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Congress wants to put a price on your life

By Grace-Marie Turner

Speaker Nancy Pelosi [has committed](#) to pushing her drug price control bill through the House, attached to the giant and highly partisan \$3.5 budget reconciliation package.

It's unlikely that her radical drug proposal could pass on its own.

In their plans to lower prescription drug prices, Speaker Pelosi and House Democrats want to use a formula that would base U.S. prices on those set by other developed countries. These countries use a variety of techniques, including a rationing scheme called "Quality Adjusted Life Year" or QALY, that puts a dollar value on a person's life. Government agencies use the formula to decide whether to cover and pay for a particular drug—usually a new drug—and which patients can get it.

Supporters of measures currently before Congress do not explain to voters that this mechanism is a component of their proposal, which they advertise as allowing the government to "negotiate" prescription drug prices for Medicare. They don't explain how patients could be denied access to drugs by this QALY scheme, which is a hidden but central feature in the House plan.

Senate Democratic leaders, sensing this could be a problem, have said they will [create new mechanisms](#) to control prices and not rely on other countries' models. They are being advised the U.S. could set up [waiting lists](#) for access to new drugs, for example. Others suggest copying the [Veterans Administration's complex web](#) of price controls, but that would mean seniors would have access to fewer drugs, especially newer drugs, than they do today.

Imitating any [government cost-reduction scheme](#) inevitably will lead to rationing, shortages, and reduced innovation. No matter how the Democrats' price control mechanism is structured, it would dry up research into new medicines and limit access for patients.

We helped organize focus groups this summer to assess attitudes toward QALYs and found that people think the approach is:

1. **Discriminatory:** Voters, particularly seniors, are concerned. Like disability and patient advocacy groups who have expressed concerns, they can easily envision how the application of the QALY formula could be discriminatory against older people, people with disabilities, those who suffer from chronic diseases, and other vulnerable patients.
2. **“Playing God:”** QALY or some alternate mechanism which the government or its “experts” use to assign value to human life are antithetical to many Americans, particularly seniors who depend on Medicare, and the idea is sufficiently disliked as to disqualify support for any policy proposals that contains these or similar mechanisms.
3. **Putting a Price on Life:** The idea that some entity (government) might put a price on the value of a human life is both believable and, at the same time, repugnant.

Explaining the QALY concept

Many developed countries have government-run health care systems that are largely or entirely funded through taxation and therefore must operate within budgets established by their elected officials. As a result, politicians determine how health care resources are allocated to their citizens to stay within the budgets.

When it comes to government decisions about drug coverage in these countries, if a drug is deemed too expensive relative to its value (as determined by an arbitrary mechanism like the QALY), the government can decide not to pay for it or strictly limit who gets it.

Only [half of new drugs](#), on average, get approved for payment in these countries. When payment for a new drug is approved by the government, only those who meet the value threshold as determined by economists—not doctors—will have a chance to receive it.

But what politicians define as value will likely differ from what a patient battling a disease values to get more time with their family or to be at home instead of in the hospital.

Future patients will suffer, too. Investments in research will shrink, leading to fewer new medicines being developed, and those available today will be more difficult for patients to access.

The Congressional Budget Office acknowledges, in a new [white paper](#), that at least 60 new treatments and cures will be sacrificed if this or a similar proposal is enacted. And this is a conservative estimate; CBO says there is enormous uncertainty in its estimates.

Discriminatory

Under the QALY mechanism, if a person has a disability or chronic disease, the yearly value of their life is considered to be less, or if they are older, they have fewer years to live and as a result they may not qualify to get the drug.

In the UK, for example, the government sets the monetary value of a year of perfect health somewhere between \$28,000 and \$42,000.

The QALY measure “assigns a lower value to the lives of people with disabilities and chronic illnesses,” according to [a letter to Congress](#) from the National Council on Disability, an independent federal agency that focuses on disability policy. It says that “countries that rely on the QALY have restricted or denied patients with disabilities access to effective drugs used to treat chronic conditions and to breakthrough medications.”

