

Dr. Lynn McPherson:

This is Dr. Lynn McPherson and welcome to Palliative Care Chat. The podcast series brought to you by the online master of science, PhD and graduate certificate program in palliative care at the University of Maryland. I am delighted to welcome you to our podcast series, titled founders, leaders, and futurists in palliative care. A series I have recorded with Connie Dahlin to support coursework in the PhD in palliative care, offered by the University of Maryland, Baltimore.

Hello everyone. This is Dr. Lynn McPherson, the Program Director of the online PhD, Master science and graduate certificate program in palliative care at the University of Maryland, Baltimore. I'm very excited to be here, joined again by Connie Dahlin, who is a professor in our program, teaching in the very first course, and our guests today. Oh my gosh. We're so excited Dr. Joanne Lynn. So Connie, I'm going to turn it over to you to introduce Dr. Lynn.

Dr. Connie Dahlin:

So for our students, you will have to be reading about Dr. Lynn in many of your articles and the background. I think, one of the things you've heard from some of our other interviews of how important Dr. Lynn was in the support study and how that was so grounding in many ways good and bad. And then her subsequent work in terms of research and quality, working at Ran, thinking about all the communication pieces with this. And so I'm going to let her give more of a background because you can read more in the bio, but we always like to give more focus on hearing from the people themselves. So Dr. Lynn, do you want to talk a little bit about, your background and coming into this and then we'll go from there?

Dr. Joanne Lynn:

Well, I sort of stumbled into the field early in my career. I was a Robert Wood Johnson clinical scholar for just a year and a half at George Washington's program. And then I finished up my residency and that program, and didn't really have much prospects because I was pregnant and it's 1977, women doctors who were pregnant were very difficult to employ. So I was doing all manner of dumb things like triage at the VA, and insurance physicals and so forth, and got offered the opportunity to work half time at George Washington in the new geriatrics program doing the things that the geriatricians did not want to do, so that was the hospice program, which was a pilot program by Blue Cross and the nursing home residents who were not going anywhere, who they had figured had no real prospects and the clinic patients who had been assessed and there was nothing reversible.

So they thought they were throwing me kind of to the dogs. And it was wonderful. It was just a terrific nursing home. The hospice program was one of these missionary hospice programs that was just a delight. The nurses were perfect. They taught me everything I needed to know. At that time, the only resource we had with Cicely Saunders little book and we were probably about the sixth hospice program in the country, entirely inpatient at the end of a wing of a nursing home. The nursing home work itself was wonderful. The aids were just so devoted to the residents. It was a very old nursing home, very much sponsored by its community. And I just loved it. It was just wonderful. And so I started working, I was also half-time at GW teaching ethics. So I was in the middle of all these court cases that were brewing up about end of life care. And so I was writing Supreme court briefs and going to various places to help consult on these cases that were very important in the 1980s. And worked with Hastings and worked with lots of legal briefs and so forth about end of life care while being a hospice doctor.

And then got the chance to work with the President's commission on Ethics and Medicine. And pretty much wrote the Decided to Forgo Life-Sustaining Treatment book that they put out, which was

fairly groundbreaking at the time, saying such things as you shouldn't use a feeding tube in people with persistent vegetative state unless the family truly wants it, that dementia is a serious illness and should be treated as a serious illness. So those were sort of the groundings of my work. And I was continuing as a nursing home doctor and the hospice physician and a home care physician for the city.

And then Bill Canals had developed a scoring system for ICU patients called a Patchy and was interested in expanding that to a larger population. The Robert Wood Johnson foundation leadership had just gone through a couple of really miserable courses with their parents' end of life care. So RWJ asked Bill if he was interested in trying to do something. And he said, "But one condition is you have to have somebody who knows geriatrics and ethics." And I was hanging around as a not-fully employed person. So I jumped into that having very little background in research and learned a lot, Marilyn Burglar taught me a tremendous amount about survey research before she died. And Joan Tino was a terrific companion and a co-traveler. Would you like me to shut that off?

