

EPISODE – Author Interview: How Should Willingness-to-Pay Values of Quality-Adjusted Life-Years Be Updated and According to Whom?

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TIM HOFF: Welcome to the *Ethics Talk Author Interview Series* from the *American Medical Association Journal of Ethics*. I'm your host, Tim Hoff. This new series provides an alternative format for accessing the interesting and important work being done by journal contributors each month. Joining me for this episode is Dr Paul Menzel. Dr Menzel taught Philosophy and Biomedical Ethics at Pacific Lutheran University from 1971 'til 2012, and he is the author of *Strong Medicine: The Ethical Rationing of Health Care and Prevention vs. Treatment: What's the Right Balance?* He joins me today to discuss his article, *How Should Willingness to Pay Values of Quality-Adjusted Life Years Be Updated and According to Whom?* in the August 2021 issue of the journal, *Economic Decision Modeling in Health Care*. To read his full article, visit our site, JournalOfEthics.org. Dr Menzel, thank you so much for joining me.

DR PAUL MENZEL: Thank you, Tim.

HOFF: To begin with, what is the key ethical argument being made in your article?

MENZEL: It's a bit about willingness to pay, but it's most importantly about the quality-adjusted life year. Willingness to pay, when it's used as a group preference, though it may be composed by, comprised of gathering a lot of individual preferences and should be gathered that way, is not particularly an ethical problem if the preferences that people put into the process that generates a certain willingness to pay a certain amount for a life year are, in fact, from the pool of people who will be affected by the decisions that that willingness to pay per life year is used for.

HOFF: Mmhmm.

MENZEL: And that is almost always the case. Because we're talking about a pool of people who are covered by care and decisions of prioritization—if you want to call them rationing, although I prefer to call them now, 20 years after that book, prioritizing decisions—are made largely for a measure, a particular health treatment, that is compared with others and then put in a guideline as either covered always, not covered, etc., advised always, not advised, etc.

HOFF: Mmhmm.

MENZEL: There's no particular problem with that, I think, because people are inevitably members of groups, and that's how we pay for health care. We pay through insurance pools.

HOFF: Mmhmm.

MENZEL: There is a bit of a problem that arises when you ask whose input should be put into that process. But as I said, as long as it's the people who are affected, potentially affected, by the decisions, it's fine.

HOFF: Mmhmm.

MENZEL: Now, when we get to the quality-adjusted life year, that's where the problems get big. The quality-adjusted life year is a construct. It is not a real thing out there in people's preferences. It is the attempt of health policy folk, including health economists who initially devised this, to put quality improvement health measures and life extension health measures on the same scale of benefit or value. And the only way to do that, an economist typically thinks—psychologists and I also say this, and I think ethics, a philosophical ethicist would tend to back them up generally, though, not always—is by trade-off preferences. So, if I trade in quality-of-life improvement if I have a chronic illness, for example, with life extension, that is, I say I'm willing to give up so much time in life in order to get a full cure, that would be the kind of trade-off that would put life extension, or extra life, on the same scale with quality improvement. And that's what the quality does. And so, you ask people typically what are called time trade-off preferences. Now, one problem that emerges when you do that—and it's not, and the problem isn't per se in the fact that this thing we call the quality-adjusted life year is a construct. It's a human construct. That's not the problem—the first problem that arises is who do you ask to get these time trade-off questions?

HOFF: Mmhmm.

MENZEL: Do you ask people just in public imagining themselves having this condition and then needing to make the trade-off between extra life or sacrificing extra life in order to get a full cure for their quality conditions, or do you ask the people who actually experience that?

HOFF: Mmhmm.

MENZEL: I argue that, ethically, there's a very powerful argument to be made for asking the people who have those lives with those conditions. So, you should ask actual patients or people with the actual conditions that are being evaluated. So, you don't ask members of the general public about what life you'd be willing to give up if you had paraplegia in order to get a cure for your paraplegia, back to full limb mobility.

HOFF: Mmhmm.

MENZEL: You would instead ask people who had paraplegia or people who had been cured of paraplegia maybe by an operation, for example. But it's people with experience I think you should ask because the real condition that you're affecting by these trade-offs that create the quality-adjusted life year are the people who have the condition, ultimately.

HOFF: Mmhmm.

MENZEL: I think there's a very powerful argument to that, even though there's been a lot of resistance to it, because it's much simpler just to get these measures from the general public imagining some of these conditions.

HOFF: Mmhmm.

MENZEL: So, if we said it should be the people who actually have conditions, generally, then we encounter, however, a deeper problem. So, you can already see that I think there's a lot of ethical problems that surface in the quality-adjusted life year, even though I've been a very strong defender of using it in certain contexts.

