaning supplies, and other necessities for care recipients.

As part of the federal American Rescue Plan under the Older Americans Acts, funding has been allocated to the National Family Caregiver Support Program (NFCSP) to assist family and informal caregivers in covering costs for in-home support services, including

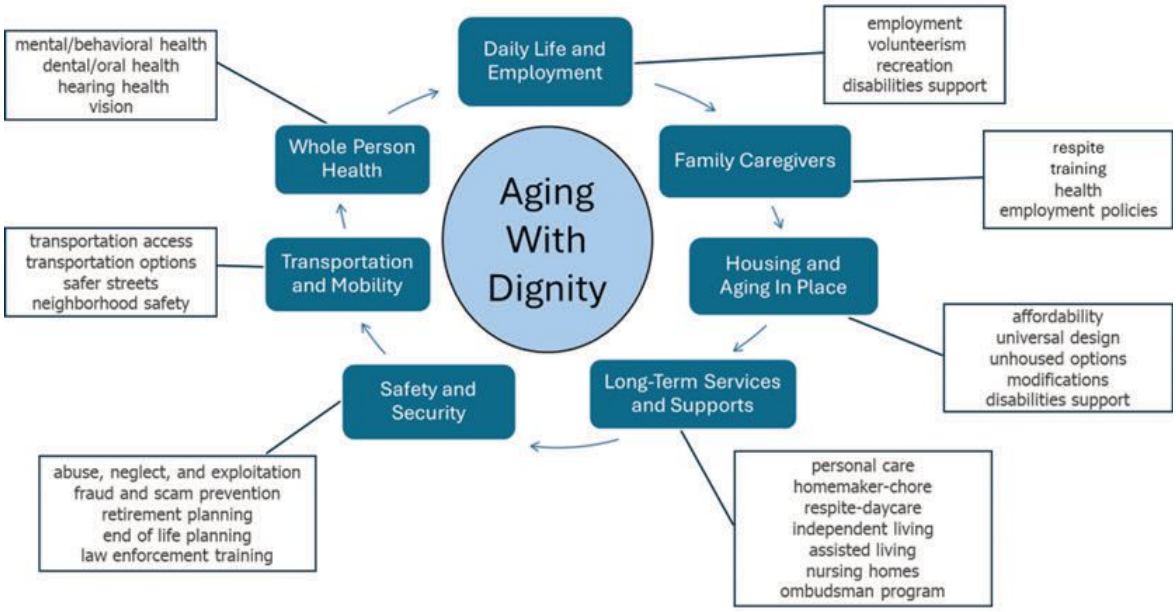


Figure 3. Aging with Dignity report outlines its seven broad goals: Daily Life and Employment, Family Caregivers, Housing and Aging In Place, Long-Term Services and Supports, Safety and Security, Transportation and Mobility, and Whole Person Health

respite care and training. The NFCSP provides grants to states to fund caregiver services, including respite care, to help family and informal caregivers keep older adults in their homes for as long as possible.

Geriatrics Workforce in Missouri

A shortage of healthcare workers, especially nurses and physicians will impact an increasing number of older adults as their medical requirements grow. There is an increasing need for medical providers who are trained to care for the complexities of the aging population. The demand for professional caregivers is also rising. According to the Bureau of Labor Statistics, home health aides and personal care workers are among the fastest-growing occupations, with more than one million new job openings projected by 2029.[23] Home health agencies rely on Medicaid and Medicare to cover roughly three-quarters of their workers' wages.

Geriatricians are specialists in the care of older adults. These physicians may be board certified in geriatric medicine following internal medicine or family medicine residency or board certified in geriatric psychiatry following general psychiatry residency training. There are 164 geriatric medicine and 61 geriatric psychiatry fellowships nationally. These fellowship programs are one year in duration. In Missouri there are three geriatric medicine fellowships with a total of nine positions and in Kansas City, Kansas, one program with four positions.[24] There is one geriatric psychiatry fellowship in Missouri offering three positions each year. Unfortunately, many of these positions remain unfilled both locally and nationally.

Currently, Missouri has 109 board certified geriatricians and 21 board certified geriatric psychiatrists.[25] In addition, there are 118 certified gerontological nurse practitioners in Missouri and 336 advance practice nurses identified as working in the field of gerontology.[26] Clearly there are not enough specialty trained providers in the field for the growing older population. National and regional efforts have thus focused on educating the health care workforce in aging-related care, as it is expected that most elderly will see non-geriatrician physicians or nurse practitioners.

Missouri Senior Living and Support Services

In 2024, Governor Parson signed an executive order to establish a Master Plan on Aging by December 2025 to reduce age and disability discrimination, eliminate barriers to safe and healthy aging, and help

Table 1. Department of Health and Senior Services Resources

MO DHSS Senior Resource	Contact	Phone
Division of Senior and Disability Services	health.mo.gov/seniors/ hcbs/	866-835-3505
Missouri Senior Resource Line	https://health.mo.gov/seniors/senior-resource-line.php	800-235-5503
Adult Protective Services	health.mo.gov/abuse	800-392-0210
Alzheimers State Plan	MOAlzStatePlan@health.mo.gov	573-526-4542
Office of Long-Term Care Ombudsman	LTCOmbudsman@health.mo.gov	800-309-3282
Bureau of Senior Programs	info@health.mo.gov	573-526-4542
Silver Haired Legislature	SHL@health.mo.gov	573-751-2413
Area Agencies on Aging	info@health.mo.gov	573-526-4542
Home and Community Based Services	LTSS@health.mo.gov	866-835-3505
Nursing Homes and Other Care	info@health.mo.gov	573-751-6400
Missouri Caregiver Program	https://cabllc.com/caregiver-training-and-relief-program/	573-415-7343
State Health Insurance Assistance Program	missouriship.org	800-390-3330
Senior Community Service Employment Program	scsepemployment@health.mo.gov	573-526-4542

Missourians age with dignity.[27] A statewide needs assessment was conducted via 12 Town Hall sessions with input from more than 1,700 individuals to develop this Plan. The resulting Aging with Dignity report outlines its seven broad goals: Daily Life and Employment, Family Caregivers, Housing and Aging In Place, Long-Term Services and Supports, Safety and Security, Transportation and Mobility, and Whole Person Health (Figure 3).

Services for older adults in Missouri are largely under the authority of the Missouri Department of Health and Senior Services (DHSS) which oversees the Senior & Disability Services and the Area Agencies on Aging (AAAs). Missouri's 10 AAAs provide senior programs and services such as legal, caregiver, transportation, and home modification assistance in their local areas. Information is available through the Missouri Senior Resource Line (Table 1).[28]

The Senior and Disability Services manages concerns about elder abuse and neglect through Adult Protective Services. Reports can be made to the Adult Abuse and Neglect Hotline. Since 1975, DHSS also oversees The Long-Term Care Ombudsman Program to investigate and respond to complaints in long-term care facilities. Volunteers provide advocacy and assistance to residents and families with their concerns. DHSS supports the Silver Haired Legislature (SHL), a body of formally elected but voluntary citizens over age 60 who support each AAA in identifying legislation of importance to the aging community. SHL focuses on policy priority areas that affect seniors in their communities.[29]

Missouri has approximately 1,100 licensed chronic care facilities with a capacity of 80,000 beds. The state's 300 long-term care, 208 adult day care, 361 memory care, eight long-term acute care, 134 hospice, 126 home health care, and 33 acute rehab centers provide Medicare and/or Medicaid services, largely to the older adult population.[30,31] Missouri is also home to three PACE (Program for the All-Inclusive Care of the Elderly) sites located in St. Louis, Kansas City, and Springfield. PACE is a comprehensive health and social care model administered to Medicare/Medicaid dual eligible adults over age 55. PACE provides services utilizing an adult day center structure with the goal of maintaining independent home living.

Missouri Medicare and Medicaid Services

Medicare Parts A and B cover health care services such as inpatient hospital, nursing home care, hospice care, medical tests, surgery, outpatient visits and home care services for homebound beneficiaries. Part C, also known as Medicare Advantage, expands traditional benefits with coverage for items such as hearing aids, dentures, and glasses. Part D provides prescription drug coverage, and in 2025 will eliminate the "donut hole," by capping the out-of-pocket annual prescription drug costs at $2,000 per person.

In 2022, 19% of the Missouri population received Medicare or a combination of Medicare and private insurance.[32] Eleven percent had Medicaid alone or Medicaid plus private insurance and 1% of Missouri residents were "dual eligible" meaning they qualified for both Medicare and Medicaid coverage.

Missouri SHIP (previously Missouri CLAIM) is the official Missouri State Health Insurance Assistance Program (MO SHIP) and has been providing free and confidential Medicare coverage counseling for the past

30 years. Over 200 volunteers provide information on Medicare, Medicaid (MO HealthNet), Medicare Advantage Plans, Part D Drug Plans, Medigap, and supplemental insurance programs for seniors. Missouri HealthNet offers three managed care health plans for income qualifying older adults: Healthy Blue, United Healthcare, and Home State Health.

There are 134 Medicare Advantage plans and 10 Medigap plans offered in Missouri for 2025. Medicare Advantage Plans come in five forms: Health Maintenance Organizations (HMO), Preferred Provider Organization (PPO), Private Fee For Service (PFFS), Special Needs Plans (SNP), and Medical Savings Account Plans. Medicare Advantage plans have grown in popularity, with over 30.8 million enrollees in 2023, covering more than 50% of all Medicare recipients[32]. There are eight companies offering Medicare Advantage programs in Missouri with varying plan options based on geography within the state: Aetna Medicare, Anthem Blue Cross and Blue Shield, Anthem HealthKeepers, Cigna, Essence Healthcare, Humana, UnitedHealthcare and WellFirst Health.[33]

Special Needs Plans (SNPs) provide supplemental benefits and services to those with specific chronic diseases or care needs. There are three groups served by SNPs: Dual Medicare/Medicaid Eligible SNP (D-SNP), those with a qualifying Chronic Condition SNP (C-SNP), and those who reside in Institutional care (I-SNP)

To be eligible for Medicaid, older adults must have an income below 85% of the federal poverty level ($15,650 in 2025 for a household of one). Of Missourians who receive Medicaid, 10% (about 91,000), are over age 65 but consume 19% of the Medicaid spending budget.[19,34] In 2023, Missouri Medicaid expenditures for older adults were $1.73 billion ($1,600 per month per beneficiary) and accounted for 35% of the Missouri state budget. Two-thirds of that funding was provided via federal subsidies.[34]

Medicaid beneficiaries are eligible for the Home and Community-Based Services (HCBS) program which provides financial assistance for household chores, shopping, transportation, and personal care services, and other services within their own homes or communities. This is more cost-effective than care in institutional settings. Medicaid supports this assistance through their community-based long-term services and supports (LTSS) program.

Missouri Veterans Population

In Missouri, 2% of the population receives health insurance via the military or Veterans Affairs systems.[34] Missouri has the sixteenth highest veteran population in the nation with over 340,000 residents, about 7% of the adult population. This is 1% higher than the US average of 8%.[35] Nationally and in Missouri, about half of veterans are over age 65. Although the veteran population is declining, veterans will be utilizing greater health care services as they age.

Veterans have access to a range of benefits and services provided by the Department of Veterans Affairs (VA) to address their healthcare, social, and financial needs. There are four VA medical centers and over 40 Community-Based Outpatient Centers (CBOCs) and other community healthcare facilities in Missouri. Long-term care services, including nursing homes, residential care, and home-based community services, are available for eligible veterans who require ongoing care. Missouri hosts seven Veterans Homes, with a total 1,238 long term care beds, that are located in Cameron, Cape Girardeau, Mexico, Mount Vernon, St. James, St. Louis, and Warrensburg.[36]

The VA Aid and Attendance (A&A) benefit provides additional financial assistance to veterans receiving a pension who require help with daily activities such as bathing, dressing, or feeding, while the Housebound Benefit supports those confined to their homes due to a permanent disability. The VA also conducts geriatric research and offers specialized programs to address the unique health challenges faced by aging veterans.

The Non-Service-Connected Pension provides financial aid to veterans with limited income who are permanently disabled or aged 65 and older, even if their disabilities are not related to military service. Veterans supporting a dependent parent may qualify for the Dependent Parent Benefit, which offers financial assistance for their care. For those unable to maintain substantially gainful employment due to service-connected disabilities, the Total Disability Individual Unemployability (TDIU) program compensates them at the 100% disabled rate, regardless of age. To access these benefits, elderly veterans or their families would apply through a local VA office.

Conclusion

As Missouri's population ages, we must be ready for the health care and financial impact of this demographic

change. The complex social and medical needs of our older adults will benefit from coordinated state and federal services. Resources and support for older adults through the Missouri Department of Health and Senior Services, the Senior & Disability Services and the Area Agencies on Aging will be needed to successfully implement the Master Plan on Aging in our state. These efforts will reduce age and disability discrimination and eliminate barriers to safe and healthy aging, and help Missourians age with dignity.

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Loneliness and Social Isolation in Older Adults

by Jafar Ohiokpehai, MD, Julie K. Gammack, MD, Mehwish Siddiqui, MD & Tarisai Nyahoda, MD

Future research should explore the most effective programs to reduce loneliness and social isolation to improve the health of our older Missouri population.



Jafar Ohiokpehai, MD, (pictured), Geriatric Medicine Fellow, Division of Geriatric Medicine is at the SSM Health/Saint Louis University School of Medicine, St. Louis, Missouri. Julie K. Gammack, MD, CMD, FACP, Professor of Medicine, DIO, Sr. Associate Dean for Graduate Medical Education, is at the SSM Health/Saint Louis University School of Medicine, St. Louis, Missouri. Mehwish Siddiqui, MD, Assistant Professor of Medicine, Division of Geriatric Medicine, is at the SSM Health/Saint Louis University School of Medicine, St. Louis, Missouri. Tarisai Nyahoda, MD, Assistant Professor of Medicine, Division of Geriatric Medicine, is at the SSM Health/Saint Louis University School of Medicine, St. Louis, Missouri.

Abstract

Loneliness is a distressing feeling that accompanies the perception that one's social needs are not being met by the quantity or the quality of one's social relationships. It is a subjective experience of a perceived discrepancy between the preferred and actual level and quality of social interaction.[1] In contrast, social isolation is an objective lack of meaningful and sustained social contacts, interactions, networks or belonging. Social isolation describes a paucity of social relationships, while loneliness depicts the lived experience and recognition of that absence.[2]

Although sometimes used interchangeably, loneliness and social isolation are unique conditions that share overlapping features, risk factors, and consequences. One may feel lonely with or without being socially isolated, just as one may or may not feel lonely despite being alone. These conditions do often coexist, as demonstrated in a study of older adults during the COVID-19 pandemic. In this study, both loneliness and social isolation were present in one-third of individuals; one-third of those who were lonely were also socially isolated, and 94% of those who were socially isolated were also lonely (Figure 1).[3]

Loneliness is neither a disease nor classified as a mental health disorder. Some have suggested that loneliness is a new geriatric syndrome: a health condition highly prevalent in older adults that is multifactorial in cause and contributes to adverse health outcomes. The COVID-19 pandemic unmasked and magnified the detrimental effects of social isolation and loneliness in older populations. We are learning more about the physical and psychological impacts of loneliness and ways to mitigate social isolation.