Dr. Connie Dahlin:

That's fine.

Dr. Joanne Lynn:

I assume you can edit it out. The overall effect of support was very different than it was designed to be, I mean, for Bill Canals and the people he recruited from the five sites, the real endeavor was around these predictive models. And Frank Harrell, was terribly central in doing the statistics and we taught the field a lot about propensity scoring and so forth, and it was a very good endeavor on that side. But it also failed. We did the best intervention that was known at the time, which was to try to enhance people's understanding and enable their choices. And the bottom line was, that it made no difference. And you can find some tiny differences in it, but it is basically a negative study.

And it documented that people had tremendous amounts of untreated pain, that they didn't know what was going on, that they just sort of followed the flow. We documented a lot about what was going on, but the intervention didn't work, and there was quite a flurry of articles and critiques saying we had done it wrong, and we actually wrote an article in the supplement to Jags about answering to the extent that we could these critiques about it. But it was very hard. I think it is still very hard to get the field to believe that the patterns of care are stronger than choice.

I keep pointing out to people that the revolution in the 70s and childbirth was not that women got the choice to be treated decently. It was that if you said nothing, you got treated decently and you got support to progress feeding, and we've got support for a natural childbirth, and you've got a support for bonding with the child and so forth. So now, the real revolution was a change in the pattern of care. And I think that it's all too easy to read. We had 130 or so articles that'll support. Many were quite groundbreaking. The ones that I refer to most are the ones that show that the patterns of the five different institutions were very determinative in what it was that people experienced. So yeah, the place that was in a rural area, and everybody knew each other, and we had the same doctor in the hospital as you headed home. And they knew the home care nurses was just very, very different than the big urban hospital, which much to my surprise, did not have a single doctor who had a DEA license in the county. They could not write the prescription for an opioid, for a person being discharged. You had to go to your primary care doctor.

The differences were just stark. In the community setting that I was describing, if somebody died at home, everybody brought a casserole. If somebody died at home in the urban setting, you had the homicide squad show up. The community patterns were just terribly, terribly strong. And it's been

very hard to get people to really work with that. You keep thinking that one doctor, one patient, maybe a couple of family members can make the difference, and they can within a range, you can keep a person out of the hospital. You can make sure they get their pain treated. But we also need to change those patterns and incentives. And that's been very hard to get the field to focus on.

So anyway, the support study did a lot of very good things, but much of its lessons are still not really incorporated. We did a breakneck analysis to affect a Supreme court case. Because we had interviews at various times ahead of death and hospital data. So we took the time of death and counted backwards. We've called it the Hebrew analysis. You read from the right to the left. And so we standardized the date of death and then look backwards at how the person was, and what they or their family were saying on various days. And it showed that a week ahead of death, in most illnesses, it was still quite uncertain that the person would die very soon.

So this idea that you could find the hospice patients six months out was just silly. You couldn't find the hospice patients two weeks out, at 99 percent of the liability, you could at 50-50. But at 50 50, you are going to have a whole lot of survivals a year out. So this problem of prediction has still not quite been incorporated. And you still see all these statutes the key to the six month prognosis without ever saying whether it's a 50-50, or 99 percent. And on that turns a thousand fold difference in who's qualified. So the fundamental statistics have just never quite become part of our common understanding and knowledge, even though we had good data and support to show that the average heart failure patients had a 70 percent chance if I remember right of living for, I forget whether it was two or three months, one week ahead of their actual death.

Lung cancer has changed a lot now, but the lung cancer patients were down to about 30 percent. It's still 30 percent chance to survive for a few months, a week ahead of your actual death. So support has that data, but it's been very hard to get people away from presuming that they knew what they were talking about when they talked about prognosis. So, anyway, that's sort of where we stood at 1995 when we published the main support report.