HOFF: Mm.

MENZEL: The biggest problem is that people who have these conditions that we're trying to evaluate want both the quality improvement in their lives and the life extension. They don't want less priority put on extending their lives because they say they're willing to trade off several, a certain percentage of their life extension in order to get a full cure.

HOFF: Mm, mmhmm.

MENZEL: Because if they look at their life itself compared to death— Death is like zero, and any life that's worth living is like almost infinite value compared to the zero, I mean, in the mathematical sense.

HOFF: Sure.

MENZEL: You divide something by zero, and it's always infinite.

HOFF: Hmm.

MENZEL: It's always infinity. So, the person who lives in a very compromised condition values their life, that is, not dying next year or not dying tomorrow. They value their life extension just as much as any non-chronically ill, non-disabled person values their life. This is a hard point for some economists who've worked with, and policy people who've worked with, the quality-adjusted life year to absorb.

HOFF: Hmm.

MENZEL: But people can understand it immediately. Don't we understand if we, as let's suppose, we do not have a person who does not have that condition, say, paraplegic? When we imagine that person, and we think about it seriously, we put ourselves in their shoes, we can see and understand immediately that if we were that way, life would be as precious to us then as it is to us now.

HOFF: Mm.

MENZEL: So, why do we resist this conclusion I come to that the value of life extension is relatively equal for everyone, no matter what the quality of their life? I'll depart from that at the end of this discussion a bit, so there are some qualifications on it. But I think we must absorb that relative equal value of life. I call it the stubborn equal value of life.

HOFF: Mmhmm.

MENZEL: But no, the value of quality improvement to a person with paraplegia is also equally stubborn. It isn't that they are not willing to say, "Well, if you had a cure for me and

it wouldn't shorten my life, to just take a stab at the cure at all, I run no risk of my life being short, yeah, I'll take it!" There may be a few people who wouldn't take, with paraplegia, who wouldn't take that, but virtually all of them would take it. So, they want the quality improvement, but they want it without having to register a trade-off preference that puts them further down the line in the priority for life-extending treatments.

HOFF: Hmm.

MENZEL: And that's something that we should readily understand. Now, the health economics profession, because it hasn't given up on the quality, just hasn't absorbed that ethical point. I don't want to be too hard on them because the quality is a neat invention otherwise.

HOFF: [chuckles]

MENZEL: But there is a fundamental ethical problem here.

HOFF: Yeah, that's come up a couple of times in, I feel like, recent episodes of the podcast about the research that shows that people who are imagining their quality of life if they had to live with some chronic illness or chronic pain or something like that, they imagine it oftentimes much worse than the folks who actually live with those illnesses report their lives to be. So, there's this disconnect between this sort of imaginative quality of life versus this lived quality of life that I think you touch on there.

MENZEL: And it's part of that, not all of that, but part of that fact that the person who actually has it rates their quality of life higher than the person just imagining that they would have this condition is what's called adaptation.

HOFF: Mmhmm.

MENZEL: And there's a really interesting, rich literature about adaptation, both psychologically and ethically.

HOFF: Hmm.

MENZEL: Are we just caving into reality when we shouldn't? Is adaptation a kind of loose excuse?

HOFF: Mmhmm.

MENZEL: Or is it just what you need to do when you have that real life? I tend to say the latter.

BOTH: [chuckle]

HOFF: Huh, interesting. What's the most important thing for health professions students and trainees, who oftentimes make up a large portion of our readership, to take from your article?

MENZEL: There's sort of a specific point to take from it, which is the ethical point that even though people have chronic conditions that are indeed burdensome for them, that does not mean that their life and what you can do to help extend their life or prevent them losing it

now is any less important than helping save the life or extend the life of a person who doesn't have that condition. It really, for health care providers, there should be just this deep, intuitive, the value of all lives are equal, is equal. That's the first thing, I think, for providers to take away from this. The second thing is be a little suspicious about constructs.

HOFF: Mm.

MENZEL: When you first read, some of my students, when they first read a piece on the quality-adjusted life year, they first read it, before they really try to absorb what it is, they react a little suspiciously to this. Well, it looks like a kind of odd quantity in many of their eyes, not in all.

HOFF: Hmm.