Epidemiology and Risk Factors

Currently, 18% of Missouri residents are age 65 or older, an increase from 14% measured in 2010. In the US, 29% of people live in single-person households. This number is increasing and has particularly grown during the COVID pandemic. Using "lives alone" as a surrogate for loneliness, a study by the Chamber of Commerce ranked St. Louis (City) to be the third "loneliest" city in the US with 47.5% of the population living alone.[4] Springfield and Kansas City ranked twenty-ninth and thirtieth respectively with 39% of the population living alone. St. Louis ranked first in the country for men living alone. Due to differing definitions and measurements, it can be difficult to quantify and compare loneliness and social isolation between different

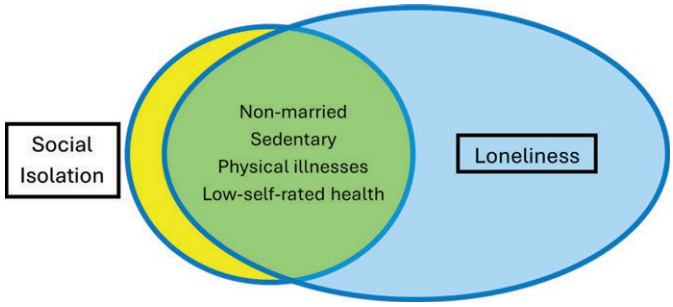


Figure 1, Coexisting Social Isolation and Loneliness[3]

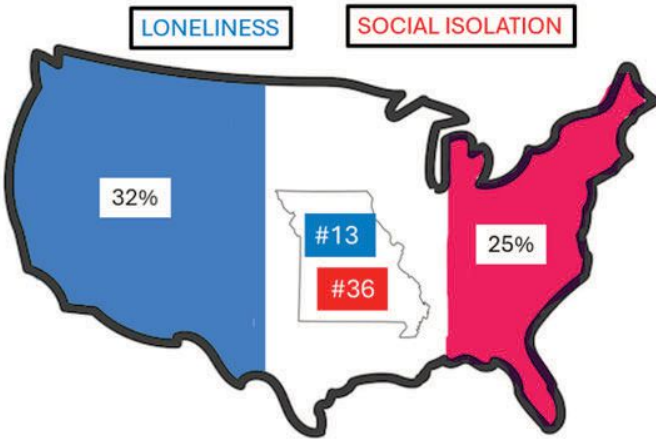


Figure 2. U.S. and Missouri Loneliness and Social Isolation Demographics

populations. However, one database from United Health suggests that Missouri is the thirteenth loneliest and thirty-sixth most socially isolated state (Figure 2).[5]

Social isolation and loneliness are common problems for older adults and are a growing public health concern. An estimated 28.5% of older adults worldwide are likely to experience loneliness. The National Academies of Sciences, Engineering and Medicine (NASEM) reported that 32% of older adults report loneliness and 25% are considered to be socially isolated.[2,6] Older adults tend to have an increased risk of social isolation due to functional limitations, loss of spouse, loss of relatives and friends, fewer resources to provide physical or emotional support, and lack of access or skills to utilize technology or transportation services. Factors that make older adults at increased risk of loneliness include lower socioeconomic status, being widowed, living physically isolated, lack of transportation, and sensory impairment. Older adults also have increased risk of frailty which is independently associated with loneliness.[7]

Consequences of Social Isolation and Loneliness

It is reported that the negative impact of loneliness on health equates to smoking 15 cigarettes a day. Loneliness is linked to poorer self-rated health status. Furthermore, loneliness increases adverse health outcomes such as frailty, sleep disturbance, obesity, cardiovascular events, and immune dysfunction. Chronic loneliness has also been associated with increased prevalence of frailty and depression.[8] Those who suffer a high degree of loneliness are twice as likely to develop cognitive impairment and dementia.

Being socially isolated is associated with significantly higher rates of developing loneliness and depression.[8] Socially isolated older adults also have consistently worse mental health and cardiovascular health outcomes.[9] In one meta-analysis, adults with adequate or strong social relationships had a 50% increased likelihood of survival compared with those with weaker or insufficient relationships.[10] Frail older adults are at an increased risk of mortality, and this risk is even higher for those who are also lonely or socially isolated.[11]

To optimize well-being and health outcomes in older adults, it is critical to identify those who have loneliness and/or social isolation as well as those who are at risk of becoming lonely and socially isolated. Identifying and addressing the risks factors and contributors to these conditions offers the possibility of improved physical, functional, and cognitive outcomes.

Loneliness and Social Isolation Screening

There is currently no gold standard in identifying loneliness, but there are several screening tools that are frequently used in clinical and research settings. For a scale to be useful it should be reliable, well-validated, brief, easy to use, and require minimal training, especially if the scale is self-administered. The most common loneliness scales include single-item questions of loneliness, the UCLA Loneliness Scale, the De Jong Gierveld Loneliness Scale, and the Campaign to

Table 1. Loneliness Scales

Loneliness Scale	Items	Score Range	Phrasing	Notes
Single Question	1	Yes/No	Negative	Under reporting
UCLA-3 Item	3	3 (low) – 9 (high)	Negative	Under reporting
Campaign to End Loneliness	3	0 (low) -12 (high)	Positive	For measuring change; not screening
De Jong Gierveld	6	0 (low) – 6 (high)	Negative /Positive	For research, complex scoring

End Loneliness Tool (Table 1).[12] Common tools for measuring social isolation include the Berkman–Syme Social Network Index, Lubben Social Network Scale, Duke Social Support Index, and Multidimensional Scale of Social Supports. Each of these tools have their respective strengths and limitations.

Loneliness Assessment

Single-item screenings for loneliness universally include the word "lonely." Questions such as, "Do you feel lonely?" "In the last two weeks, have you felt lonely" or "How many days have you felt lonely during the last week?" are quick and useful when getting an affirming response. This approach may lead to under-reporting due to the negative stigma associated with being lonely, negative phrasing of the question, and the potential challenge for a person to identify their feelings as loneliness.

The UCLA 3-Item Loneliness Scale asks three questions and has been widely studied across diverse populations.[13] It can be applied to both community-dwelling and institutionalized older adults. Weaknesses include direct questions with negative wording that may cause under-reporting, similar to single-item questioning.

The De Jong Gierveld Loneliness Scale is a 6-Item tool with three possible responses. It is more difficult to score and may be challenging to understand for individuals with cognitive impairment. Its strengths include measuring both social isolation and emotional loneliness. This tool contains both negative and positive phrasing and has been used primarily for research purposes.[14]

The Campaign to End Loneliness Tool is very concise and includes three questions that have only positive wording. Unlike the De Jong Gierveld Loneliness scale, it may not discern the type of loneliness an older adult is experiencing. This scale was developed to measure change and was not intended as a screening tool.

Social Isolation Assessment

Social isolation may be quantified on an individual or population level. Population assessment uses multiple variables such as: living in poverty, living alone, marital status, having never married, having a disability, and having impairment in independent living. These data are often extracted from the US Census and other federal or state databases. Using these criteria, a social isolation index or score can compare the degree of social isolation in one population to another group. Missouri's social isolation index has risen from 53 (0 low – 100 high) to 64 over the past 15 years and currently ranks thirty-sixth in the US in social isolation of its population.[5] Higher social isolation predicts poorer health outcomes and increased mortality.

On an individual level, screening for social isolation often quantifies both the perception of social support and the quantity of interactions. The Berkman–Syme Social Network Index is a 4-Item "how often" questionnaire focusing on the frequency of social contacts in a non-elderly adult population.[15] This tool was recommended by the Institute of Medicine as appropriate for inclusion in the electronic health record.

The Lubben Social Network Scale (10 and 6-Item) is derived from the Beckman-Syme index but developed for use in older adults. This tool focuses more on the quality and frequency of interactions than the type of social activity.[16] The index is very useful in large surveys and can be beneficial for screening

institutionalized and dependent seniors. It also assesses social isolation and loneliness. A weakness is that it does not evaluate emotional loneliness and, therefore, may not capture feelings of isolation if the older adult has few social relationships.

The Multidimensional Scale of Perceived Social Support (MSPSS) is a 12-Item questionnaire using a 7-point Likert scale of perceived adequacy of social support from family and friends. This tool does not assess other social activities. The Duke Social Support Index is a 35-Item measure of various dimensions of social networks, interactions, and supports requiring a lengthy interview. An abbreviated 11-Item scale has been developed but the complex scoring system limits use as a clinical screening tool.

Interventions to Reduce Loneliness and Social Isolation

Various patient-focused and community-based initiatives have emerged to support the health, well-being, and social engagement of older adults. On an individual level, these programs focus on improving physical fitness, mental health, and social connectivity, ensuring that older adults maintain independence and a high quality of life.[17] At the population level, initiatives focus on resources and infrastructure to support community programs for the most vulnerable and underserved.

Patient-Focused Initiatives

Measuring the benefit of programs at an individual level is difficult, as the literature is of limited quality or has mixed social and health improvement outcomes.[18] The challenges of these studies include limited long-term follow-up, limited age range of participants, variability in the definitions of social isolation and loneliness, variability in measurement tools and outcome measures, and small sample sizes. Studies have noted that interactive, group-based activities focused on education or socialization are of higher success.[6]

For veterans, the US Department of Veterans Affairs (VA) offers recreational therapy programs aimed at improving physical and mental well-being. Community libraries offer enriching programs for older adults on practical topics such as tax preparation and gardening. The St. Louis and Kansas City regions offer mobile library service for homebound adults, book discussion kits to facilitate reading groups, and offer large-print media resources. Libraries offer Chromebook and Wi-Fi hotspot kits to improve home internet access for seniors and provide opportunities for online learning.

In Missouri and Southern Illinois, SSM Health is leading efforts to respond to loneliness and isolation in the greater St. Louis region. The program, called Visit a Bit, provides coordinated weekly visits by a volunteer for older adults that are living alone or in a senior community. Volunteers engage in social activities and provide education on healthy habits, while creating an opportunity to build rapport and companionship.

Another initiative in the Midwest region to address loneliness in older adults is through Care Connection for Aging Services. This non-profit organization serves 13 West Central Missouri counties. They provide an array of services including recreation, fitness and nutrition services, family/caregiver support programs, benefits counseling, and Medicare program navigation.

Increasing social engagement through volunteerism is another way of reducing isolation. Older adults who volunteer as few as two hours per week have a significantly lower level of loneliness.[19] Many churches, long-term care facilities, and hospitals welcome older volunteers. The State of Missouri Long-Term Care Ombudsman Program trains volunteers to provide advocacy for residents residing in nursing homes. In Columbia, the Central Missouri Community Action center offers volunteer programs and services that support local families.

Population-Based Initiatives

At a population level, use of community-based networks such as senior living communities, community centers, and fitness programs, have demonstrated reduction social isolation. A successful example of a program available for community-dwelling older adults is the SilverSneakers senior fitness program available via Medicare Part C coverage. This program provides access to fitness classes specifically designed for older adults, promoting physical activity and wellness. Additionally, free group exercise sessions are available to members, encouraging social interaction while enhancing physical health.[17]

Initiatives like the American Association of Retired Persons (AARP) Network of Age-Friendly Communities (AFCs) create opportunities for older adults to receive affordable housing, safe outdoor spaces, convenient transportation, social participation opportunities, and accessible health and wellness services. Compared to control communities, AFCs (including nearby

Springfield, IL and Nashville, TN) significantly improved social interactions in older adults.[20]

Another population-based method of addressing loneliness in older adults is Person-Centered Integrated Care (PIC) Networks that deliver preventive care at the community level. These networks promote healthy aging through multi-domain assessments, individualized care plans, and coordinated resource management. Although most described PIC networks are found in Europe or the United Kingdom, some well-describe networks are established in the U.S. including the Program for All-Inclusive Care of the Elderly (PACE), Naturally Occurring Retirement Communities (NORC), Village to Village Networks (V2V), and Community Aging in Place Advancing Better Living for Elders (CAPABLE) communities. Missouri is home to three PACE sites (St. Louis, Springfield, Kansas City), one NORC (St. Louis), one V2V network (St. Louis), and two CAPABLE communities (St. Louis, Kansas City).[21]

Community Health Workers (CHWs), defined by American Public Health Association as, "a frontline public health worker who is a trusted member of the community" are increasingly utilized by public health organizations to bridge the gap between the community and healthcare systems. CHWs provide health education, outreach, advocacy, and assistance in navigating social and medical systems. A study of CHW during the COVID-19 pandemic identified loneliness as a common theme addressed during client visits.[22] Use of CHWs is considered a cost-effective strategy to improve the management of chronic conditions in underserved communities. The Missouri Department of Health and Senior Services has adopted this model and since 2019 provides both state certification of CHWs and CHW provider training programs. There are currently 26 CHW certified training programs in Missouri.[23,24]

For those in assisted living and skilled nursing facilities, social activities are regularly accessible on site and an integral component of the care model. To foster socialization, residents can routinely participate in exercise and music therapy, movies, games, arts and crafts, religious services, and pet therapy. Pet ownership has been shown to reduce loneliness, but the effect appears to be mitigated by social factors and male gender.[25] Pet therapy has been associated with a 35% reduction in loneliness and depression in older adults.[26] Use of robotic animals for companionship and to reduce depression has also been studied. Acceptance of the robotic animal is often positive, but high cost and limited meaningful outcomes are barriers to adoption.[27]

Technology Initiatives for Social Engagement

Technology, especially social media and video calling, allow older adults to maintain meaningful connections with family and friends. These programs apply interactive technologies to support behavioral changes in cognition, physical, and social interaction. Access to online classes, activities or groups can provide a sense of community and connection for individuals. These platforms can also be used to screen for healthcare needs among high-risk individuals and identify resource needs to maintain independence and well-being. To date, most studies of technology to reduce loneliness and social isolation are small, of low quality and inconclusive.[28]

Common barriers to the use of technology are the cost of equipment, access to the internet, and individual skill and willingness to utilize the technology. Telephone or virtual coaching may be an easier method for some older adults to address wellness and loneliness through coach-initiated encounters. A systematic review of telephone-based coaching to promote safe physical activity demonstrated improvement in moderate-to-vigorous physical activity, overall well-being, and quality of life which could indicate improved socialization.[29]

Virtual Coaching and/or empathy driven, conversational artificial intelligence (AI) are technological approaches that may be effective in the management and prevention of social isolation. Seva, an AI-powered app, serves as a virtual companion, engaging users in conversations about a wide range of topics, from weather and sports to history and movies. This app provides companionship and is available for free on both Android and Apple smartphones. In addition to conversation, Seva can help seniors manage daily tasks by reminding them to take medication and attend important social or medical appointments.[17] Whether in a traditional telehealth format or AI-enabled application, these technological methods highlight a novel strategy to curb social isolation.

Other helpful apps include Pocket Physio, which offers guided exercises to improve physical health, and Lumosity, a cognitive training app designed to improve memory and mental agility through games. Additionally, the Imutt app provides a virtual pet experience, allowing users to interact with and care for a digital dog, which can help reduce stress and increase feelings of companionship.[17]

Conclusion

Loneliness and social isolation are commonly seen in the older adult population. The presence of these conditions predicts poorer health outcomes. The use of standardized screening tools can help identify those individuals who are at risk for or who currently experience loneliness and social isolation. Interventions to improve social engagement can be directed at an individual or can be integrated into the social support systems of a community. Use of technology can allow isolated individuals to access and expand their social networks with the hope of reducing loneliness. These initiatives not only promote physical well-being but also ensure that older adults remain socially connected and mentally engaged, to enhance their overall quality of life. Future research should explore the most effective programs to reduce loneliness and social isolation to improve the health of our older Missouri population.

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Cognitive Stimulation Therapy: Making a Difference for Older Missourians Experiencing Dementia

by Ebow Tawiah Nketsiah, MSW, Marla Berg-Weger, PhD & Max Zubatsky, PhD

Cognitive Stimulation Therapy is shown to improve cognitive function, quality of life, and physical health in individuals with dementia.



Ebow Tawiah Nketsiah, MSW, (pictured), is a PhD Candidate, Saint Louis University School of Social Work, St. Louis, Missouri. Marla Berg-Weger, PhD, LCSW, is Professor Emeriti, Program Director, Geriatric Workforce Enhancement Program, Saint Louis University School of Social Work, St. Louis, Missouri. Max Zubatsky, PhD, LMFT, is Associate Professor, Director, Medical Family Therapy Program and Aging & Memory Clinic, Department of Family & Community Medicine, Saint Louis University School of Medicine, St. Louis, Missouri.

Abstract

Cognitive Stimulation Therapy (CST) is an evidence-based, non-pharmacological intervention designed to enhance cognitive function, quality of life, and emotional well-being in individuals with dementia. With the high prevalence of dementia and Alzheimer's disease in Missouri, CST provides an effective approach to address dementia-related symptoms. This paper aims to inform healthcare professionals about the benefits and practical applications of CST, demonstrating its effectiveness in addressing the cognitive, emotional, and social needs of dementia patients. Despite the heavy reliance on pharmacological treatments for dementia, CST stands out as a viable alternative, offering improvements in memory, language, executive function, and alleviating symptoms of depression and anxiety. CST's adaptability across diverse settings, including community centers, residential care homes, and virtual platforms, ensures broad accessibility. Research and training initiatives led by Saint Louis University further highlight CST's growing role in dementia care within the US healthcare system. Embracing CST in clinical practice is not just an option but a necessity to improve the lives of individuals with dementia and alleviate the growing burden on healthcare systems in Missouri and beyond.

Dementia and Alzheimer's Prevalence in Missouri

The trend of dementia in Missouri reflects a significant and growing public health concern, mirroring broader national trends in the United States. As the population ages, the prevalence of dementia, particularly Alzheimer's disease, continues to rise, placing increasing demands on healthcare systems and families. As of 2020, it was estimated that over 122,000 Missourians aged 65 and older, representing 11.2% of its population are living with Alzheimer's disease, compared to 10.9% in Indiana and 10.2% Washington.[1] The prevalence of dementia and Alzheimer's in Missouri is expected to increase by nearly 8.3% by 2025.[1] Currently, over 223,000 caregivers in Missouri provide a total of 350 million hours of unpaid care, highlighting the significant burden on families and communities.[1] The financial impact is also substantial, with Medicaid costs for caring for people with Alzheimer's reaching $973 million in 2020, projected to increase by 16.8% by 2025. [1] Moreover, the mortality rate for Alzheimer's disease in Missouri as of 2018

stood at 43.1 deaths per 100,000, emphasizing the severe impact of this neurodegenerative condition on the population.[1] Immediate attention is required to address this burgeoning crisis, with a focus on non-pharmacological interventions such as CST.