Dr. Connie Dahlin:

Well, I think you speak to a couple of issues that are so interesting, right? Because one is, and Lynn has heard me say this before, part of it, was we moved, and you talk about this with a real program. We moved everything from the community to these urban centers for our convenience, right? But it doesn't necessarily help the community and its communities you're speaking to, or a community to itself, right? Every community has different resources in the way that it is. And so how do you support that? I think the other part that you speak to is, it's an interesting part in, and we heard about how the hospice benefit sort of was kind of a deal with the devil because what was going to happen if we didn't have the hospice benefit, wasn't good either, right? So it was sort of one of those compromises, but I think it also speaks to this part based on what you're talking about with these percentages, that even a week ahead of what people were dying, we're asking people to make this choice, right? And I was just listening to Respecting Choices, some of their courses yesterday, when they were talking about teaching basic advanced care planning, and they were talking with somebody and they were saying, "If I have a 10 percent chance, I still want to live." Well, it's an interesting part, right?

And when you think about some of our colleagues, who've had serious illness who had been doing this work, who still said they wanted full court press. I mean, so it's an interesting part about human nature and in palliative care, this living with serious illness and where are we kind of pushing patients? So I think that some of the issues still stand to what you said in terms of we aren't good prognosticators. And I think that...

Dr. Joanne Lynn:

And more important, we can't be.

Dr. Connie Dahlin:

Right. We can't be. And then this part that you're speaking to, I'd be curious what you think about, because based on what you're saying, I know that after support, we had the whole Robert Wood Johnson Initiative to focus on care at the end of the life. And I think we're trying to see how people did it, but what you're kind of saying is that was important, but really at the end of the day, we have to change the culture of a healthcare organization to make change. Now, maybe I heard that wrong for you, but that feels like something we focused on the field, but we haven't necessarily focused on the cultural change at different places.

Dr. Joanne Lynn:

Yeah. I mean, telling the results of the support study of RWJ was an experience. We arrived at RWJ for a meeting, I remember it being a 10:00 AM, maybe better than 11, but it was in the morning, and something had happened that required them to get moved to after lunch. So one of the RWJ communications people came in to tell us of their plans for how to disseminate the support findings, not knowing that it was a negative study. And so they had this whole array of things ready to go, to show how valuable support had been. Three of the hospitals had already agreed to continue the intervention and Bill counsel, they were kick me under the table saying, "Don't say anything. We aren't disclosing this until we actually have the meeting with the people at the top." And I mean the most I said was, "I hope it will be here this afternoon." But because everybody assumed that we were doing a wonderful job and everybody loved the intervention, not, well, not everybody. I mean, there's some doctors who were a bit peeved, but mostly people really liked it. But it didn't make any difference if anything we could measure.

So RWJ shifted and did that work in trying to get lots of community and local and state initiatives going and did a whole lot of PR about it. We got on every major journal and newspaper and so forth. And then Soros picked it up. And I'm sure you've heard a lot of the Soros from Kathy and others. But the field sort of took a turn at that point. Remember I was working also in long-term care. So a piece of my life was in hospice care, and a piece of my life was in home and community based care and nursing home care, very little in the hospital, did a little bit of hospital work, but that was basically in the community.

And when we got together to do the first set of the standards of what became palliative care, I was on that committee, and I actually resigned before the report came out because I didn't want the field to be blighted by having a minority report that early in its development, but no one else would go along with training people for advocacy. So the one thing we know in 1995 is that we don't want to be really old in this system. The one thing we clearly know is that this system is fundamentally wrong. And so we really need to be teaching people how to be effective in changing how the system works. And there just was no interest in that. People want it to be academicians. They wanted NIH to be funding them. They wanted tenure, they wanted career tracks. Yeah. And that's where we went. And to this day, we still don't train people in how to go to a state hearing or how to understand what you need to do.

We have organizations now that have hired people to do those things, but we have not really taught our participants, the people who are really doing the work to speak up, and doctor types, and nurse types are very, very poor at being advocates. They're not like businessmen and they're not like lawyers. So we assume that somehow the structure of our systems is kind of okay, or is somebody else's job, minimally, it's our job, and the fact that the field really turned away from that and from a long-term

care has really troubled me. Palliative care has become caricaturizing as goals and symptoms, and as a consultant field just like nephrology or cardiology, they call in the palliative care expert.