MENZEL: It is a construction. It's not like looking at a person suffering right in front of you. I mean, that's a reality influenced, of course, by your biases and maybe the biases of others around them, which shape the reactions and expressions of the person who's suffering. I mean, there are lots of variables there, too. But fundamentally, their suffering is not a construction. Whereas the quality-adjusted life year is fundamentally an artificial construction. So, health care providers should be academically astute. They should be able to absorb, for example, in this case, what a quality-adjusted life year is, that policy, health policy, people are using. But they should not, but they should be a little suspicious because academic construction, construct-, item creators, [chuckles] constructors you might call them, I mean, they can get, there's a theoretical beauty that they can get carried away with, I would say.

BOTH: [chuckle]

HOFF: Sure.

MENZEL: Now, I'm an academic, and I love this stuff. But I think providers should be suspicious of it.

The second thing, or another thing, that I think they can take away from this, should take away from this, is that the use of the prioritizing device we call a quality-adjusted life year, or a willingness to pay for anything for, say, separately, like quality improvement and that willingness to pay for life extension, if we divide it in two, that is used for policy purposes. You don't typically use that at the bedside.

HOFF: Hmm.

MENZEL: So, should the willingness to pay data be updated? Well, sure, it should be updated for policy purposes. But how much influence is that going to have on bedside practice?

HOFF: Mmhmm.

MENZEL: Well, it will in the sense that certain recommendation guidelines will be different, perhaps. Because of the adjustment, some things will be included that weren't that's covered, should be covered, that weren't included before or vice versa. But the individual practitioner is generally not making individual bedside decisions: "Oh, I see the cost of

treating you per the quality-adjusted life year, for you is a little too high, you as an individual.”

HOFF: Mm, mmhmm.

MENZEL: That’s much more dangerous territory, I think. It’s not the proper place generally for this. Although there are, again, some exceptions to it. That’s what I would say.

HOFF: Great. Thank you. And you alluded to this earlier that there are some caveats and extensions that you might add to your article. So, if you could sort of expand your article to include an important point that wasn’t addressed, what would that be?

MENZEL: Well, I said that the subjective value of life for virtually everybody is equal. That is, a life extension that is life living compared to not living, compared to death. And I have explained why I think that’s true and why we should all be able to agree to that, even though we ourselves are not the people who have what is normally referred to as compromised lives. But there are exceptions to it, and the biggest one, I think, is severe dementia.

HOFF: Mm.

MENZEL: That is, I do not think the value, the subjective value, of life to a severely demented person is as great as the subjective value of life is to a quadriplegic, a paraplegic person who’s suffering with other pain for quite a long time and a chronic illness, whoever all those other people are whose value, the value of whose lives is virtually equal to all of them. The value to the person whose life it is of a person in severe dementia is diminished.

HOFF: Hmm.

MENZEL: Now, is this, in saying that, am I discriminating against the mentally disabled? I think not. Because if you put yourself in the life—and I’ve been very close to some people who have had severe dementia—you put yourself in their shoes and at the severe stage. I’m not talking about the early and middle stages here. They can have lives that they very much value themselves, very much, equally to you and me. But at the very severe stages, they cannot anticipate tomorrow. And when they get to tomorrow, they cannot remember yesterday. Now, when you think about valuing survival, you and I value our survival because we value getting to tomorrow. That’s what survival is. And when we get to tomorrow, if we do survive, we say, “Oh, fantastic! I lived from yesterday to today.”

BOTH: [chuckle]

MENZEL: But suppose a person is just not mentally able to do any of that. To them, what value does life have? Well, it still has some value because it is life of the moment. But with only the moment—the eternal present, some people have called it in severe dementia—what is the amount of value that they are subjectively able to appreciate? I think it really withers. I think life itself, the self itself, is withering at that time. I know a lot of people don’t like to hear that, a phrase like that, because they think it’s being discriminatory against the mentally disabled, in this case, the severely demented. But I think if you look at just the state that they’re in, the value of their lives to them is a lot lower than it is to other people. That’s the big exception, and that’s one I’ve been working on a lot in the last five years.

HOFF: Hmm. Well, I can see why you might not have delved into that in your article. It sounds like, you know, enough, there's enough there to develop a whole lot more writing.

MENZEL: Exactly. That's another— Exactly. Exactly.

HOFF: Yeah. [bright theme music fades in] Well, in any case, Dr Menzel, thank you very much for joining me and going over your article and for sharing your expertise.

MENZEL: Thank you very much.

HOFF: That was Dr Paul Menzel, the author of the article, *How Should Willingness to Pay Values of Quality-Adjusted Life Years Be Updated and According to Whom?* in the August 2021 issue of the journal, *Economic Decision Modeling in Health Care*. To read his full article, as well as the rest of our August 2021 issue, visit our site, [JournalOfEthics.org](https://www.journalofethics.org).