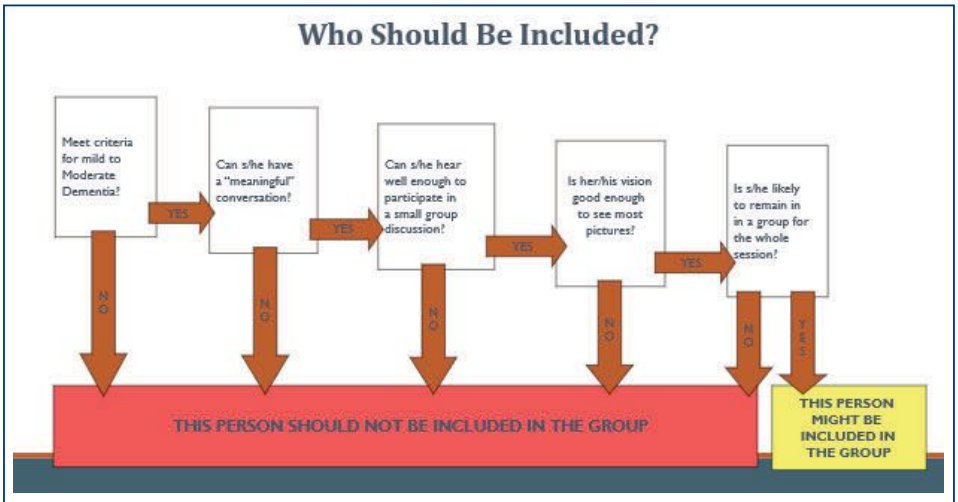


Figure 1. Inclusion Criteria for Participants Entering a CST Group

Lack of Non-Pharmacological Interventions for Dementia

Most of the efforts towards treatment and intervention approaches for dementia and Alzheimer's disease have been pharmacological.[2,3] Present therapies, including acetylcholinesterase and N-methyl D-aspartate (NMDA) receptor antagonists and monoclonal antibody treatments, are based on disease pathophysiology. Treatments work to alter neurotransmitter functions and reduce amyloid plaque burden as the fundamental causes of disease symptoms.[4] Although, these pharmacological and medical efforts have shown promise in improving symptom management and slowing the disease progression, high costs, side effects, and short-term efficacy are associated with several medications.[2,3] However, pharmacological interventions are underutilized and lack widespread implementation. The absence of comprehensive non-drug approaches limits the therapeutic alternatives available to patients and places an increasing strain on healthcare systems.

Non-pharmacological treatments, such as CST, physical activity, and nutritional therapies, have shown promise in improving cognitive function and quality of life. CST has also shown to improve cognitive function, quality of life, and physical health in individuals with dementia.[5,6,7,8,9] These non-pharmacological interventions reduce the likelihood of adverse side effects and some of the challenges that pharmacological intervention present in the treatment of dementia.[2,10]

Cognitive Stimulation Therapy

CST was developed over 20 years ago as a robust evidence-based, non-pharmacological treatment for dementia.[11] Although this intervention originated in the United Kingdom, CST has been implemented in over thirty countries across North America, Africa, Australia, Asia, and Europe.[8,11,12] CST is a 14-session group intervention conducted over seven weeks (twice weekly). The curriculum-based sessions include activities that emphasize memories related to childhood, cuisine, faces, and scenes and participants make connections of these memories to the present through discussions of current events. The intervention is designed to include up to eight individuals per group with mild to moderate dementia and two trained facilitators.

Through exercises that target executive function, multisensory stimulation, skill-building (such as naming, understanding, and language usage), and reminiscence, each session is designed for improving familiarity and cognitive function through group interaction. Each session comprises an opening, theme song, current events, primary themed activity, suggested at-home activities, and a conclusion.[8] CST can be facilitated by a range of experts and trained individuals who work with older adults living with dementia. Healthcare professionals including psychologists, occupational therapists, physical therapists, nurses, and social workers can be trained as CST facilitators. With CST training, family caregivers, professional care workers, and lay persons can co-facilitate sessions. Saint Louis University's Family Center for Healthy Aging is currently the only US-based institution that delivers training for CST practitioners and trainers. This training institute is led by the Saint Louis University CST Training Team in conjunction with the founders of CST at University College in London.[13]



Figure 2. Group members and facilitators engaging in a CST group activity at Saint Louis University.



Figure 3. Cognitive Stimulation Therapy group session led by Janice Lundy, BSW, MA, MHA, Director, Social Work and Geriatric Care Management, and Debbie Hayden, RN, BSN, OTR/L, Director of Occupational Therapy, at Mercy Hospital Perry, Perryville, Missouri.

Studies have consistently revealed that CST improves cognitive function, notably memory, language, and executive function.[14] Beyond cognitive benefits, CST has been linked to improved quality of life, such as improved mood, more social contact, and a greater sense of well-being.[5,6,7,8,15] CST has also been shown to improve symptoms of depression and anxiety, which can be common in people living with dementia.[16] By engaging participants in structured mental activity and social interaction, CST not only improves cognition but increases emotional and psychological well-being, making it an important tool in dementia care. To be most effective, CST requires potential participants to meet a set of criteria to be included in groups or for referrals as an evidence-based intervention (Figure 1). These requirements are:

- Prior diagnosis of dementia
- Adequate hearing and vision to actively and meaningfully engage in a group environment
- Capacity to complete a one-hour group session
- No prior CST group experience

CST in North America

Through presentations, research, group facilitation, and practitioner and trainer training, CST has been introduced in North America over the past decade by faculty and clinicians at the Saint Louis University's Family Center for Healthy Aging (Figure 2). Here in Missouri, the Family Center for Healthy Aging has extensively led researchers to examine the effectiveness of CST and its applicability to the American older population. A CST research and training team includes an interprofessional team of researchers and clinicians at Saint Louis University, Mercy Hospital Perry (Perryville, Missouri), and A.T. Still University and the Northeast Missouri Area Agency on Aging (Kirksville, Missouri) (Figure 3). Since 2015, CST has been researched and implemented across North America with a specific emphasis in Missouri. This research has shown that CST is a cost effective noCST-pharmacological treatment for dementia that improves cognition, quality of life and depressive symptoms among persons living with mild to moderate dementia.[16,17,18,19] CST has also shown feasibility in different settings and population including community-dwelling and residents in long term care facilities.[17,19,20]

Variations in CST

In an effort to broaden the applicability of CST, researchers and clinicians have incorporated and evaluated other domains of cognitive and physical functioning into CST to expand the impact of this intervention, including extending the intervention, adding exercise, and emphasizing theme-based sessions. Maintenance CST (MCST), for example, aims to sustain the therapeutic benefits of the initial therapy by continuing the sessions over a more extended period.[15,21] Individualized CST (iCST) customizes activities of the therapy to meet the specific needs and preferences of each participant, often involving caregivers more directly in the process.[22,23] Other domains incorporated into CST include physical activity, which combines cognitive exercises with physical movement to address both mental and physical health of participants.[24] Virtual CST (vCST) uses technology to deliver the therapy remotely, making it accessible to those who cannot attend in-person sessions especially during the pandemic.[16,25] Recently, a study by Nketsiah et al. incorporated spirituality into CST for person with dementia in Missouri and found significant improvement in depressive symptoms among participants in the study.[16]

Settings for CST

CST can be offered in various settings to accommodate the diverse needs of individuals with dementia. These

settings include community centers, residential care homes, adult day care facilities, memory care clinics, and even in-home environments.[17,19] Each setting provides unique benefits and challenges, adapting the CST program to fit the specific context. CST has also shown effectiveness and adaptability in both rural and urban settings.[16,17,19]

Updated Key Principles

1	Mental stimulation
2	New ideas, thought and associations
3	Using orientation, sensitively and implicitly
4	Opinions rather than facts
5	Using reminiscence as an aid to the here-and-now
6	Physical movement
7	Providing triggers and prompts to aid recall and concentration
8	Continuity and consistency between sessions
9	Implicit (rather than explicit) learning
10	Stimulating language
11	Stimulating executive function
12	Person-centred
13	Respect
14	Involvement and inclusion
15	Choice
16	Fun
17	Maximising potential
18	Building / strengthening relationships

Figure 4. Making a Difference 1- Revised Manual for CST Group Leaders[27]

Emerging Topics

The emergence of vCST and telehealth approaches for dementia has revolutionized the delivery of care for individuals with cognitive impairments. Driven by advances in technology and the increasing need for accessible interventions, especially highlighted during the COVID-19 pandemic, vCST provides a flexible and adaptable option to engage persons with dementia in meaningful cognitive activities. These digital platforms offer interactive sessions that can be accessed from the comfort of one's home, reducing barriers such as travel and mobility challenges that often limit participation in traditional, in-person CST. Virtual CST not only maintains the core elements of cognitive stimulation—such as enhancing memory, quality of life, and mood—but also incorporates personalized content and adaptive learning techniques that can cater to individual needs. Additionally, the telehealth format allows caregivers and family members to be more involved in the therapeutic process, fostering a supportive treatment environment. As these technologies continue to evolve, vCST is charged to become an essential component of comprehensive dementia care, providing a valuable resource to improve the quality of life and cognitive function for individuals living with dementia.

In addition, CST is increasingly being explored beyond its traditional application for dementia, extending to other brain health conditions such as other forms of dementia, mild cognitive impairment (MCI), and even chronic traumatic encephalopathy (CTE). This expansion reflects a growing recognition of CST's potential to enhance cognitive and psychosocial outcomes across a broader spectrum of neurological disorders. For persons with MCI, CST may serve as a preventive intervention, aiming to slow cognitive decline and delay progression to more severe forms of dementia by engaging participants in targeted cognitive and social activities.

Similarly, CST's adaptability makes it suitable for other dementias, such as vascular dementia or Lewy body dementia, where tailored programs can address specific cognitive deficits and behavioral challenges associated with these conditions. Emerging discussions around applying CST to CTE, a condition often seen in athletes and people who have suffered repetitive head injuries, highlight the therapy's versatility in addressing cognitive dysfunctions beyond typical age-related neurodegenerative diseases. As research continues to explore these innovative applications, CST's role in brain health is expanding, offering promising avenues for intervention across diverse cognitive disorders and contributing to a more holistic approach to neurological care.

In recent years, there has been a strong movement to make older adult group services billable within larger healthcare systems and organizations.[26] CST has gained momentum as a reimbursable service through certain codes and ways to track health outcomes for those with mild to moderate dementia. Group facilitators in Perryville, MO have utilized Occupational Therapy and

Speech Therapy codes to bill for group therapy sessions in their hospital system. These providers chart specific diagnostic symptoms, treatment goals, and care plans for each patient who takes part in the intervention.

CST training is offered in several states across the US, including multiple options per year from the Saint Louis University's Family Center for Healthy Aging. SLU is also designated as the North American Cognitive Stimulation Therapy Training Institute, providing practitioner training and train-the-trainer intensives to facilitators who will deliver CST groups at their respective sites. Using standardized facilitator manuals, trainers highlight the key principles of CST during training conferences[27] (Figure 4). Physicians, Geriatricians, Mental Health Professionals, and other healthcare providers have found past trainings beneficial not just for developing CST, but having a meaningful referral source for patients newly diagnosed with dementia.

For more information about the intervention, training, implementation, and reimbursement, information is available at: https://www.slu.edu/ medicine/family-medicine/family-therapy/facultyclinics/memory-clinic.php or email: cst@health.slu.edu. SLU works with multiple partners to help train and implement CST.

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Advance Care Planning: What, When, and How?

by Lina Toledo-Franco, MD, John Peters, DO, Ashna Fatima Kamal, MD & Christina Traber, GNP-C

Advance care planning is a dynamic process that should take place within the provider-patient relationship with the intention to understand the person's values and goals.



Lina Toledo-Franco, MD, FACP, (pictured) is Assistant Professor, Director, Division of Palliative Medicine, Fellowship Director, Geriatric Medicine, Hospice and Palliative Medicine at SSM Health/Saint Louis University School of Medicine, St. Louis, Missouri. John Peters, DO, is an Internal Medicine Resident, at SSM Health/Saint Louis University School of Medicine, St. Louis, Missouri. Ashna Fatima Kamal, MD, is a Hospice and Palliative Medicine Fellow at SSM Health/ Saint Louis University School of Medicine, St. Louis, Missouri. Christina Traber, GNP-C, is a Certified Geriatric Nurse Practitioner, Division of Geriatric Medicine at SSM Health/Saint Louis University School of Medicine, St. Louis, Missouri.

Abstract

Advance care planning (ACP) is a fundamental part of the patient-provider relationship. It is a process that evaluates a person's values and determines preferences for care in various clinical scenarios, based on personal goals and expectations.

ACP has two main goals: 1) identifying the surrogate decision maker; and 2) establishing the patient's goals of care for treatments or procedures which align with their wishes.

ACP provides an opportunity to help patients and their families to prepare, on their own terms, for the changes brought by serious or progressive illness. This fosters a collaborative, therapeutic relationship in planning for the future.[1] When addressing goals of care, it is essential to evaluate the perceived burden of certain procedures or life conditions such as depending on others for activities of daily living (ADLs) or living in a long-term care facility.

As providers, we use patient history, laboratory data, exam findings, pathology reports, imaging studies, and more in making medical decisions for patients and recommending a plan of care. ACP can provide additional valuable information to guide patient-centered medical management.

In this article, we will discuss the current state of goals-of-care conversations, compare the different ACP documents currently available, and provide guidance to providers on how to engage in these conversations. This includes addressing patient's values, wishes, and fears, without diminishing their sense of hope.

Background

In 1990, through federal legislation, the Patient Self-Determination Act was established. This law requires health care providers that participate in Medicare and Medicaid programs to:

- Inform patients of their rights under state law to make decisions concerning their medical care.
- Periodically inquire if a patient has executed an advance directive and document the patient's wishes regarding their medical care.
- Avoid discriminating against persons who have executed an advance directive.
- Ensure that legally valid advance directives and documented medical care wishes are implemented to the extent permitted by state law.
- Provide educational programs for staff, patients, and the community on ethical issues concerning patient self-determination and advance directives."[2]

According to the Centers for Medicare and Medicaid Services (CMS), ACP is a "voluntary, face-to-face discussion between a physician or other qualified health care professional and the patient, their family member, caregiver, or surrogate (as appropriate) to discuss health care wishes if they become unable to make their own medical decisions."[3] These discussions aim to understand what the person would want if they became severely ill and unable to decide on a clinical plan of care. This includes, but is not limited to, code status and life support preferences, the selection of a healthcare power of attorney, and the preparation of a living will.

Time spent in ACP face-to-face conversations can be billed if it is entirely dedicated to exploring the patient's values and preferences and is documented appropriately. Creation of legal documents is not a requirement to bill for an ACP visit. Documentation must include the voluntary nature of the conversation, who was present, description of advance directives, and the patient's diagnosis with evident changes in their clinical condition. If the patient is unable to participate, an explanation of the reason should be provided. Time spent in the face-to-face time must also be documented. The outcome of the discussion should include the patient's healthcare wishes should they become unable to make their own medical decisions. Ideally, the selection of a surrogate decision maker should also be accomplished through this process.

ACP Billing is Time-Based and Providers Should Use:

- CPT code 99497 for the first 30 minutes (starting at minute 16, as the initial 15 minutes are not counted: this code applies to discussions lasting 16-45 minutes).
- CPT code 99498 is used for each additional 30 minutes beyond the initial 45 minutes.

ACP can be billed as part of an Annual Wellness Visit (AWV) or as a separate Medicare Part B service. There are no limits to the number of times ACP billing can be submitted for the same patient within a given period. However, documentation must show a change in a patient's health status or end-of-life wishes when billing multiple times within the same year.

Research demonstrates that ACP discussions can increase patient satisfaction, reduce family anxiety, depression, and stress, lower end-of-life hospitalizations, minimize treatment burden, promote timely hospice utilization, decrease cost of care, and reduce inpatient mortality and length of stay.[1,5] Discussing patient preferences in advance of emergency situations has been shown to increase the concordance between desired and delivered care.[6] This underscores the role of ACP discussions in patient care, enabling patients to make informed medical decisions that align with their goals and prognosis. As stated by Thomas LeBlanc, MD, palliative care specialist at Duke University School of Medicine: "It's not a focus on end of life care, rather a focus on how the patient wants to live."