Whereas I really saw it as the anchor of comprehensive care of very sick people. Remember I was mostly in people's homes, even if it was at a nursing home, it was where they lived. And you really had to participate with the overall system. And if you couldn't get food delivery, that was a real calamity. It was a calamity on your shoulders every bit, as much as anybody else, you couldn't just offload it. If this person really can't get food tomorrow, you've got to figure out a way to get them food, and that becomes the priority, not whether you're elegantly managing their cardiac drugs. And I always worked in wonderful teams and the hospice team was terrific. The nursing home team was just wonderful. So it was a shared responsibility. I don't mean it was all on the doctor, but that was the whole point was that you had to develop a good team and you had to be, I mean, we went toe to toe with the city. Remember Washington is sort of a city state. So we went toe to toe with the city over who could pronounce death because we ended up having to move people to the emergency room, move bodies to the emergency room claiming they were still alive.

And I had to ride ambulances to keep the EMTs from doing CPR on a patient who I had pronounced dead because you couldn't pronounce death out of the hospital. So we finally got nurses able to pronounce the fact of death and the doctor still had to do the certificate, but the certificate could be done at a later time. But you have to really work against those stupidities in the system to make it possible, to do very different things.

When I started working in DC, more than 70 percent of people died in the hospital, everybody else went through the ER to be pronounced dead. And by the time, I left for Dartmouth in 1993, my little practice, which was George Washington's practice had one-tenth of the deaths in DC and only 30 percent were in the hospital. So yeah, we changed our little system, and we had virtually 100 percent advanced care plans and they were prominent on the record. But they weren't necessarily recognized when the person work in the hospital that the idea that we have mostly changed the course of the end of life for people who made it to adulthood didn't get killed in an auto accident or a gunshot wound, the people who died of illnesses or old age, we've mostly converted that to long-term care. I mean, even cancers are now long term care. People live with them a very long time, and yet the field has still stayed with goals of care and symptoms. And it doesn't really get into the more dominant way people live with serious illness, which has become living a long time with very serious disabilities and illnesses.

Dr. Lynn McPherson:

To jump in and ask one thing. So you talked about how it was so expensive and so forth. You've been very prolific in publishing books? Is that what prompted books such as *The Common Sense Approach to Improving Palliative Care Without Losing All Your Money*?

Dr. Joanne Lynn:

Well, I mean, money has a piece of it because I mean, doctors and the medical care system had been feeding at the trough in just an outrageous way. When I first came out of medical school actually, I took a course offered by the Medical Society on how to set up an office back when that was the thing to do. And in the aim for a physician income, I was said to be twice that of the average school teacher. What are my colleagues doing earning half a million a year? Not in geriatrics, not in palliative care, but in cardiology and interventional work, it is not uncommon to find people expecting to make a quarter million a year. And there are not a lot of school teachers making half of that. And obviously, the insurance companies and the big hospitals systems and so forth are just making money hand over fist, and expecting to have budgets that kind of eliminate my last three zeros.

So in the world of home care, when you're dealing with families, it is a big problem to incur a \$1,000 debt. In the medical care system, a \$1,000 debt is your a \$1,000 error, it's just irrelevant. We do that every day. So I call it the decimal point error, that in home care, and then you go to a nursing home care, and then to a hospital type care, you're moving a decimal point across each time, that's where people bothered to care. And the average American is still earning on the order of 50 to \$60,000, you have to be thoughtful about the evenly co-pays and deductibles in that kind of arrange.

I had a colonoscopy couple of years ago that I hadn't inquired a lot about and the GI person sent it off for all kinds of tests. And it ends up costing \$7,500. Now, yeah, I should have been prudent and asked about the merits of all these genomic tests and so forth. And of course, my insurance picked up almost all of it and my flex fund picked up part of it. So it didn't hurt me much, but that would have sunk most of the families I took care of, even just the copay and deductible whatever they were insured. So, we have to start somehow figuring out how to be better servants of our communities. And in old age, that's a quite inequitable community. I mean, Medicaid, at least in DC and in states with good Medicaid programs does have a decent safety net, but the average African-American family hits retirement age with one-tenth of the assets that the average white family does. So we are working with the effects of a lifetime of reduced opportunities. Women, obviously, also have a big head. It's only about half, women get half of what men do at the time of retirement. So we have to really learn to work with our communities.