Our focus group participants said this is unacceptable. The name of physicist Stephen Hawking was brought up unaided by participants as an example of how diminishing the worth of a person’s life based on their disability is not only morally wrong but also fails to account for the contributions that person might make to society.

“What would we have done without Stephen Hawking? I mean, come on, when you come to disabled, he is and he’s very valuable to humankind—among others that have disabilities,” said a Pennsylvania woman. “So how can you value that life just based on their pain and experience?”

Concerns about the discriminatory impact of the QALY led to Congress voting to prohibit its use when it passed the Affordable Care Act in 2010. But what if Congress changes the law to allow it—not explicitly but by importing the drug pricing schemes of other countries? This is Speaker Pelosi’s stealth plan to get around the law she helped enact in 2010.

“They’re Playing God”

Congress wants to reduce the amount the government spends on drugs for Medicare beneficiaries. The route to government savings would be via denying seniors access to drugs or rationing who gets them. An earlier estimate of a similar plan by the Centers for Medicare and Medicaid Services showed that [up to half of the savings](#) would come from seniors not receiving necessary medicines and treatments.

“I don’t like this government deciding who’s going to get the drug,” a retiree in New York told the focus group. “That should be between you and your doctor.”

One patient said: “It’s definitely wrong. They’re playing God, and it’s not their place to determine who gets to live and who gets to die, and it doesn’t matter what their quality of life is. That’s nobody’s business.”

A senior asked: “Who is making the decisions on every American in this country? That would scare me a lot.”

“And I mean, who’s to say a 30-year old’s quality of life is going to be better than a 60-year old’s?” said a Pennsylvania man. “A 60-year-old could have lived a beautiful life, have a beautiful family, grandchildren, retired, enjoying life, and the 30-year old could be out doing crazy sports, drinking, and using drugs. I’m not saying they do, but their life is a whole lot more loose and free, not, you know, the responsibility maybe of [someone with a] family that they’re dedicated to...”

And the focus group participants were not happy that Congress would try to slip this past them.

“I haven’t heard of this before. I have no idea who introduced it. I just hope they revise it before it does down a really bad path,” a Pennsylvania senior told us. “I think they need to come up with a better proposal.”

A caregiver from Georgia said: “I think it’s very wrong. They shouldn’t be able to determine how long a person has left and pull resources from them. They should be able to have what they need and fight to live longer. If they have the will to do that, the government shouldn’t be able to determine how long a person has left.”

“There’s all this money put into the scientific research to create these new drugs to make our lives better when it becomes available. How can we deny that? I mean, what’s the point of doing all this research if we’re not going to use it? How can we turn down these new treatments?” an Arizona patient with chronic disease told us.

“They should not make the decision of who gets to live and who gets to die, who’s deserving and who’s not,” she said. “No price can be put on a life...When the government decides what a life is worth, that rubs me the wrong way. They should not be playing God,” she said.

(We have used descriptions rather than names in quoting those who participated in the focus groups to protect their identity and facilitate an open discussion. The sessions were conducted via Zoom earlier this summer and included participants from around the country, including seniors, patients with chronic disease and their caretakers, and women.)

Putting a Price on Life

Deploying QALYs or any similar version of a rationing scheme is antithetical to American values. And it is illegal. The Rehabilitation Act prohibits discrimination on the basis of disability in all programs or activities conducted by the Department of Health and Human Services—including Medicare.

The House bill, the Elijah E. Cummings Lower Drug Costs Now Act, would try to upend that law by stealthily importing drug rationing programs from other countries, creating its own loophole to get around the law that protects patients from discrimination and hoping people don't notice.

The American people won't stand for it, and woe to the member of Congress who votes for a bill that puts a price on life and later has to go back to explain the vote to constituents.

Once QALYs are revealed, people want nothing to do with it. And they won't accept a warmed-over adaptation that purports to devise an American version of a rejected policy.

“Who decides whose quality of life is more important? Who is to say whose life is more valuable? That's the problem. I don't agree with that whole idea,” a Georgia woman said.

Grace-Marie Turner is president of the Galen Institute, a non-profit research organization that focuses on market-based health policy solutions. She can be reached at gracemarie@galen.org