Current Status

ACP conversations and documentation rates remain low nationwide. According to the National Center for Health Statistics (2011), 28% of home health patients, 65% of nursing home residents, and 88% of hospice care patients had an advance directive on record. A systematic review from July 2017 found that 36.7% of U.S. adults had completed an advanced directive and 29.3% had a living will. Among the 150 studies with almost 800,000 adults, more than 80% of subjects were older than age 65 and 62% lived in a long-term care setting. Similar proportions of patients with chronic illnesses (38.2%) and healthy adults (32.7%) had completed advance directives.[7]

In a January 2019 study, examining the prevalence of advance directives among ICU patients requiring mechanical ventilation, fewer than 50% of patients overall had an advance directive. Significant differences were noted across age groups: the completion rate was lowest among the "young old" (32.8%) and highest among the "oldest old" (53.6%). The study also raised concerns about potential disparities related to race, although specific data on racial subgroups were not provided.[8]

During the early months of the COVID-19 pandemic, there was increased focus on ACP discussions and end of life decision-making. In June 2020, the National Poll on Healthy Aging surveyed US adults aged 50–80 about their ACP activities before and during the pandemic. The survey revealed that 59% of participants had spoken with a family member or close friend about their medical care wishes and 29% of participants initiated these conversations within the first 90 days of the pandemic. Forty-six percent reported having completed at least one advance care planning legal document, with 7% doing so during the first 90 days of the pandemic.[9]

Racial and ethnic disparities in health-related outcomes extend to serious illnesses, end of life care, and advance care planning. These disparities have been partially attributed to differences in completion of advance directives, engagement in ACP, perceptions of care

quality, hospice enrollment, and end of life care service utilization.[10] Compared with white counterparts, African Americans have been found to be less likely to complete advance directives and have care preferences respected.[11]

Data from the 2009–2010 HealthStyles Survey explored the relationship between advance directive completion and demographic or socioeconomic factors. Among 7,946 respondents, 26.3% had an advance directive. The most frequently reported reason for not having one was lack of awareness. Completion rates were higher among older individuals, those with more education and higher income, and those with chronic diseases or regular healthcare access. Advance directive completion was less common among non-white respondents.[12]

National data from 2011 on advance directives in long-term care populations (nursing homes, home health, and hospice care) was derived from the 2004 National Nursing Home and the 2007 National Home and Hospice Care Surveys. These reports highlighted disparities in ACP by age and race. Disparities were more pronounced in home health and nursing home populations than in hospice care populations.[13] Although racial disparities persist, the gap between White and African American populations has narrowed in recent years, with more African Americans participating in goals-of-care conversations.[14]

Despite the prominence of advance care planning, relatively few patients complete advance directives. Completion rates vary widely, often influenced by factors such as ethnicity, age, and gender. Moreover, even when advance directives are completed, they are often not followed during a crisis.

Several barriers may contribute to this:

- Treating physicians may be unaware of the existence of the document. Fewer than one-third of individuals who complete an advance directive have discussed its content with a physician.
- Surrogate decision makers may lack a clear understanding of the patient's wishes.
- Uncertainty regarding the patient's prognosis may complicate decision-making.
- Disagreement among family members about the goals and plan of care may interfere with the implementation of the advance care plan.

Additionally, terms like "terminally ill" or "meaningful life" are often interpreted differently by patients and physicians, complicating the translation of advance directives into actionable care plans.

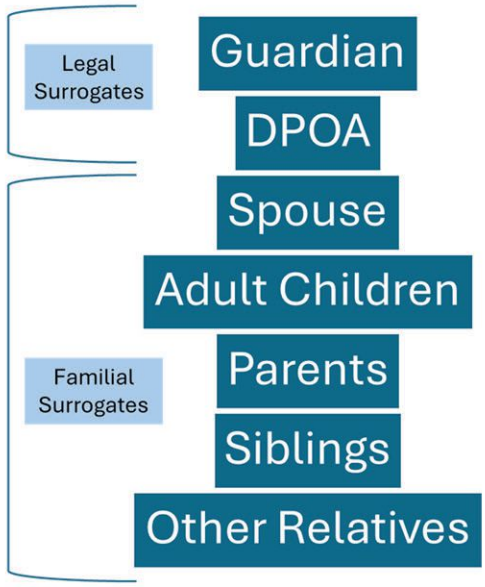


Figure 1. Common Hierarchy of Surrogate Decision Makers

Patients with Physician Orders for Life-Sustaining Treatment (POLST) forms are more likely to have their wishes respected, as these documents provide specific, actionable medical orders tailored to the patient's goals of care.[15]

Surrogate Decision Maker

The first step in developing an advance care plan is to identify a surrogate decision maker and, if possible, complete Durable Power of Attorney for healthcare (DPOA) paperwork. This document legally authorizes the selected person to make decisions on behalf of the patient if they become incapacitated. It is essential to determine who the patient trusts to understand and honor their wishes. This chosen individual may not always be a family member. Some patients prefer an emotionally strong surrogate to make difficult decisions, such as letting the patient die, without being influenced by personal feelings. Ideally, the surrogate should make decisions that align with the patient's beliefs and goals, a principle known as "substituted judgment."

In the absence of formal DPOA documentation, state legislation often dictates which relatives can make decisions on the patient's behalf. In most states, this follows a familial hierarchy (Figure 1). However, challenges can arise regarding the role of step-children, separated or estranged spouses, non-married same-sex and domestic partners, and non-biological relatives. In

Table 1.
Characteristics and Comparison of ACP Documents

	Living Will	Durable power of attorney for healthcare (DPOA)	Physician Orders for Life-Sustaining Treatment (POLST) or Medical Orders for Life-Sustaining Treatment (MOLST)	Out of the hospital DNR
Use	Tells what procedures the patient wants done or refuses (CPR, ventilator, tracheostomy, artificial nutrition or hydration)	Names the person who is chosen to make healthcare decisions on their behalf in case the person is unable	Medical orders to avoid/approve certain procedures (CPR, intubation, artificial feeding) 4 sections: • code status • overall goals of care (comfort measures, limited care, aggressive ICU measures) • artificial nutrition and hydration • life sustaining treatments	Indicates to EMS personnel that the patient would not want CPR if cardiac or respiratory arrest happens at home Each state has its own unique paperwork
Legal Document	Yes	Yes	No	No
Legal requirement	Depends on the state (needs to be notarized or signed by two witnesses) MO/ IL: Two witnesses required for a living will	Depends on the state (needs to be notarized or signed by two witnesses) MO: The notary acknowledgment is required by Missouri law IL: One witness is required for power of attorney for health care * POA cannot also be the document witness	Must be completed and signed by a physician (medical orders) and also signed by the patient or surrogate	Must be completed and signed by a physician (medical orders) and also signed by the patient or surrogate
Active only at loss of decision making capacity	Yes	Yes	No	No
Validity	Valid until a new document is completed	Valid until a new document is completed	Valid until a new document is completed	Valid until a new document is completed or the form is destroyed
Pros	Forms are available online These are not medical orders The provider has to write medical orders with a plan of care that aligns with the directives	Can name any person that is considered would respect the person's wishes and evaluate the clinical situation based on the patient's perspective and values (doesn't have to he a relative) Can name more than one person (alternate proxy) Having a POA that serves as a bridge communicating with the family can be helpful when there is conflict and different opinions regarding the plan of care	Can be applied to the home setting (for EMS at arrival) Includes more information than Out of the Hospital DNR form More states are adopting the use of POLST in their medical setting	It is useful in the home setting and if hospital if transferred with the patient
Cons	Vague and leads to different interpretations ("if meaningful recovery is unlikely") Can't predict every potential medical scenario Frequently use the term "heroic measures" without description of heroic Can be completed without the advice or support from a clinical provider, despite discussing medical interventions	Not specific for other aspects besides healthcare POA (medical treatments, financial) Some states allow the surrogates to withdraw or withhold life sustaining treatments, while others limit decisions that can be made and request more evidence on the patient's wishes to withdraw or withhold life sustaining treatments	Specific for end of life (should not be completed by someone without a terminal condition) Depending on the state can only be signed by a physician and not a physician assistant or nurse practitioner	Does not include any other aspects besides CPR
Input from surrogate decision maker required	Possible if the clinical scenario has not been explored in the advance directives (e.g. disease would lead to marked disability but life can be prologued)	That is the intent, although, POA can make decisions that do not align with patient's prior wishes and have other reasons to opt for certain medical plan.		No but EMS shall not comply with an out of the hospital DNR order when the patient or the patient's representative expresses to such personnel in any manner, before or after the onset of a cardiac or respiratory arrest, the desire to be resuscitated
Additional information	In many states it is not valid during pregnancy		Some states have ruled that POLST overrides any conflict with advance directives and surrogate decisions	Not valid during pregnancy

Missouri, there is no legally mandated hierarchy, and the individual best able to reflect the patient's wishes and values is deemed qualified to make decisions. To avoid confusion or conflict, it is recommended that providers inquire about the patient's preferred decision-maker during clinic visits or hospital admissions.

Some patients may hesitate to appoint a surrogate, fearing it could diminish their independence. Providers can reassure them that the DPOA only becomes active when the person loses decision-making capacity. It's helpful to emphasize that designating a trusted person ensures the patient's voice is heard, minimizes family conflict, and avoids decisions based on emotions rather than the patient's wishes.

If a patient verbally identifies a surrogate, this should be documented in their medical chart and this decision should be respected. However, for legal purposes, patients should be encouraged to complete

a DPOA document, especially if family conflict is anticipated. Members of the patient's treatment team should not act as surrogate decision-makers.[16]

We recommend inquiring about a DPOA at hospital admission and confirming the presence of advance directives. If no surrogate is named, asking the patient who should make decisions on their behalf and documenting their response is crucial in should decisional incapacity develop during hospitalization.

In situations where no surrogate is designated and family members disagree, the treatment team should work toward a consensus. Palliative care teams, family meetings, and ethics committees can provide invaluable support in these circumstances. The primary focus should remain on determining what the patient would have wanted, asking questions like, "What would the patient choose now, in this clinical situation, if they could tell us?"

If a DPOA has been completed, the legally appointed surrogate becomes the decision-maker at the time of decisional incapacity.

Legal Guardianship

A legal guardian is a representative appointed by the court when a patient has been deemed incapacitated by legal standards and is unable to make decisions.

ACP Documentation: Type of Advance Directives

Current advance care planning documents help guide healthcare decisions when a person is unable to communicate their wishes (Table 1). These documents outline the procedures the patient would prefer or wish to avoid in scenarios involving a poor prognosis, low likelihood of survival, or life-altering events. Advance directives are not limited to the elderly or seriously ill, as unexpected medical events can happen at any time. These documents should be completed by adults with decision-making capacity, and providers are responsible for respecting and adhering to these stated preferences.

Common types of advance care planning documents include:

- Living Will: Specifies the types of medical care the individual wants or does not want in specific circumstances.
- Durable Health Proxy (a.k.a. Durable Power of Attorney for Healthcare–DPOA): Legally designates a surrogate to make healthcare decisions if the patient becomes incapacitated.
- Physician Orders for Life-Sustaining Treatment (POLST) or Medical Orders for Life-Sustaining Treatment (MOLST): These documents provide actionable medical orders, often for individuals with serious or terminal illnesses.

Other less common forms include Out-of-Hospital Do Not Resuscitate (DNR) orders, specific directives such as "Do Not Hospitalize" or "Do Not Intubate," and organ and tissue donation forms. While these forms can exist independently, many decisions (e.g. CPR, intubation, and other life-sustaining measures) are commonly included in a Living Will or POLST/MOLST.

POLST forms are particularly useful for patients in advanced stages of life-limiting conditions, enabling emergency medical responders to quickly assess and respect treatment preferences during critical situations. All these documents are widely available online, often for a fee. Numerous tools and forms are also accessible online to help individuals understand and articulate their wishes effectively.

How to Have ACP Conversations

Early and proactive ACP discussions are ideal, however it's never too late to engage a patient about their future goals. While everyone is a candidate for ACP discussions, certain situations should act as clear triggers. These include a new diagnosis of a serious illness, frequent hospitalizations for a chronic disease, life-changing events, or an acute worsening of a known illness. A clinic appointment following a hospital admission provides an excellent opportunity to address goals, especially if the admission involved an acute exacerbation of a chronic condition requiring invasive interventions (e.g. ICU admission or intubation). Another opportunity to initiate these discussions arises when a patient mentions a loved one's illness, particularly if it involved procedures such as dialysis or life support. It is recommended to address goals periodically, even if none of these events occur.

A helpful prompt to start these conversations is the surprise question: "Would you be surprised if the patient died in the next year?" A negative answer to this question is a strong indicator to begin or revisit ACP discussions, as it suggests a high risk for short term medical decline. The surprise question has been validated across various conditions and healthcare settings, especially when estimating prognosis is challenging.[17]



Figure 2. SPIKES Mnemonic for Breaking Bad News

Establishing goals of care is the outcome of meaningful conversations—sometimes multiple discussions—where the provider learns about the person, not just the patient. We approach this dialogue as "goals in life," exploring what brings the patient joy, what they consider important, and what they look forward to. Providers can also ask about treatments that might be considered too burdensome, even if it could help achieve their goals.

Having ACP conversations to clarify life goals before a crisis occurs empowers the healthcare team to guide decision-making during such crises. Once an individual's life goals are understood, discussing their clinical condition and prognosis becomes more productive, leading to the establishment of personalized goals and a corresponding care plans.

The conversation about treatment options becomes personal, based on what is known about the patient, not solely the medical facts. It is important to recognize that both life goals and care goals may evolve based on the situation, expectations, and likelihood of successfully achieving those goals.

The process of ACP varies depending on the setting in which the patient is located. Ideally, it should occur over one or more clinic visits with the primary care provider or the specialist managing the patient's condition. When decisions are delayed until the hospital setting—such as during an acute event or decompensation of a chronic condition—the stakes and stress levels are higher. Decisions in these situations are often rushed and made by providers who lack an established relationship with the patient.

Early conversations are particularly beneficial for conditions that naturally or predictably progress to a state of decisional incapacity. Diseases like dementia, recurrent strokes, and Parkinson's Disease can lead to altered mental status as they progress, similar to ESRD or cirrhosis. In those cases, discussions may be more hypothetical, requiring detailed explanation of natural course of the disease. This can be overwhelming for patients and families, so empathy is essential, as is assessing understanding and addressing questions and emotions.

We recommend starting this conversation by explaining disease progression and leaving patients with "homework" to discuss their perceptions of the illness and goals with their loved ones. For example, you might say: "I'd like you to think about what's most important to you and what limits you'd want to set in case you get very sick. Please discuss this with your family, and we can revisit the conversation at your next appointment."

We frequently hear that the patient would not want to remain in a vegetative state. However, many clinical scenarios involve changes in quality of life and functional dependence that fall short of that extreme. Advance directives are sometimes difficult to interpret in specific scenarios, so exploring goals and burdens can provide more actionable insights when those situations arise.

Guidelines and other articles recommend initiating these conversations by assessing the patient's and family's understanding of the disease and current condition.[18] The SPIKES protocol uses a six-step process for delivering bad news and is a useful tool in disclosing a diagnosis and establishing next steps in care[19] (Figure 2). Before diving into the medical condition, it is essential to know the person underneath the patient by understanding their values, hopes, and expectations. Questions about quality of life, goals, and burdens are key in tailoring care to the individual and establishing a relationship with patients and families.

Quality of life is a dynamic concept that evolves over time and in response to circumstances. People

can adapt to challenges and modify what was considered a good quality of life. By understanding what constitutes a good quality of life for the patient, providers can make more personalized recommendations when critical decisions arise. For example, if a patient enjoys gardening or fishing and values independence, they may consider losing these abilities an unacceptable burden. In the future, if that patient presents with a stroke, the conversation on next steps should start by evaluating how interventions can be offered to maintain quality of life and avoid treatment that is considered too burdensome.

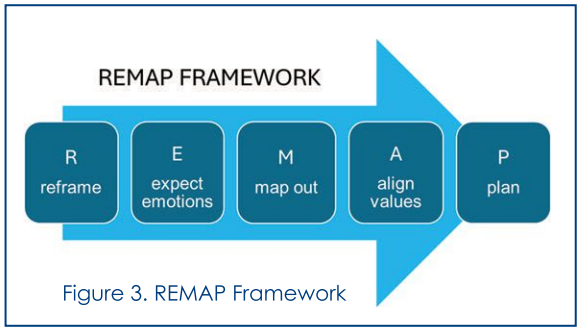


Figure 3. REMAP Framework

Once this basic but important information has been obtained, it is critical to also understand how much the patient knows about their disease and how much they wish to know. In some cultures, patients don't want to know and prefer to delegate decision-making to family members. Providers should always ask respectfully and avoid making assumptions. For instance:

"To provide the best care for you, is there any cultural or religious information I should be aware of? How much would you like to know about your condition and be involved in treatment decisions?"

Patients' perceptions of their condition and prior complications can influence what they consider burdensome and affect their expectations. For example, patients receiving treatment such as hemodialysis for end stage renal disease may be more accepting of burdensome interventions.[20] On the other hand, individuals who have previously expressed a desire to avoid a diminished quality of life may adapt their perspectives if faced with unexpected challenges and potential new disabilities.

Historically stroke specialists have been concerned about the effect of 'therapeutic nihilism' on outcome and mortality; where expectations of poor outcomes become self-fulfilling once treatments are stopped.[21] The solution for this is to have clear goals of care, base treatments on patient's values, and estimate the bearable treatment burdens.