My parents were GPs in West Virginia, and before insurance was commonplace, only the miners had insurance and everybody else did not. And families had to make really tough choices. If mom went to the hospital that meant the junior didn't go to college. So in the absence of insurance, even in a much more prudent medical care system, the doctor had to really be thoughtful about what they were imposing on their community. And we've lost that. And instead are just, as I say, sort of feeding at the trough with an entitlement and Medicare and kind of the echoes of that throughout all of commercial insurance.

So I'd really call on students to be really eager to stay abreast of Kaiser Health news. And you'll get to know your Congress people and your senators and your local representatives and your state representatives and counted as part of the overhead of working in this arena is, that you really must be engaged in change, that you face having half of middle-class Americans unable to afford housing, food, and medical copays.

By the end of this decade, we really need to be speaking up and finding the solutions. I've been working the last year and a half as a volunteer in Congressman Tom Swazis office developing the Wish app, which we just got introduced last week. And it's a way in which a small tax on wages would develop a social insurance that would provide for coverage of catastrophic long-term care, which is defined differently depending on your lifetime income. So most people would only wait a year or a year and a half, but very high income people would wait four to five years before they would get this benefit. And so \$3,600 a month benefits. So it's a substantial supplement to your social security at the time in which you're quite disabled. So it hold a lot of families together in a way that we don't do now.

So I certainly have not been all that I think I should have done, but the colleagues around me, I think do so much less that we don't write to our Congressman. We don't buttonhole them when they do their tours of local care, we don't even have convergent ideas. There's all this enthusiasm right now for home and community-based services, which are terrific. I mean, that's a lot of what I did. But they also are desirable in a way that nursing home isn't. So home and community-based services has made an entitlement, balloon incredibly. Yeah. I mean, I'd take home and community-based services today. Sure. Come help me make supper. But I wouldn't take a nursing home.

So where is the conversation about what limits to place on home and community-based services? I've tried getting it started in various places and it's like I don't know speaking scatological language or something and nobody wants to touch it. But we have to have some limits, 24-hour daycare costs a quarter million dollars a year. We are not going to put a quarter million dollars a year into lots and lots of elderly people. We might put it into 30 year old lawyers, or a 30 year old businessman or something, who really can operate as ordinary normal roles if they have somebody helping them. But we are certainly not going to be that.

But then what's a home and community based services entitlement? For a while, it will be limited by the workforce and you can't actually implement the entitlement if you can't get somebody able to work. But in the long run, that's a really dangerous idea, and yet it's terribly popular in their multiple bills on the hill to implement it, by very respected people. And so where in our field is there that conversation? Well, it's not in palliative care and it's barely in geriatrics.

In GS, the American Geriatric Society finally came out against, aducanumab, the new Alzheimer's drug. It has a statement opposing its FDA approval and is now working to try to get CMS to make it a very limited benefit under Medicare which I think is a very good thing for geriatrics to do. But geriatrics has to be the weakest professional organization in medicine. We're actually losing people. And the average geriatrician is over 50 years old. So, where is the advocacy? I've talked to ARP and their only advocacy is saving social security. So there are some other topics you might want to weigh in on. That one's very important but don't make it their only thing and they've made it the only thing for the coming...