The REMAP framework (Reframe, Expect Emotions, Map Out, Align Values, and Plan for the Future) outlined by Childers et al. is a practical approach to ensure empathetic and productive discussions (Figure 3).[22] In the Reframe step, providers assess the patient's understanding of their situation and provide missing information. This builds a foundation for further discussion and ensures all are on the same page. Next, Expect and address the emotions produced by the information from the Reframe step. Using empathetic responses and strategic silence, providers allow patients to Express Emotions prior to continuing with the ACP discussion. Next, Map Out the future. Providers will ask about patient values, quality vs. quantity of life, willingness for hospitalization or long-term care placement, what hobbies they enjoy, how they spend most of their time, etc. This step also addresses what the patient does not want, or what would be considered too burdensome. It's reasonable for patient to be undecided on a treatment course, but asking them what is too burdensome can help establish boundaries in their care and narrow options. In the Align Values step, providers will reiterate the patient's values. Phrases like "It sounds like you value X the most." And, "You definitely don't want to go through Y, correct?" This helps the patient feel heard and reduces the chance of miscommunication. Finally, Plan for the future, bringing everything together. Treatment recommendations should always be attached to one of the patient's values, such as: "It sounds like you prefer Z option which would help you with achieving X. You would not have to undergo Y if you went with Z." This can help patients feel more comfortable with their decisions as it is framed by their own goals. Benefits and consequences of decisions need to be outlined clearly for the patient.

Goals of care can include attempting to cure the disease (with aggressive therapy, which may be burdensome), improving function, decreasing pain, spending time with loved ones, doing what is considered important, and living as long as possible, no matter the cost. When the goal is to live as long as possible, it is important to establish what we call "lines in the sand," which are the conditions a person may not want to endure, even if it means gaining additional time. Some people may say they don't believe anything

would be too much of a burden, but a discussion about the limits of medicine and the point at which prolonging life is no longer possible should still take place. Most likely, this conversation will require multiple visits and acceptance of the progression of the disease. A good approach is to have alternative plans and goals if the treatment burden becomes too great, if complications arise, or if the response is not what was expected. In the acute setting, establishing time-limited trials to evaluate improvement can be useful in facilitating acceptance of the prognosis and disease progression. The ACP process should conclude by documenting the conversation as a narrative, detailing what is important for the person, and placing this report in an easily accessible location in the chart.

Hope should be included in the conversation, especially when prognosis is limited, to delineate what the patient/family may be wanting and expecting. Hope and goals can change throughout the disease process. Some may hope for time with family while others hope to live as long as possible. A good approach is to ask the patient what they are hoping for, what they are expecting, and what they are fearing could happen. Knowing this, one can frame hope with realism: "If your main goal cannot be accomplished, what is the next most important thing for you?" "If your time is limited, what is important and how do you want to spend that time?"

At all points in the disease process, patients should be reassured that they will not be abandoned and will continue to get care and symptom management independent of their treatment decision.

Silence is the most important skill needed during difficult conversations and providers are not usually skilled at using silence. Our human response and training tempt us to "fix things" and provide reassurance as an automatic response. Silence requires practice and a conscious awareness to listen without interruptions. Learning to read the room and be aware of non-verbal communication allows us to guide the rest of the conversation. Understanding and naming emotions gives everyone a space to accept their feelings. When a situation is highly emotional, avoid additional conversation or providing more information. If needed, wrap up the conversation and offer to continue it later. This gives everyone time to process the information and saves energy when the conversation is not leading to any conclusion. Some people are more focused on data than others. For data-seeking individuals, numbers are important, and statistics help to support decisions. In highly emotional people, data is not as important as focusing the conversation on values and goals.

Code Status Discussions

Code Status should be framed within the context of prognosis and the likelihood of success. It should be addressed like other medical procedures using a patient–specific clinical scenario. It is often more effective to recommend "do not attempt resuscitation" (DNAR/DNR) when clinically appropriate, rather than asking patients to decide without guidance. It's crucial to clarify that DNR refers only to the case of cardiac arrest and does not mean withholding other treatments. This recommendation should not be made precociously. It should utilize the provider's judgement after careful assessment of a patient's hopes, values, fears, and care goals. DNR discussions should acknowledge prognosis and indicate what resuscitation efforts would not help the patient meet their goals.[23]

Unfortunately, many patients arrive to the emergency department (ED) without having prior goals of care conversations. While the ED environment is not ideal for in-depth conversations, it's recommended to ask about advance directives and address immediate concerns with a plan to revisit these discussions later. Code status documentation at hospital admission can be addressed by asking the patient about advance directives, and if they have none, ask how they would feel about life support based on their condition and diagnosis. Always plan to revisit the conversation once the patient is admitted to the floor and can have a more in-depth conversation. Asking what is important for the patient is something that can be achieved even in a busy ED environment with more detailed information to be obtained later.

As a part of ACP discussion, it is important to educate patients about the realities of cardiopulmonary resuscitation (CPR). Media portrayals often misrepresent the outcomes. For example, survival to discharge after in-hospital cardiac arrest is approximately 15–20%, far less than what is depicted on television. The Go-Far score can help predict neurologically intact survival after in-hospital CPR, evaluating for clinical condition, comorbidities, age and if admitted from a nursing facility[24]

It is crucial to clarify that the choice to be DNR only takes place in case of cardiac arrest, and patients

will continue to get full treatment for their medical conditions. DNR does not mean do not treat. Also, if the patient chooses to remain full code, it is important to clarify that CPR does not guarantee success, especially in critically ill patients.

Do not attempt resuscitation orders (DNAR/DNR), in case of cardiac arrest, are usually accompanied by a do not intubate order. It is important to clarify that resuscitative measures during cardiac arrest will include intubation and artificial ventilatory support. In context of cardiac arrest, a patient should not be intubated if CPR isn't attempted. Alternatively, a patient can choose to avoid CPR (including intubation) in case of cardiac arrest but still allow short-term intubation for a potentially reversible condition, like pneumonia.

Conclusion

ACP is a dynamic process that should take place within the provider-patient relationship with the intention to understand the person's values and goals. Ideally, conversations should begin early in the course of a chronic disease, especially if it is expected that the patient may lose decision-making capacity later. These conversations are not limited to end-of-life care but encompass what constitutes a good quality of life, what burdens patients are willing to bear, and their goals in life when facing a serious disease or a life changing condition. With this understanding, it is easier to create a patient-centered plan of care.

Frequent reassessments are essential as diseases progress or life-changing events occur. Including hope in these discussions, whether it's hope for time with loved ones or achieving specific goals—can provide comfort and direction, even when prognosis is limited. Above all, patients should be reassured that they will not be abandoned and that their care will continue to align with their values and goals.

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A Comprehensive Review of Non-Rapid Eye Movement (NREM) Parasomnias

by Meet S. Parikh, MS, Mahesh M. Thakkar, PhD & Tejas R. Mehta, MD

School of Medicine
University of Missouri Health

By delving into the complexities and nuances of NREM parasomnias, this review seeks to inform and guide future research and clinical practice.



Meet S. Parikh, MS, is at the Harry S. Truman Memorial Veterans Hospital, Columbia, Missouri. Mahesh M. Thakkar, PhD, (pictured), is a Professor, Director of Research, University of Missouri - Columbia School of Medicine and the Harry S. Truman Memorial Veterans Hospital, Columbia, Missouri. Tejas R. Mehta, MD, is the Robert L. Anderson Fellow, Jr., Movement Disorders Fellow at the University of Florida, Gainesville, Florida.

Abstract

NREM (Non-Rapid Eye Movement) sleep is necessary for normal physical and intellectual performance and behavior. NREM parasomnias are defined as conditions where different symptomologies are associated with various behaviors happening during NREM sleep. Moreover, the underlying mechanism and proper treatment of the various conditions are yet to be explored in the realm of NREM parasomnias. In this review article, we summarize the fundamental mechanisms underlying the NREM sleep parasomnias as well as portray an algorithm to treat those conditions. We also briefly discuss important studies associated with NREM parasomnias and their related advancements in the treatment.

Introduction

The term "Parasomnia" derives its meaning from a combination of the Greek prefix 'Para' (meaning alongside) and the Latin noun 'Somnus' (meaning sleep), which was coined by a French researcher, Henri Roger in 1932.[1] Parasomnia is an unusual sleep condition characterized by abnormal, unpleasant motor, verbal, or behavioral events occurring during sleep or transitions to and from sleep.[2] Both NREM and REM sleep stages manifest with a higher incidence of parasomnias observed in children compared to adults.[3] According to the Diagnostic and Statistical Manual of Mental Disorders-5 (DSM-5) and the International Classification of Sleep Disorders-3 (ICSD-3), parasomnia can be observed in both NREM and REM sleep states.[4] It encompasses sleepwalking, sleep terrors, and confusional arousals, collectively referred to as disorders of arousal (DOAs), along with lesser-known conditions like sleep-related sexual behaviors and eating disorders.[5] The spectrum of disruptive sleep disorders known as parasomnias varies in prevalence among different age groups.[6] Conventionally, NREM parasomnias often persist into adulthood more frequently than anticipated, with a lifetime prevalence of approximately 7%. It is often considered a childhood development disorder, too.[7] Prevalence among adults 15 years and older is estimated at 2.9% to 4.2%.[8] In adults, NREM parasomnias, including sleepwalking, confusional arousal, and sleep terror, collectively impact a significant portion of the population, with lifetime prevalence rates ranging from 10.4% to 22.4%. These results highlight how crucial it is to comprehend and treat parasomnias at every stage of life to improve sleep quality and general well-being. Over the past 20 years, there has been a surge in research on NREM parasomnias

due to the growing interest of physicians in this field.[9] This growing interest has facilitated advancements in understanding the characteristics, mechanisms, causes, and treatment of NREM parasomnias. The purpose of this work is to provide an extensive and up-to-date review of NREM parasomnias based on recent empirical findings.

General Characteristics and Epidemiology of NREM Disorders

Sleep disorders are increasingly recognized and are associated with significant morbidity.[10] There are four main categories of sleep disorders in recent classification: dyssomnias, parasomnias, medical/psychiatric sleep disorders, and proposed sleep disorders.[11] Parasomnia sleep disorders involve abnormal activities during sleep, such as sleep terrors or sleepwalking, whereas dyssomnia sleep disorders result in trouble falling asleep or staying asleep.[12] Atypical sleep-related behaviors and/or experiences, usually involving motor movements with variable semiology, are the hallmarks of parasomnias. An insufficient dissociation of alertness from NREM sleep is the cause of sleepwalking (SW), sleep terrors (ST), confusional arousals, and associated illnesses.

NREM sleep parasomnias mainly encompass:

1. Confusional arousals (CA): When a patient experiences episodes of confusion and disorientation in bed, it is referred to as CA.
2. Sleep terrors (ST): Sudden terror attacks (STs) are characterized by significant autonomic arousal indicators.
3. Sleepwalking (SW): Episodes of ambulation or other sophisticated actions carried out outside of bed include SW.

Thus, these three conditions collectively constitute disorders of arousal (DoA). Over the years, focus has also been focused on two other distinct phenotypes: sleep-related eating disorder (SRED) and sleep-related aberrant sexual behaviors, sometimes known as Sexsomnia. Polysomnography (PSG) offers limited diagnostic markers of disorders of arousal in the absence of an episode of NREM. NREM parasomnias predominantly manifest during slow-wave sleep (sleep stage N3) but can also originate from sleep stage N2.[13] Various physiological phenomena may precipitate these parasomnias by hindering complete cortical arousal from the sleep state. Instances of sleepwalking or sleep terrors are seldom observed during PSG.[14] Sleep terrors may entail notable tachycardia and tachypnea.[15] Parasomnias have been reported in approximately 4% of the adult population.[16] Sleepwalking typically emerges in childhood, reaching its peak around ages 11-12, with both sleepwalking and sleep terrors generally diminishing in later childhood and adolescence but sometimes persisting into adulthood, albeit rarely.[17] Studies suggest that 1% to 6.5% of children and adolescents experience sleep terrors, while 5% to 30% experience sleepwalking.[18] For adults, the prevalence of sleepwalking is estimated at 2% to 5%.[19] Individuals aged 15 and older found sleep terrors in 2.2%, sleepwalking episodes in 2.0%, and confusion during arousal in 4.2% of respondents.[20] Additionally, 2.0% reported engaging in violent behavior during sleep. Pure sleep terrors are more common in young children, occurring in around 3% of children and less than 1% of adults.[21] The peak occurrence of NREM parasomnias is in childhood, with sleep terrors peaking around 1.5 years of age and sleepwalking at age 10.[22] A decrease in NREM parasomnias as children age into adolescence is well-documented. Studies have found no significant sex differences in these behaviors in individuals over 15 years old, but sleep eating is more prevalent in adult females.[2] Adult males are more likely to exhibit dangerous nighttime behaviors such as violence during sleep or sexsomnia.[23]

Plausible Mechanisms Underlying Parasomnia

NREM parasomnias differ from normal NREM sleep at the level of electrophysiology, cellular function, and molecular signaling. These differences involve abnormal patterns of brain activity, dysregulation of neurotransmitter systems, disturbances in neuronal circuits, and genetic or environmental influences that predispose individuals to these sleep disorders. NREM parasomnias often coincide with disruptions in the typical electroencephalographic (EEG) patterns observed during normal NREM sleep. Studies have shown alterations in EEG activity during NREM parasomnias, including the presence of arousals and fragmented sleep architecture compared to normal NREM sleep patterns.[24] These findings suggest that abnormal electrophysiological processes contribute to the manifestation of NREM parasomnias by disrupting the transition between sleep and wakefulness. Muscle activity often obscures the underlying EEG, revealing patterns such as diffuse rhythmic delta activity, intermixed delta and theta activity alongside alpha and

beta activity, or prominent alpha and beta activity.[25] A patient experiencing an episode of NREM parasomnia had wake-like beta activity recorded to motor and cingulate cortices by Terzaghi et al. Additionally, there was an increase in frontoparietal associative cortices' delta activity, which is indicative of N3 sleep.[26] Other studies, including one which provided three pieces of evidence for the co-existence of N3 and arousal prior to an episode of sleepwalking, observed a decreased connectivity in the delta frequency band in posterior areas, increased functional connectivity in alpha and beta frequency bands in the anteroposterior network, and increased spectral power in delta and theta frequencies.[27-29] Suppressed slow wave activity (SWA) and promotion of faster cortical activity expedites transitions from NREM sleep to wakefulness. The reduction in SWA intensity accelerates the conversion from NREM sleep to wakefulness, with most awakenings originating from lighter sleep stages (N1 or N2) characterized by minimal SWA. Conversely, arousals from deep NREM sleep (N3), marked by continuous SWA, have a higher threshold, and typically result in prolonged awakenings accompanied by strong sleep inertia, often described subjectively as "sleep drunkenness," which promotes a return to somnolence.[30] In NREM parasomnias, impaired arousal mechanisms and persistent sleep drive hinder the brain's transition to full wakefulness, with most episodes arising from N3 sleep.[14] At the cellular level, abnormalities in the balance of neurotransmitters such as gamma-aminobutyric acid (GABA), serotonin, and dopamine have been implicated in the pathophysiology of NREM parasomnias.[31] These regions subsequently promote wakefulness through both direct activation of the cerebral cortex and by inhibiting thalamic reticular neurons, thus blocking spindle oscillations.[32] The isolated activation of motor neurons and reduced activity in executive function and memory regions explain the impaired judgment and amnesia observed in NREM parasomnias.[33] At the molecular level, genetic factors, and alterations in gene expression within specific brain regions are thought to influence susceptibility to NREM parasomnias. In adults, a variety of factors that lead to arousals from sleep have the potential to precipitate confusional arousals.[34] Studies have identified mutations or variations in genes involved in neuronal excitability, neurotransmitter function, and sleep-wake regulation that may predispose individuals to these disorders.[35] Additionally, environmental factors such as stress, sleep deprivation, or medication use can influence molecular pathways involved in sleep regulation and contribute to the development of NREM parasomnias.[36] These molecular mechanisms interact with genetic predispositions to disrupt normal sleep patterns and promote the occurrence of parasomnias.

Proposed Classification and Definition

Parasomnias may include perceptions, hallucinations, and autonomic symptoms. Motor behaviors, sometimes dangerous when ambulating, can lead to injuries. These behaviors occur when the cortex partially awakens from deep, NREM sleep, frequently because of coexisting circumstances that increase sleep inertia and/or cause recurrent arousals.

Confusional Arousals

In the late 1980s, French physician Charles Guilleminault and colleagues discovered confusional arousals and sleep terrors as distinct sleep disorders through clinical observations and sleep studies.[37] Guilleminault et al. outlined the characteristics of confusional arousals as episodes of partial sleep awakening with confusion, disorientation, and potential inappropriate behaviors during NREM sleep, predominantly occurring in the early part of the night.[38] Newly become moms may experience confusional arousals, characterized by confusion and disorientation upon awakening from deep sleep, often during the first half of the night. These episodes may result from interrupted or anticipatory sleep due to caring for a newborn.[39] Likewise, in newborns, confusional arousals also involve sudden awakenings with confusion and disorientation, typically due to interruptions in sleep cycles, such as hunger or discomfort.[40] Confusional arousal entails amnesia of the event, with absent or sketchy recall in the morning. Associated motor behavior may manifest as simple and nongoal oriented.[41]

Two variants of confusional arousals in adults and adolescents:

- Sleep-related sexual behaviors: Aggression or violent behavior is atypical but may follow forced awakening from sleep. According to the American Academy of Sleep Medicine (2020), when sexual behavior occurs within the range of confusional arousals, individuals are further classified with sexsomnia.[42] There is no sexual predilection in confusional arousals. Dubessy et al. delve into the characterization and clinical aspects of Sexsomnia and elucidate its implications for diagnosis and management.[43] Sexsomnia occurs alongside other NREM parasomnias like

Table 1. Classification of parasomnias (excluding REM parasomnias): This table provides comprehensive information on different eeg characteristics, difference in mechanism, and provide targeted drug therapy.

#	Parasomnia	EEG Characteristics	Mechanism	Targeted Drug Therapy
1	Confusional Arousals	Frequently an increase in SWA, commonly referred to as hypersynchronous delta	Dysregulation of arousal mechanisms	low doses of a benzodiazepine or selective serotonin reuptake inhibitors
2	Sleepwalking	Increased slow-wave activity (SWA)	Incomplete arousal from deep sleep	Benzodiazepines and especially clonazepam
3	Sleep Terrors	Abnormal slow-wave activity (SWA)	Incomplete arousal from deep sleep	Antidepressant Citalopram or Amitriptyline
4	Sleep related eating disorder	Amnestic SRED, like SW, is often related to sedative	recurrent episodes of nocturnal eating after arousal with adverse consequences.	selective serotonin reuptake inhibitors (SSRIs) Like Topiramate, Clonazepam
5	Parasomnia Overlap disorder	All events usually start in stage N3 NREM sleep and terminate either in wakefulness or lighter NREM sleep.	an admixture of two arousal disorders, comprising waxing and waning of the multiple behavior types	short-acting benzodiazepines, such as diazepam and alprazolam
6	Sleep-related Bruxism	Increased muscle activity during sleep	Unknown	Clonazepam, muscle relaxants

somnambulism, while another variant in adults, severe morning sleep inertia, resembles typical confusional arousal but arises from light NREM sleep rather than slow wave sleep.

- Severe morning sleep inertia: According to Jewett, upon waking from sleep, sleep inertia impairs alertness and performance across various tasks, dissipating asymptotically over two to four hours following habitual wake time, with no significant influence of sleep stage at awakening or behavioral/environmental factors detected. These findings refine models of alertness and performance and have implications for scheduling work immediately upon awakening in occupational settings.[44] Functional imaging studies, along with scalp and intracranial EEG, suggest that the sleep inertia phenomenon arises from a heterogeneous cerebral state blending local sleep and wake patterns of activity at the neuronal and network levels.[45]

Sleepwalking

The formal study of sleepwalking is often credited to French neurologist Alfred Maury in the mid-19th century.[46] Various studies have investigated the neurobiological underpinnings of sleepwalking in humans. Zadra et al. advocate the EEG functional connectivity methods to elucidate the pathophysiology of sleepwalking, highlighting the prevalence of the disorder and the significance of pre-episode slow-wave sleep EEG fluctuations.[47] Desseilles et al. employed positron emission tomography (PET) scans to analyze regional cerebral glucose metabolism in sleepwalkers.[48] Siclari et al. (2017) utilized high-density EEG recordings to explore cortical dynamics during sleepwalking episodes.[49] Thus, these studies collectively contribute to our understanding of the underlying mechanism behind sleepwalking.

Sleep Terrors

Over the years, researchers have referred to dramatic events like sleep terrors, which represent a partial arousal state from deep sleep, as night terrors, parvor nocturnus (in children), and incubus attacks (in adults). Sleep terrors in children were identified by researchers Petit and colleagues, who conducted a study in 2015 involving 1940 children.[50] Psychopathology is rare in the affected children but may be a more significant factor in adults with sleep terrors. Desjardins et al. (2019) suggested that fluctuations in slow-wave sleep EEG signals may contribute to the emergence

of sleep terrors, indicating disturbances in neuronal activity during this sleep stage.[47] Furthermore, Marek et al. demonstrated abnormal patterns of brain activity during sleep terror episodes, implicating dysregulation in neural networks associated with arousal and emotional processing.[51] Yamada, T. studied 93 pairs of same-sex twins at age three, followed by 61 pairs, showing notable variations in night terror concordance rates.[52] Martinez et al. conducted a randomized controlled trial to evaluate the effectiveness of different treatment approaches for managing sleep terrors in children.[53] Overall, these findings suggest that sleep terrors result from complex interactions between genetic predispositions and disrupted neuronal activity.

Sleep-Related Eating Disorder

Studies such as those conducted by Winkelman et al. (1998) and Howell et al. propose that abnormalities in sleep architecture and disruptions in the regulation of sleep-wake cycles may contribute to the development of the sleep-related eating disorder (SRED), characterized by recurrent episodes of involuntary eating and drinking during sleep, often accompanied by partial arousal from slow-wave sleep.[54,55] Studies show cortical dysfunctions persist in anorexia nervosa post-weight gain, but some suggest EEG normalization, especially regarding initial alpha and beta alterations after refeeding. Additionally, research refutes eating disorders being variants of depression based on sleep EEG disturbances.[56-58] A PSG study suggested that sleep-related eating seems to have a peak incidence in young adulthood and is more common in females than males.[57] These findings underscore the multifactorial nature of SRED and highlight the importance of further research to elucidate its pathophysiology.[59] Thus, the association with weight concern has been identified as a predisposing risk factor.

Parasomnias Overlap Disorder

The patient, experiencing severe NREM parasomnia symptoms, exhibited violent behaviors during sleep, likely stemming from repressed traumatic memories, leading to a diagnosis of post-traumatic stress disorder (PTSD).[60,61] Studies emphasize the complex interplay between trauma and sleep disturbances, with heightened arousal thresholds and hypervigilance contributing to severe parasomnia symptoms.[6.2] Studies by Morgenthaler et al. (2010) and Olson et al. (2017) investigate the prevalence and clinical features of overlap parasomnia disorder, focusing on combinations such as obstructive sleep apnea with somnambulism or REM sleep behavior disorder.[63,64] Additionally, research by Schenck and Mahowald explores the association between overlap parasomnia disorder and sleep-related eating disorder, highlighting shared pathophysiological mechanisms.[65,66] Overall, these studies contribute to our understanding of overlap parasomnia disorder and its complexities.

Sleep-Related Bruxism

Sleep-related bruxism, characterized by involuntary teeth grinding or clenching during sleep, is believed to result from a complex interplay of central and peripheral factors. Studies such as the one by Lavigne et al. have suggested that alterations in central nervous system activity, particularly involving neurotransmitter dysregulation, may contribute to the onset and persistence of sleep-related bruxism.[67] Additionally, peripheral factors such as dental occlusion and muscle hyperactivity have also been implicated in the etiology of this disorder.[68] Overall, the precise underlying mechanism of sleep-related bruxism likely involves a combination of central and peripheral factors, though further research is needed to fully elucidate its pathophysiology.

Management

Non-benzodiazepine sedatives such as Zolpidem and benzodiazepines like Temazepam and Diazepam are commonly prescribed for sleep disorders.[69] Antidepressants, including Citalopram, Amitriptyline, and the frequently used fluoxetine, along with beta-blockers like Propranolol and mood stabilizers such as Lithium, also play a significant role in managing these conditions.[29] Hypnotic drugs, particularly Zolpidem and Zaleplon, have been associated with sleep-related eating disorder (SRED) and other NREM parasomnias.[70] Clonazepam has emerged as a prominent treatment option, with pharmacotherapy often proving successful. Melatonin, noted for its good safety profile, is recommended as a first-line treatment for NREM parasomnias.[71,72] Additionally, zopiclone and psychological therapies such as cognitive behavioral therapy (CBT)and mindfulness-based stress reduction (MBSR) show promise.[73] Hypnotherapy and CBT interventions aim to reduce stress and anxiety, which are known triggers for NREM parasomnias.[74] Furthermore, selective serotonin reuptake inhibitors (SSRIs) and topiramate have shown effectiveness in specific conditions like Sexsomnia and SRED,[70] respectively, while dopamine agonists have been beneficial in SRED cases associated with restless legs syndrome (RLS).[75]

Conclusion

This review aims to bridge the gap between original studies and the latest advancements in treating different NREM parasomnias. However, multiple other potential mechanisms could impact existing drug therapies. Our main goal is to provide a brief insight into NREM parasomnias and to comprehensively discuss existing literature to establish a complete set of information. Although the fundamentals of this concept have been identified in various comorbidities, targeted drug therapies are necessary.
In conclusion, we made an effort to communicate all the important information regarding NREM parasomnias. Thus, by delving into the complexities and nuances of NREM parasomnias, this review seeks to inform and guide future research and clinical practice.

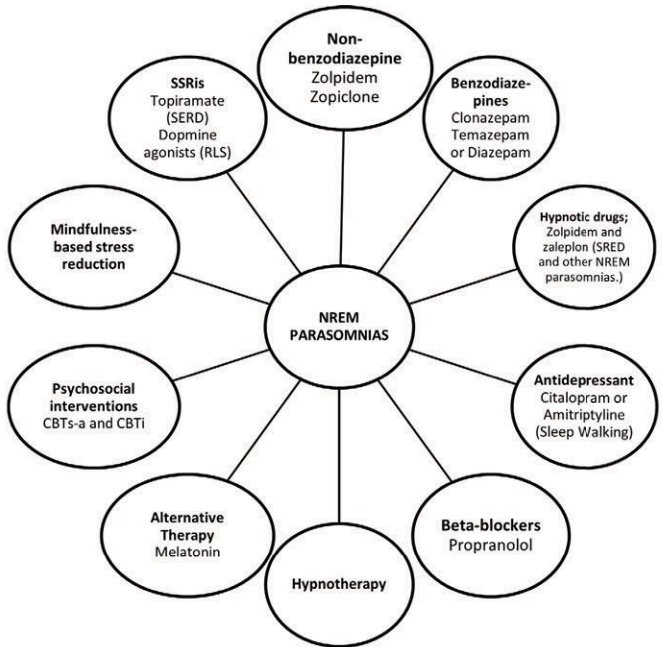


Figure 1. Therapeutic and non-therapeutic management of NREM Parasomnias

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How Does Gambling Correlate with Chronic Health Conditions?

by Henry Stevens, BS, Lillian Cooper, BS & Harit Agroia, DrPH

The findings of this study have important implications for future public health interventions and policies.



Henry Stevens, BS, (pictured), and Lillian Cooper, BS, are at Santa Clara University, Santa Clara, California. Harit Agroia, DrPH, MPH, is Adjunct Professor, Public Health and Recreation at San José State University, San José, California.

Abstract

This study investigates the relationship between gambling behaviors and health outcomes, focusing on chronic illnesses (hypertension, diabetes).

Using data from the 2023 California Health Interview Survey (CHIS), a mixed-mode survey with address-based sampling, we analyzed a large, diverse sample of California residents. We conducted logistic regression models that assessed the correlation between gambling and health outcomes, adjusting for gender and age.

Our results indicate that individuals who gambled within the past year had significantly higher odds of reporting hypertension (OR=1.35) 95% CI [1.24, 1.48] and diabetes (OR=1.32) 95% CI [1.16, 1.49] in comparison to non-gamblers. Gender and age were identified as significant predictors of health outcomes across all models, while gambling did not show an interaction effect with gender.

These findings highlight the complicated relationships between gambling behaviors and chronic physical illnesses. It is crucial we emphasize gambling as a serious public health concern. This study contributes to the existing literature by using recent and newly available CHIS 2023 data to address gaps in understanding the health risks associated with gambling.

Understanding these relationships can help develop future research, interventions, and policies to reduce the negative health impacts of gambling, particularly among vulnerable populations.

Introduction

As of December 2024, gambling is legalized at the state level, thus the legality of gambling varies drastically state by state. Currently, 44 states permit land-based casino operations, and 38 states (plus Washington, D.C.) allow live, legalized gambling. While gambling is legal in Missouri, it has not yet been implemented to its fullest extent[1,2] According to the American Gaming Association, as of 2023, an estimated 49% of all adults in the US participated in some form of gambling, while 26% visited a casino during the same period, marking the highest gambling participation rate on record in the US.[3,4] Gambling has become increasingly prevalent in the US, particularly with the expansion of online gambling and state-sponsored lotteries in recent years. While gambling can be a recreational activity for some, it may also lead to significant health consequences, including chronic illnesses and mental health conditions.

The high rate of US gambling behaviors is alarming, as pathological gambling has been found to be associated with elevated heart rate and increased cortisol levels, both physiological markers of stress.[5]

Prolonged exposure to elevated cortisol levels is extremely problematic as it contributes to poor health outcomes, including an increased risk of cardiovascular diseases like hypertension and atherosclerosis, as well as chronic conditions such as obesity, hyperglycemia, and insulin resistance—which are all indicative of type 2 diabetes.[6,7]

Given the intersection of biological, psychological, and social responses to gambling, our research study and analysis are guided by the biopsychosocial model of health. The biopsychosocial model emphasizes that, as a high-stress behavior, gambling significantly impacts both physical and mental well-being. This study seeks to answer the research question: 'How do gambling behaviors correlate with physical health outcomes (e.g., chronic illnesses, self-reported health status)?' We hypothesize that individuals who gamble will exhibit a higher prevalence of chronic illnesses.

The California Health Interview Survey, 2023 (CHIS 2023) provides a valuable dataset for exploring these connections, as it includes data for 21,671 adults.[9] There are strong links between gambling and both diabetes and hypertension. This study aims to fill a gap in scientific literature by focusing on a large, diverse sample of California residents from the CHIS 2023 dataset. This is particularly significant because the data is both recent and newly included in CHIS 2023, addressing a topic where much of the existing peer-reviewed research dates back to the early 2000s. Given these implications, gambling in the United States is an immensely pressing public health concern that must not be overlooked.

Methods

The data for this study come from the CHIS 2023. This survey is a mixed-mode online and telephone-based survey that aims to collect data on a wide range of topics, including health conditions and general demographic information. For this survey, data is collected via address-based sampling, where one participating household is randomly selected from various geographic regions to obtain a sample that is representative of the state of California. Once a household is selected, one adult is randomly chosen to complete the survey. All households which agreed to provide information are included in the dataset. Open access to this dataset was provided by the University of California Los Angeles and accessed via the website at https://healthpolicy.ucla.edu/our-work/california-health-interview-survey-chis/access-chis-data. The robust sampling method and size of this dataset provides a large, diverse dataset to analyze gambling behaviors and their correlation with health outcomes. The data for this particular study consists of responses solely from 2023 due to it being the first year that questions regarding gambling behaviors were included in the questionnaire.

For the purpose of this study, we focused on binary variables for gambling, hypertension, and diabetes. Gambling behaviors were assessed by a self-reported 'Yes' or 'No' answer to the question "Have you gambled in the last two months?" Next, we converted the responses into a binary 0 or 1, with yes = 1 and no = 0 for our logistic regression. Furthermore, we evaluated the presence of hypertension by looking at the responses to the question "Has a doctor ever told you that you have high blood pressure?" This question had three possible responses: yes, no, and borderline hypertension. For the purpose of the study, we collapsed the answers yes and borderline hypertension categories into one and made hypertension or borderline hypertension=1 and no = 0 for the logistical regression analysis. Finally, we assessed the presence of diabetes by looking at the responses to the question "Has a doctor ever told you that you have diabetes (non-gestational)? Once again, the responses were either yes or no which we converted into yes = 1 and no = 0 for logistical regression analysis. Finally, we conducted logistic regression to assess the relationship between gambling and health outcomes, adjusting for gender and age. Interaction terms tested whether gambling effects varied by gender. Each model included a crude association, adjustments for gender, age, smoking, binge drinking and we tested for an interaction by age and gender. Results were evaluated at a 95% confidence level.

To control for potential confounders in the relationship between gambling and health outcomes, binge drinking, educational attainment, and health insurance status were operationalized based on responses from the CHIS 2023 survey. Binge drinking was defined using the standard public health definition provided by the CDC, with participants categorized as binge drinkers if they reported consuming five or more drinks on one occasion for men (or four or more for women) at least once in the past 30 days. Responses were coded into a binary variable, where 1 indicated binge drinking and 0 indicated no binge drinking during this timeframe. Educational attainment was operationalized by dichotomizing participants based on their highest level of education completed; individuals who reported having a college degree or higher were coded as 1, while those with less education were coded as 0. Health insurance status was determined by participants' responses to whether they were currently covered by any form of health insurance, including employer-sponsored plans, Medicaid, or private insurance. Those with any type of coverage were categorized as insured

(coded as 1), while those without any form of coverage were classified as uninsured (coded as 0). These operational definitions were chosen to align with established public health metrics and facilitate meaningful comparisons across subpopulations.