Dr. Connie Dahlin:

So you've talked a little bit though about your work, and I'm just curious, you mentioned, I mean, it is kind of amazing that we haven't done more with nursing homes in palliative care. I mean, we know hospices consult, but you don't see very many specialty teams at a nursing home, right? Unless it's a hospice coming in. And there's this weird mix that you hear people saying, "Well, the turnover is too much both for home health aides or directors of nursing or medical directors. It's not worth our time." But we have said that for like 10 years. So the question in my mind is, for our students, this seems to be something we need to think about. And I think your comments about, we have an interesting place because nursing homes kind of have this negative view and yet we think it's okay that older adults keep getting admitted to the hospital, right? Because we don't value any sort of custodial care or supports. I think hospice to me has a more of a role because they have a benefit and they'll go in, but what's kind of the role with palliative care do you think?

Dr. Joanne Lynn:

Good nursing homes are offended by generally having to use hospice because they do it themselves. And the hospice people come in as missionaries, and arrogant, and well-paid, and they push aside the nursing home folks who know these people, who've been family for a year or five years in some cases. So there really needs to be a much more cooperative endeavor where the hospice folks and the nursing home folks agree on whether hospice is consulting or whether hospice is taking over or sort of what's going on here? The way that it's funded makes it very awkward. The hospice benefit is almost equal to the nursing home benefit, and yet they aren't paying the room and board. They aren't paying the rent, they're paying for the air conditioning and the roof and the food. So it's a troublesome entity.

But the bigger issue it seems is we have a very large number of people who are going to live a long time with serious illness and disability, and they are going to use family care, they're going to use home care, they're going to use your hospital care, and ER care, and nursing home care, and assisted

living, and foster care, and all sorts of things. We have no entity that looks at the overall experience and can tell you how people are doing in your county, or your city. Every other country has that, every other country sees this as a population that is incorporated in the city or the county, or in some cases, the parish or the state or whatever, but it has an entity that bears responsibility for the quality and cost of care, and is watching for things like equity and those watching for things like inadequate service.

Instead, we have a very provider oriented system. We pay by provider, we develop quality measures by provider. You don't have any locus at which we look at the overall experience of patients and families. You can't tell how many families are being driven bankrupt in your county. You can't tell how many had to leave work. You can't tell how many elders are abused. In most parts of the country, you can't get an autopsy now, unless it's a homicide or yellow or something like that. So there's no check on how many people are dying with terrible pressure ulcers, or neglected.

So we really need, it seems to generate a way to see that. I and my team have developed almost a thousand data elements for every county in the country, from Medicare data, using a racists, the home care assessment, MBS, the nursing home assessment, and the claim stream, and the census and the area deprivation index and the health services resources, indexes that the American hospital association generates. So you can actually see how your county shapes up on things like pressure, ulcers, readmissions, nursing home days, all those sorts of things.

There still are some big gaps. We can't see the effect on caregivers because of course, nobody measures that, but it begins to show whether you're counting. I mean, we have one county where 40 percent of people in fee for service Medicare, who are duals are getting benzodiazepines, a drug that should generally not be used in the elderly at all. And that county ought to really step up and start seeing what they're doing and drugging all these people. So beginning to develop the capability of seeing whole populations, I think is a piece of where we need to go. And palliative care needs to participate in that.

The palliative care in the medical arena, is mostly a hospital-based endeavor, and mostly does goals of care and symptom management. And that's very good. I'm not the crying that at all. That's a very good thing, but it means that whoever is trying to do comprehensive care management is being disabled. If they call in palliative care for the family conversations, because now the consultant is getting the goals of care and the people who need to implement it are often not at the table because this is being done in the hospital, and it's actually being implemented in the community. So we need some sort of vision of how geriatrics, we have medicine, palliative care are going to begin to take care of this large and growing population. Now, I work mostly with elders or people who are at least are over 50. But the same sorts of things happen with children and young adults who become seriously disabled, whether it's from substance use or from genetic illness, or cerebral palsy or whatever, we all draw from the same well.