Smoking, binge drinking, and education were included as control variables due to their potential to confound the relationship between gambling and health outcomes like diabetes and hypertension. Smoking and binge drinking are established behavioral risk factors for diabetes and hypertension and frequently co-occur with gambling. As a proxy for socioeconomic status, education influences gambling behaviors and health disparities. By controlling for these variables, we aimed to isolate the independent effect of gambling on diabetes and hypertension.

Table 1. The socio-demographic breakdown of the study population based on age, gender, race/ethnicity, health conditions, health behaviors, and social factors. 16 participants' responses were dropped from the depression/anxiety category due to them electing not to answer the associated questions.

Variable	Total Sample 21,671	Gambling (Yes) 5,762 (26.6%)	Gambling (No) 15,909 (73.4%)
Demographics			
- Mean Age (SD)	52.5 (17.1)	53.2 (15.9)	52.3 (17.5)
- Male (%)	9,279 (42.8)	2,675 (28.8)	6,604 (71.2)
- Female (%)	12,392 (57.2)	3,087 (24.9)	9,305 (75.1)
Race/Ethnicity			
- White (%)	10,719 (49.5)	2,815 (26.3)	7,904 (73.7)
- African American (%)	1,023 (4.7)	365 (35.7)	658 (64.3)
- Latino (%)	3,333 (15.4)	904 (27.1)	2,429 (72.9)
- Asian (%)	3,364 (15.5)	759 (22.6)	2,605 (77.4)
- American Indian/Alaska native (%)	162 (0.8)	65 (40.1)	97 (59.9)
- Other single/multiple race (%)	3,070 (14.2)	854 (27.8)	2,216 (72.2)
Health Conditions			
- Hypertension (%)	8,753 (40.4)	2,641 (30.2)	6,112 (69.8)
- Diabetes (%)	2,809 (13)	884 (31.5)	1,925 (68.5)
- Depression/Anxiety (%)*	2,541 (11.7)	644 (25.3)	1,897 (74.7)
Health Behaviors			
- Current Smoker (%)	1,172 (5.4)	461 (39.3)	711 (60.7)
- Binge Alcohol Use (%)	3,561 (16.4)	1,184 (33.3)	2,377 (66.8)
Social Factors			
- College degree or Above (%)	12,122 (55.9)	2,955 (24.4)	9,167 (75.6)
- Insurance (%)	20,991 (96.9)	5,606 (26.7)	15,385 (73.3)

*16 participants were dropped based on "proxy skipped" response

Results

When analyzing our results, we must first look at the sociodemographic characteristics of the study population. In terms of gender, the study population consisted of more females than males with females making up 57.2% of the study population while males made up 42.8%. Despite the study population consisting of more females than males, the proportion of females who self-reported gambling is fairly consistent with the proportion of males who self-reported gambling with 24.9% of females reporting they had gambled in the last 12 months and 28.8% of males reporting gambling as well.

When looking at the racial and ethnic demographics of the study, we see that the study population is 49.5% white, with Asian and Latino individuals making up the next two largest groups with 15.5% and 15.4% of the population respectively. Across racial and ethnic categories, the majority of groups reported anywhere from 22%-28% of the population gambled in the last 12 months with the exception of African Americans and American Indian/Alaska Natives reporting 35.7% and 40.1% respectively.

In terms of health behaviors, we recorded self-reported smoking and binge drinking status. We found that 5.4% of the study population reported being a current smoker. Among the smoking population, 39.3% reported gambling in the last 12 months and 60.7% did not. Similarly, 16.4% of the study population reported binge drinking. Among those individuals, 33.3% reported gambling in the last 12 months, and 66.8% did not. Overall, across all of the sociodemographic factors we analyzed, there were consistent distributions of those who reported gambling between groups within the same overarching category, such as across, gender, racial/ethnic groups and across health behavior groups.

Table 1 shows the socio-demographic breakdown of the study population based on age, gender, race/ethnicity, health conditions, health behaviors, and social factors. Sixteen participants' responses were dropped from the depression/anxiety category due to them electing not to answer the associated questions.

The first logistic regression model, Table 2, which looks at hypertension suggests that gender, age, and gambling in the past 12 months are significant predictors of the outcome variable hypertension (HTN). Females are less likely to experience HTN compared to males, and older individuals are more likely to experience HTN compared to younger individuals. Additionally, individuals who have gambled in the past 12 months are 1.35 times more likely to experience HTN when compared to those who have not (OR: 1.35) 95% CI [1.24, 1.48]. However, there is no significant interaction between gender and gambling, suggesting that the effect of gambling on the outcome of HTN is similar for both males and females.

When we include an adjustment for smoking, binge drinking, and education level, we see that gambling

Table 2. Depicts the outcomes of the logistic regression investigating the relationship between gambling habits, gender, and age on hypertension. The table shows the crude odds ratio (OR), as well as the OR adjusted for gender and age. Results were evaluated at a 95% confidence interval.

	Crude OR	OR adjusted for gender	OR adjusted for gender and age	OR adjusted and with interaction
Outcome (y): Hypertension	Model 1 OR [95% CI]	Model 2 OR [95% CI]	Model 3 OR [95% CI]	Model 4 OR [95% CI]
Gambling	1.36 [1.28,1.44]	1.33 [1.25,1.42]	1.35 [1.27,1.44]	1.35 [1.24,1.48]
Gender		0.66 [0.62,0.69]	0.68 [0.64,0.72]	0.68 [0.63,0.73]
Age			1.05 [1.05,1.05]	1.05 [1.05,1.05]
Gambling*Gender				1.0 [0.88,1.14]

in the past 12 months was associated with a 34.04% increase in the odds of having hypertension (OR = 1.3404, p < 0.001). Current smoking was associated with a 15.21% reduction in the odds of hypertension (OR = 0.8479, p = 0.007), indicating a significant but inverse relationship. Binge drinking in the past 30 days was associated with a 26.50% increase in the odds of hypertension (OR = 1.2645, p < 0.001). Educational attainment showed a protective effect, as individuals with a college degree or higher had 29.06% lower odds of hypertension compared to those without a college degree (OR = 0.7094, p < 0.001).

Table 2 depicts the outcomes of the logistic regression investigating the relationship between gambling habits, gender, and age on hypertension. The table shows the crude odds ratio (OR), as well as the OR adjusted for gender and age. Results were evaluated at a 95% confidence interval.

Table 3 depicts the results of the next logistic regression model which suggests that gender, age, and gambling in the past 12 months are significant predictors of diabetes. Females are less likely to develop diabetes compared to males, and older individuals are more likely to develop diabetes compared to younger individuals. Additionally, individuals who have gambled in the past 12 months are 1.32 times more likely to develop diabetes (OR: 1.32) 95% CI [1.16, 1.49]. However, there is no significant interaction between gender and gambling, suggesting that the effect of gambling on diabetes is similar for both males and females.

When controlling for smoking, binge drinking, and education level, the analysis shows that individuals who engaged in gambling in the past 12 months are 31.8% more likely to have diabetes compared to those who did not gamble, after controlling for the other variables (OR = 1.3178, p < 0.001). In contrast, current smoking status appears to be associated with lower odds of diabetes. Specifically, smokers have 14.98% lower odds of having diabetes compared to non-smokers, although this result is marginally significant (OR = 0.8502, p = 0.055), indicating a weak association. Binge drinking in the past 30 days is strongly associated with an increased likelihood of diabetes. Those who engaged in binge drinking are 129.8% more likely to have diabetes compared to non-binge drinkers (OR = 2.2978, p < 0.001). Finally, having a college degree or higher is associated with a 42.43% reduction in the odds of having diabetes, suggesting that higher educational attainment has a protective effect (OR = 0.5757, p < 0.001).

Table 3 depicts the outcomes of the logistic regression investigating the relationship between gambling habits, gender, and age on diabetes. The table shows the crude odds ratio (OR), as well as the OR adjusted for gender and age. Results were evaluated at a 95% confidence interval.

Discussion

The results of this study are consistent with previous research connecting gambling behaviors to chronic illnesses. Specifically, gambling was significantly associated with increased odds of hypertension and diabetes. Thus, our findings aligned with studies that highlight the physiological impacts of gambling, such as elevated cortisol levels and heart rate.[10] Overall, our findings indicate a correlation between gambling behaviors and chronic physical illnesses.

In addition, several limitations of this study must be acknowledged. First, the CHIS dataset relied on self-reported data (either online or over the phone), which introduces the potential for recall bias, confusion, or inaccuracies in responses. Second, the cross-sectional design prevents the ability to establish causal relationships between gambling and health outcomes. Third, the findings may have limited generalizability to the broader population, as the data was solely collected from California residents. Fourth, a small percentage of participants did not respond to certain questions in the survey, and we chose to exclude these individuals from the analysis. This decision may have introduced bias into our results, as the reasons for their non-responses remain unknown. Last, we only considered a limited range of psychosocial variables in this study, focusing primarily on gender and age, leaving other potential influencers such as socioeconomic status unexamined. Nevertheless, despite these limitations, our findings contribute valuable insights into the health implications of gambling.

Table 3. Depicts the outcomes of the logistic regression investigating the relationship between gambling habits, gender, and age on diabetes. The table shows the crude odds ratio (OR), as well as the OR adjusted for gender and age. Results were evaluated at a 95% confidence interval.

	Crude OR	OR adjusted for gender	OR adjusted for gender and age	OR adjusted and with interaction
Outcome (y): Diabetes	Model 1 OR [95% CI]	Model 2 OR [95% CI]	Model 3 OR [95% CI]	Model 4 OR [95% CI]
Gambling	1.32 [1.21,1.43]	1.3 [1.19,1.41]	1.31 [1.2,1.43]	1.32 [1.16,1.49]
Gender		0.72 [0.67,0.78]	0.76 [0.7,0.83]	0.76 [0.69,0.84]
Age			1.04 [1.03,1.04]	1.04 [1.03,1.04]
Gambling*Gender				0.99 [0.83,1.18]

Future research could address these gaps by employing longitudinal designs to establish causal relationships between gambling and health outcomes. Additionally, investigating specific gambling behaviors, such as frequency, type, or expenditure, could provide a more nuanced understanding of how gambling affects physical and mental health. Expanding the scope of psychosocial factors may help us to further understand the complex relationship of factors that influence health outcomes. Lastly, it is imperative to compare results across different populations and regulatory environments in order to ensure the generalizability of results and better understand the role of external factors in gambling-related health risks.

The findings of this study have important implications for future public health interventions and policies. For example, targeted education campaigns could distribute educational materials and resources about chronic diseases throughout the communities identified as at risk. These campaigns could include educating pathological gamblers on the signs and symptoms of chronic illnesses, such as diabetes and hypertension, as well as the risks of not treating them properly. Educating individuals who gamble or have a gambling problem about their increased risks for disease opens the door for them to take preventative measures. Additionally, the implementation of stress management programs tailored to individuals who gamble may help to reduce some of the physiological impacts of gambling-related stress. Policymakers should also consider stricter regulations on gambling advertisements, particularly those targeting vulnerable populations, in order to reduce exposure and potential harm. Lastly, incorporating more questions about gambling behaviors into broader health surveys could also facilitate increased data collection and better inform public health initiatives aimed at addressing the negative health impacts of gambling.

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Disclosure

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Gambling in Missouri: Show Me the Results

by Henry Stevens, BS

In Missouri, riverboat gambling, lottery, and horse racing are legal forms of gambling, although Missouri currently has no horse racing tracks. Riverboat gambling is currently the primary form of legal gambling in Missouri, and the Missouri Gaming Commission (MGC) regulates riverboat gambling activities (Revised Statutes of Missouri, Section 313.805).



Missouri has a Voluntary Self-Exclusion Program for persons who believe they engage in problematic gambling, and violation of the exclusion results in criminal trespass charges (Missouri Code of State Regulations, 11 CSR 45-17). However after five years, you can apply to the MGC to have your name removed from the exclusion list, but if you offend after reapplication, you are banned for life. In November 2024, Missouri citizens approved Missouri Amendment 2, the Sports Betting Initiative, legalizing regulated sports betting in Missouri and directing the MGC to implement the program no later than December 1, 2025. This measure amends the state constitution and will allow for the expansion of legal gaming in Missouri.[1]

Since Missouri legalized online sports gambling, the state has observed significant shifts in its gambling landscape, accompanied by rising concerns about addiction. The 2022 Missouri Gambling Prevalence Study estimated that approximately 4% of Missouri adults, equating to about 200,000 individuals, met the criteria for a gambling disorder, with an additional 21% (around one million people) at risk. This indicates that nearly one in 20 residents has a gambling problem, and one in five is on the verge.[2]

The increased accessibility of online sports betting has raised alarms regarding potential spikes in problem gambling among vulnerable populations. Studies have shown that online gambling legalization leads to more irresponsible gambling spending among lower-income consumers than among higher-income gamblers. To expand, a study from the University of California San Diego found that online gambling legalization leads to far more problematic gambling among lower-income gamblers, emphasizing the high financial risk associated with online gambling[3].

In response to these concerns, Missouri has proactively adopted safeguards to mitigate harm. The state has established a $5 million compulsive-gambling fund aimed at preventing problem gambling and avoiding the rise in addiction seen in other states following legalization.[4]

Overall, the legalization of online sports gambling in Missouri has transformed the state's gaming sector and prompted a cautious, evidence-based approach to managing gambling addiction. By leveraging experiences from other states and community-based resources, Missouri strives to ensure that the benefits of legalized gambling do not come at the expense of public health. Ongoing research and adaptive policy measures remain immensely crucial to ensure a balanced approach that maximizes benefits while minimizing addiction risks.

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Statistics as a Tool in the Physician's Black Bag

by Robert W. Baer, PhD

Each time we encounter new medical information presented using unfamiliar statistical terminology, we have an unprecedented opportunity to self-educate.



Robert W. Baer, PhD, is Professor of Physiology at the Kirksville College of Osteopathic Medicine, A.T. Still University of Health Sciences, Kirksville, Missouri. In addition to physiology, he teaches evidence-based medicine to first year medical students and biostatistics to graduate students.

Abstract

The era of evidence-based practice began in the 1990s with the hope patient outcomes would be improved by eliminating clinical bias and clinically unsound practices. Clinical guidelines which had been previously written by panels of experts were slowly replaced by careful analysis of existing clinical studies and more rigorous designs of new clinical studies based on sound scientific and statistical principles. This still leaves the practitioner with the responsibility of understanding what the evidence is showing them. This article reviews the statistical thinking that underlies the evidence-based literature. We will review some evolutionary changes to statistical analysis being advocated by statisticians and discuss some nuances related to the use of statistics describing diagnosis and treatment in clinical settings.

Introduction

Years ago, I was asked to do some statistical consulting for a prominent surgeon who was writing up his pre-clinical experiments for a new *in utero* procedure. I looked at his dataset and began to explain how he could go about analyzing the data. After only a couple of sentences, he interrupted me and said, "I don't want to know all that, just give me a p-value." I took his dataset, did the statistical analysis for him, and supplied him with the desired p-value. The next time I saw this surgeon, I had moved across the country, and he was on the national evening news explaining the tremendous impact of his new procedure. Neither he nor the news anchor even once mentioned statistics or p-values.

The moral of this story might appear to be that physicians don't need to understand statistics to help their patients. In fact, this surgeon understood that he would need to do some statistics that produced a p-value if he was going to get his animal study published and convince his colleagues that he could safely perform the operation on human patients. In this article, we will discuss some big picture statistical concepts, including some unappreciated aspects of the p-value, in the hopes that they can help you conduct a more effective, evidence-based clinical practice. We will start with some basics, turn to some recent statistical trends, and finish with common statistics used in clinical diagnosis and treatment.

Descriptive Statistics and Confidence Intervals

If one reads the clinical literature, one is likely to encounter confidence intervals. A 95% confidence interval (95% CI) is

an estimate of how confident we are about where the middle value of the population falls. It does not tell us about the spread of values within the population. It is really a statement about the validity of the statistical technique we have used to determine the center of the population. The confidence interval is directly related to the spread of values in the population and inversely related to the square root of the sample size. The more confident we wish to be about having included the real center of the population, the wider the confidence interval will need to be. Confidence intervals are based on standard error and not standard deviation. They depend not only on both sample size and sample spread but also on sampling theory.

Al Kibria[1] tells us that based on the NHANES database[2] the population mean diastolic blood pressure is 70.7 mmHg with a 95% CI of (70.4, 71.0) mmHg. This interval can be easily calculated from the reported mean (70.7 mmHg) and the reported standard error (0.2 mmHg). The reason this 95% confidence interval is so tight is that the data came from 16,103 subjects, and thus, the standard error is small. This confidence interval helps us fix the middle value of the population with a known certainty.

Confidence Intervals Don't Describe Clinical Variability

Let's use the diastolic blood pressure example again, but this time to see what range of diastolic pressures, we might expect in 68% of patients. If diastolic blood pressure were to be normally distributed, 68% of the pressures would fall between one standard deviation below and one standard deviation above the mean diastolic blood pressure. Notice that we are using standard deviation and not standard error. Standard deviation can be calculated by multiplying standard error by the square root of sample size. Thus, from Al Kibria[1] we get a standard deviation of $\sqrt{16103} \cdot 0.2 = 25.4$ mmHg. Based on our normality assumption, 68% of all individuals would have blood pressures of 70.7±25.4 mmHg or between 45.3 and 96.1 mmHg. This interval is much wider than the 95% CI of (70.4, 71.0) mmHg that we calculated above. It makes the point that 95% confidence intervals have nothing to do with the range of values that we might expect in our patient population. In summary, confidence intervals depend on standard error and tell us where the central value of the population might lie. Standard deviation is the variable of interest if we wish to know what range of values we might expect to see across a heterogeneous population of patients.

Null Hypothesis Statistical Testing

Most of the current clinical and biomedical literature makes use of what is referred to as Null Hypothesis Statistical Testing (NHST). In the NHST framework, the investigator proposes a straw man null hypothesis that drug X does not improve heart attack outcomes in hypertensive patients with the hope that he can "disprove" this hypothesis. If the null hypothesis is disproved, the alternative hypothesis is invoked, and the investigator concludes that drug X is effective. When using the NHST framework, we have the potential of making two types of mistakes. We can wrongly conclude that the null hypothesis is false when it is true (type I error), or we can conclude wrongly that the null hypothesis is true when it is false (type II error).

In practice, investigators determine some maximal acceptable probability of wrongly concluding that drug X is effective called the alpha level, A common choice is alpha = 0.05. In the NHST framework, if the actual p-value is less than the alpha level, the investigator will declare a "statistically significant" difference.

Our p-values are conditional probabilities based on the premise that the null hypothesis is true.[3] Investigators are often tempted to claim that a finding is "more statistically significant" if they get a $p< 0.001$ instead of a $p< 0.05$. This is an inappropriate conclusion. In both cases their p-value falls below the alpha cutoff. Effectively, the investigator has concluded that the null hypothesis untrue in both cases. This also means that any conclusion based on the premise of the null hypothesis being true is meaningless.

Despite the ubiquitous presence of NHST and p-values in the clinical and biomedical literature, the American Statistical Association (ASA) in 2016 issued a statement condemning or at least cautioning against its exclusive use.[4] This statement followed long-standing, independent criticisms of the NHST approach.[5–7] The statement enumerated six principles. The interested reader is invited to read their entire statement, but three principles particularly worth repeating here are:[4]

- P-values do not measure the probability that the studied hypothesis is true, or the probability that the data were produced by random chance alone.
- Scientific conclusions and business or policy decisions should not be based only on whether a p-value passes a specific threshold.

- A p–value, or statistical significance, does not measure the size of an effect or the importance of a result.

We have previously discussed the first bullet point by noting that p-values are conditional probabilities about the data, given the model/hypothesis framing the experiment, and not a statement about the model/hypothesis itself. The second bullet reminds us that science is an iterative process of building a model that represents reality. Often our model is neither correct nor incorrect. Rather our model is just incomplete. This bullet reminds us that it is important to keep in mind nuances and gray areas when integrating results from new studies. The third bullet reminds us that how much something changes can be as important or more important than whether it changes.

Effect Size

The 2016 American Statistical Association stopped short of banishing the term "statistically significant." Three years later, an editorial in the American Statistician did just that.[8] The reporting of p-values was not discouraged, but the editorial emphasized the necessity of providing important contextual information. Effect sizes have been forwarded as a key component of providing context. An effect size is simply the magnitude of the change that occurs with an intervention.[9] In statistical practice, effect size measures are often normalized to some measure of variability. Examples include Cohen's d and Pearson's correlation coefficient but there are many others. The precise calculations are not important because online calculators are readily available.[10] What is important is how effect sizes can provide context to clinical studies.

If you were considering a new drug that could lower blood pressure and were told that the drug would lower a patient's mean blood pressure by 1 mmHg if taken for a year, you would likely not be impressed. If the drug lowered mean blood pressure by 20 mmHg, 10 mmHg, or even 5 mmHg you might keep reading depending on your patient's needs. The problem with p-values is that you can have situations where results are statistically significant but not clinically significant, or conversely, you can find situations where results are clinically significant but not statistically significant. Statisticians have begun to suggest novel approaches for handling these differences which include enhanced variations on the p-value.[11–13]

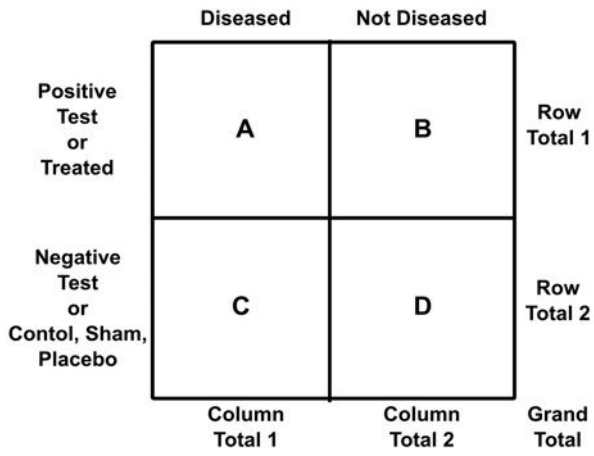


Figure 1. Using 2 x 2 tables. A standard 2 x 2 layout can be used to calculate statistics related to diagnostic testing or treatment success. The first set of row labels is used with diagnostic testing statistics. The second set of row labels is used with treatment statistics.

Diagnostic Testing and Statistics

Sensitivity and specificity are the two terms most physicians associate with diagnostic testing. Sensitivity measures the fraction of diseased patients that have a positive test. Specificity measures the fraction of not-diseased patients that have a negative test. Values for sensitivity and specificity are typically generated by diagnostic test manufactures. Categorization of diseased and not diseased patients to generate sensitivities and specificities is generally based on a gold standard test which may be expensive, invasive, or only available later in the disease progression. It is critical to understand that sensitivity only contains information about diseased patients and specificity only contains information about not diseased patients. You may wonder why we use the term "not diseased" rather than the term "healthy." It is because with diagnostic testing we are focused on a specific disease state, and the fact that a patient does not have the disease of focus does not imply that they are entirely healthy.

The calculation of sensitivity and specificity is easily appreciated from examining Figure 1 where the top row represents number of diseased and not diseased patients with positive tests, and the second row represents the number of diseased and not diseased patients with a negative test. Sensitivity is the number of patients in cell A divided by column total 1. Specificity is simply the number of patients in cell D divided by column total 2. Both are fractions that can vary between 0 and 1, but they are sometimes

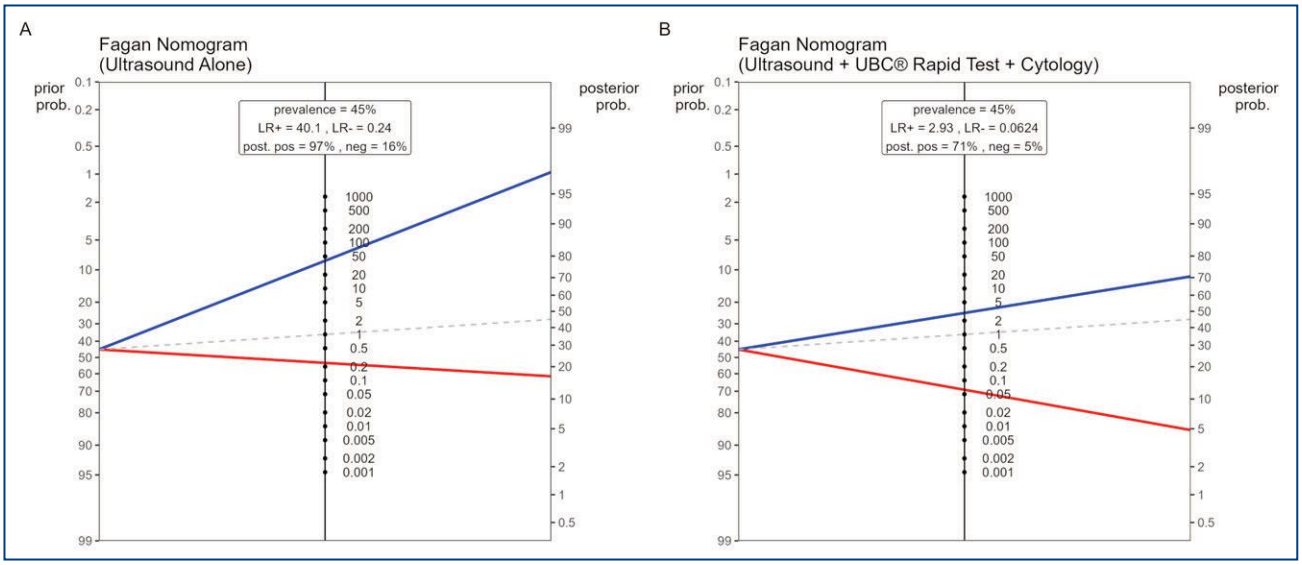


Figure 2. Fagan nomograms. These nomograms convert the pretest probability of a given diagnosis into posttest probability based on the test result. A line connecting the pretest probability to the LR+ if the test is positive or to the LR- if the test is negative is projected to the right side of the graph and the posttest probability is read. The examples show data from Barak et al.17 to compare the diagnosis of bladder cancer using ultrasound alone (panel A) or using ultrasound in combination with UBC® rapid test and urine cytology (panel B). Blue lines show effect of a positive test result on diagnostic certainty. Red lines show the effect of a negative test result on diagnostic certainty. The gray dotted lines represent reference probability that is unchanged by testing (LR = 1).

expressed as percentages by multiplying the fractions by 100. An excellent but somewhat dated resource from the American College of Physicians provides a rich description of sensitivity and specificity values for numerous common diagnostic tests.[14] Medical students are often taught that a test with a high specificity and a positive result is useful for ruling in a disease (SpPIn), and a test with a high sensitivity and a negative result is useful for ruling out a disease (SnNout). Nevertheless, sensitivity and specificity values are difficult to apply in clinical practice because they don't directly relate test results to the likelihood that a patient has a disease on the differential.

In fact, what physicians really care about the fraction of positive tests that are true positives rather than false positives, called positive predictive value (PPV). PPV can be calculated by dividing cell A by the row total 1 in Figure 1. Similarly, physicians are interested in the fraction of negative tests that are true negatives, called negative predictive value (NPV). NPV can be calculated as cell D divided by row total 2 in Figure 1.

Although PPV and NPV are closer to values of use to a physician, they are quite static numbers and are not easily applied to a physicians thinking about an individual patient. Generically, a physician takes a history and physical and, in conjunction with local prevalence, develops an initial probability that a patient has a certain diagnosis. Diagnostic tests are then run to help increase or decrease that diagnostic suspicion. This can be turned in to a semiquantitative process that considers both the initial probability and the strength of the diagnostic test. This process is based on Bayesian statistics[15] and involves the calculation of positive and negative likelihood ratios.[16] The positive likelihood ratio (LR+) is calculated as Sensitivity/(1-Specificity). The negative likelihood ratio(LR-) is calculated as (1-Sensitivity)/ Specificity.

The process of determining the posttest probability of a diagnosis involves converting the pretest probability into a pretest odds, multiplying by the appropriate likelihood ratio for the actual test result, and then converting the post-test odds back into a posttest probability. This can be done graphically using a Fagan nomogram (Figure 2). A straight line from the pretest probability and extended through the appropriate likelihood ratio intersects the right axis at the posttest probability.

As an example, consider a recent study that compared non-invasive diagnostic testing strategies for diagnosing bladder cancer. [17] In one strategy they used ultrasound alone. In the second strategy they used a 3-test combination of ultrasound, UBC® rapid test, and urine cytology.[17] In the study setting,

the pretest probability (local prevalence) of having bladder cancer was about 45%. The sensitivity and specificity for ultrasonography alone were 91.3% and 72.2%, respectively. This translates to an LR+ of 3.28 and an LR- of 0.12, respectively. The sensitivity and specificity for a 3-test combination of ultrasonography, UBC®rapid test, and urine cytology were 95.8% and 67.3% respectively. This corresponds to LR+ of 2.93 and LR- of 0.062.

The posttest probability of bladder cancer for positive and negative tests using each diagnostic regimen can be determined using a Fagan nomogram (Figure 2). The upper blue lines show us that bladder cancer is more likely in the face of a positive test, and the lower red lines show us that bladder cancer is less likely when the test is negative. The two diagnostic testing strategies differ with respect to how much the probability changes with each test result. With ultrasound alone, a positive test greatly increases the probability that our patient has bladder cancer, but a negative test only mildly decreases that probability. With the set of 3 non-invasive tests, a positive result yields a more modest increase in bladder cancer probability, but a negative result decreases the cancer probability more effectively than ultrasound alone. As the authors point out, the 3-test diagnostic strategy has advantages in this scenario because it can be more effective at delaying or avoiding unnecessary surgery which would be the next step in the face of an uncertain diagnosis. Plotting Fagan diagrams for common scenarios in your own clinical practice has the potential to improve the efficiency and reliability of your own diagnostic strategies.

Therapeutic Effectiveness and Statistics

Most clinical studies, including clinical trials, deal with the risk of having a disease. Risk is essentially the probability that a person will become ill or die within a specified period of time.[18] Generally, a new therapy is compared to a control group consisting of the existing standard of care, a placebo treatment, a sham treatment, or even an untreated group. The goal of the study is to see if the new therapy mitigates risk more effectively than the control. We can use the lower set of row labels in Figure 1 to understand some of the terminology that is expressed in making these comparison.

The risk in the treated group is often called the experimental event rate (EER) and can be calculated by dividing the number of subjects that end up in cell A by row total 1. Similarly, the risk in the control group (CER) can be calculated by dividing the number of subjects in cell C by row total 2. Two key measures of treatment effectiveness are often derived from these numbers: absolute risk reduction (ARR) and relative risk reduction (RRR). Absolute risk reduction is the difference between the risk in control subjects and the risk in treated subjects, i.e., ARR = CER – EER.[19] Relative risk reduction normalizes this difference to the control event rate, i.e., RRR = (CER – EER)/CER.[19]

When reading the medical literature, it is essential to distinguish between relative and absolute risks. Generally, absolute risk reduction is more meaningful, but relative risk reduction is often reported by pharmaceutical manufacturers who wish to make a new therapy look more effective. As an example, Marabotti[20] summarized absolute and relative risk reductions for COVID vaccine from a number of manufacturers. Absolute risk reduction ranges from 0.54% to 1.19%, whereas relative risk reduction ranges from 66.9% to 95%. To the uninitiated, it is easier to make a positive case for vaccine use by sharing the relative risk numbers than by sharing the absolute risk reduction numbers. To understand why the numbers are so different we need to look more closely.

To make ARR easier to understand, one can take its reciprocal to calculate the so-called number needed to treat, i.e., NNT = 100/ARR when ARR is in percent.[21] The number needed to treat is the number of individuals that must be treated over the duration to have one less adverse incident. The NNT for COVID vaccines summarized by Marabotti[20] range from 82 to 185 for various vaccines. For comparison, NNT = 100 for antihypertensive therapy to prevent fatal or non-fatal myocardial infarction.[22] Duration of treatment is important and needs to be considered when comparing values. NNT tends to go down with longer treatment times because there are more "potential events" that can be mitigated by treatment. For the antihypertensive studies, treatment times are typically looking at risk across a 5-year time span. The COVID studies are of shorter duration, and it is to be expected that the ARR will increase and the NNT will decrease for COVID vaccination as the post-pandemic era continues to lengthen.

One benefit of relative risk reduction values is that they tend to stay relatively constant across different practice settings.[23,24] For example, the relative risk reduction for an antihypertensive agent may be similar in a family practice setting and a cardiology setting. This is not true for absolute risk reduction. The implication is that the NNT determined from a study carried out in a cardiology practice may overestimate the effectiveness of that same drug in a family medicine setting where the NNT will be higher. This is because the baseline risk of an adverse cardiac event is lower in the family practice setting. If we examine the relationship between ARR and RRR we see that ARR = CER·RRR. In a practice setting where control event rate is low, absolute risk reduction will also be low, and number needed to treat will be high. Conversely, if we know RRR and have a good feel for our local control event rate, we can estimate ARR and NNT for our own practice setting even though we only have data derived in a specialty practice setting. This discussion highlights that we need to carefully pay attention to practice setting and duration of treatment information before applying risk measures to our own practice needs.

Statistics and Evidence-Based Practice

We have talked about some, but clearly not all, of the statistical concepts that are beneficial for understanding the clinical literature. When evidence-based medicine came into its own during the 1990s many pictured that the individual practitioner would be applying evidence at the bedside. We have made some progress toward that goal, but analyzing evidence is a job that will likely continue to be left to the professional statistician, just like clinical lab results are left to the laboratory technologists. However, the individual practitioner is left with taking the statistical information provided by these specialists and incorporating it into daily patient care. Statistics does not need to be understood all at once. Each time we encounter new medical information presented using unfamiliar statistical terminology, we have an unprecedented opportunity to self-educate. New AI tools will make this even easier as they mature. Hopefully, this life-long learning will contribute to ever more positive patient outcomes.

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