And the average practitioner doesn't even know whether there's a waitlist for meals on wheels, doesn't have any idea what the resources are in their community. I've asked probably 50 people around the country. Well, do you ever use adult protective services? And the usual answer is a rolling of the eyes. "Oh, I tried once and all they did was to alienate the family from me and put the person in the worst position." Because adult protective services is so underfunded that they could only step in where a person is about to be beaten. And simple neglect is really hard to understand. It's hard to get to know, it requires multiple visits and establishing trust. And they aren't funded for that, but who's speaking up for adult protective services? Who even knows that's the circumstance? So that's kind of been my frustration. Is that palliative care has developed a niche. It's very valuable in that niche. Much of the research has been very helpful. It has supplemented the traditional gerontological research and rehab and disability research, very substantially. And I appreciate that, but going forward, we are going to have

a tremendous number of people who cannot afford the basics. And we are going to be picking up the pieces for homeless 90 year olds who can't feed themselves.

And we can see that clearly. And we just choose not to. We choose to continue to take our salaries for nine to five jobs, five days a week, and not deal with, who's going to take care of the Saturday at 5:00 PM crisis where the caregiver falls down the steps and breaks her wrist. And now what the hell are you going to do? And who can you call? We could be planning for this, but no, we don't.

Dr. Lynn McPherson:

So given all that, what advice would you give to our PhD graduates who hopefully will shape the future in palliative care?

Dr. Joanne Lynn:

To assume that it's sort of like the biblical injunction for tithing, to assume that you ought to be spending 10 percent of your time changing the circumstances of your work. And if you're working at a pace program and it's terrific and it's wonderful, and it's only serving 10 percent of the potentially eligible people in the community, that's a problem. You need to be speaking up about it. If you can't get transportation in some parts of your county, you need to be speaking up about it. It's an overhead cost in our work. And yes, you have to work in the arenas where you can make the money to keep your home intact and where you can have a reasonable work-life balance, and yet I think you want to really work in a really good team and those teams need to be supported and they need to be geographic. They need to be speaking to power and speaking to power in very strong terms. We need to be able to say to powerful people, you're doing it wrong. You're feeding at the trough in a way that you ought to be embarrassed about.

How is it that nursing home managers and owners are taking home million dollar salaries and paying their aides insufficient to get off food stamps. I mean, it is unconscionable for the leadership in medicine, and long-term care, and insurance to be making this kind of money. Remember the admonition that I had when I first left medical school in 1970, well, probably residency in 77, that you should be aiming to earn about place with a school teacher earns. I think we should say anybody making a majority of their income from public resources should not be making more than, let's say an NIH PhD, which right now is set at something like \$190,000 a year. Let's just put a cap on.

I don't think it's mostly that. I think it's that expecting to make that kind of money distorts your dedication to the people involved. I used to take medical students on home visits and I would leave the stethoscope in my car deliberately. And I'd say after we'd been there a few minutes, I'm going to remember that I lost my stethoscope, come with me. When I go back to get it. We'd go in and get settled and talk to the family a minute and to the patient. And I'd say, "Oh, I forgot myself a stethoscope. John, come with me. We'll run out and get it. We'll be right back." As soon as we left the apartment, I'd say, start telling me all the things you've already learned. And it was always more than the trip to the car and back. I'd say, "Just remember, you could not have learned that in the office."

It's very important to get to know your people, where they live. To do enough home visits to know how people are living, to know what it looks like to be in an apartment with lead paint falling off the walls, to know what it is like for people to look at each other when you talk about an expensive drug with a 20 percent copay. People look very different in the office and they look very different than the hospital, where you don't even have their clothes on. So that's what I would tell your students is, to really engage with the community.

We have big problems. You need big solutions. We need people willing to chain themselves to the doors of the Humphrey building and to raise their voices, or at least to support the people who are willing to. I keep telling my geriatrics colleagues, and my palliative care colleagues, be a member of consumer voice, send them money, send money to the Medicare Rights Center. We have so few voices that are willing to speak up for our patients and clients that we really need to be participating with them. Most of the disease organizations are fronts for pharma. You have to be very thoughtful about supporting the cancer groups and the Alzheimer's groups and so forth. They are getting most of their money from pharma. Actually, many of the professional groups are actually getting most of their support from the parties that are making so much money. And we don't have a union voice that would speak on behalf of the caregivers and the people who are right now suffering. And I keep hoping to build a union of caregivers that would speak up, that would be willing to go.

But the caregiver groups, the four caregiver groups that work nationally have been willing to take the crumbs from the table know, "Oh, thank you. Thank you for raising the Older Americans Act by eight percent this year, 10 percent this year." When it is behind by a hundred percent. Where's stridency? Maggie Kuhn.

So anyway, yes, palliative care does good work. Research is doing good work. It's very important that those things continue, but it's also important that we change the circumstances of our work. And if you go to the AHPM agendas for the last three or four meetings, you will find it very scarce for anyone to be talking about these issues even in the public policy meetings, they do not. They talk about funding for teens. Yeah. That's important, but it's also important that we stop having no funding for meals.

One of the most shocking studies is More Than A Meal. Go look at it online More Than A meal. It's a study done by Brown university, elegant study, three arms. People who got meals on wheels, people who got food delivered that was frozen and a microwave, and people who got nothing. And what's shocking is that they recruited eight cities with more than a six month waiting list for meals on wheels. And then capitalized on it by having people get nothing while being in the study, that should chill us. And that should really upset us. A, that there are cities with six months of rights for food deliver, and B, that we would build research on the backs of people who are getting no food delivery.

Dr. Connie Dahlin:

Yeah. Almost like a placebo study, right? In a certain sense of giving them nothing, but wow. I mean, you have brought up so many interesting things of, I think this part of community and this social action part that we haven't heard from. And I think really that part for our PhD students to step up and be leaders and really think about that. And maybe that's one of the things Lynn will need to think about, thinking about a whole policy part of an advocacy part. So we may be in touch with you again soon, but this has been a wonderful range of kind of where you got involved and where you're still involved, because you're still passionate. It's very clear and we still need your voice. So thank you for all that you've done and continue to do. Lynn, do you want to have any other last minute comments?

Dr. Lynn McPherson:

No. I think your work is prolific. Everybody should read Handbook for Mortals as well as your other works. And thank you for your advocacy in our field. We appreciate it.

Dr. Joanne Lynn:

Get them to read Medicare in Communities and improve on it.

Dr. Lynn McPherson:

You've got 1, 2, 3, 4, 5 books. Is that right? Did I get them all?

Dr. Joanne Lynn:

Well, I don't know. It might be. Once tallied them up. I have 80 books and chapters. At one point I had the end of life chapter in every medical textbook, but I quickly devolve them to junior partners because it's really boring to keep writing the same thing. The only one I've kept as the Merck Manual, because it is free online and even my chapter is consulted more than a million times a year.

Dr. Lynn McPherson:

That's amazing.

Dr. Joanne Lynn:

It's just such a remarkable resource in third world countries where they now have internet, but not books. And the Merck manual is the standard in poor countries around the world. So I have a special devotion to that. But otherwise, I'm hoping that the younger generation will relearn activism or at least the support of activism. If you can't find it in yourself to do it yourself, at least know who's doing a good job and send them money, and support, and write letters on their behalf. It's very important that we don't end up at 2030 in the same place we are in 2021.

Dr. Connie Dahlin:

Absolutely.

Dr. Lynn McPherson:

Well, thank you so much Dr. Lynn. We're very appreciative. Connie, do you have anything less than from you.

Dr. Connie Dahlin:

No, thank you very much.

Dr. Joanne Lynn:

And we appreciate your leadership and the fact that you've developed a program. And yeah, good luck with it and hope it thrives enormously.

Dr. Lynn McPherson:

Thank you so much. I'd like to thank our guest today and Connie Dahlin for the continuing journey in our podcast series, titled Founders, Leaders and Futurists in Palliative Care. I'd also like to thank you for listening to the palliative care chat podcast. This is Dr. Lynn McPherson, and this presentation is copyright 2021 University of Maryland. For more information on our completely online master of science, PhD, and graduate certificate program in palliative care, or for permission requests regarding this podcast, please visit graduate.umaryland.edu/palliative. Thank you.