In each volume of the Journal, the editors select one article for our Beyond the Manuscript post-study interview with the authors. Beyond the Manuscript provides the authors the opportunity to tell listeners what they would want to know about the project beyond what went into the final manuscript. The associate editors who handled the articles conduct our Beyond the Manuscript interviews. This edition of Beyond the Manuscript features Rachel Klimmek and Jennifer Wenzel authors of "Training of Community Health Workers to Deliver Cancer Patient Navigation to Rural African American Seniors" and PCHP Editor-in-Chief Darius Tandon.

Darius Tandon: Rachel and Jennifer. Thanks for such a wonderful article submitted and accepted to PCHP called "Training of Community Health Workers to Deliver Patient Navigation to Rural African American Seniors".

At the starting point, could you give us a brief summary of the project described in the manuscript, including the purpose of the overall study and some of the results that you presented in the manuscript?

Jennifer Wenzel: The purpose of this project was to help us develop an intervention study focused on navigating rural African American seniors, both patients and their support persons or care partners—however or whichever term people prefer—on helping them to navigate them through the process of diagnosis and treatment.

This project is nested within some other projects including a cancer screening project conducted in East Baltimore at the time, with a group from the Bloomberg School of Public Health. It also folds into another pilot study that I'm working on with my collaborators at the University of Virginia and here at Johns Hopkins looking at decisions related to selecting treatment in an advanced cancer population.

It also has to do with some work that Rachel is working on as well.

Darius Tandon: Great.

Rachel Klimmek: I'm Rachel. I'm a doctoral candidate here at The Johns Hopkins School of Nursing and as a cancer nurse and I'm very interested in care of older adults in rural areas with cancer, as well as issues related to survivorship.

This study really fit very well in with that and out of this study I've currently planned a dissertation project, which is ongoing, where I'm looking at some of the things that came out of our interactions with the participants within this project we've described, which was a training of trainers.

Of community health workers [CHWs] who are in the rural communities and who are positioned to work with older adults and their support persons in terms of helping them navigate through the treatment process. I'm continuing to follow some of the older adults and support persons who are a part of some of the studies that Jennifer just described that has come out of this.

Rachel Klimmek:	The project we describe in the paper is just one element that helped build a foundation for these ongoing projects. Doing some capacity building with community health workers in the area and Jennifer perhaps will help also, as this is part of her larger program of research describe how the findings from this project fit into other ongoing projects.
Jennifer:	One of the reasons for describing the whole spectrum of studies is that this training was developed as an early phase as a companion to all of these studies in that community health workers are being used across the different studies in different ways.
	In some of the studies the community health workers are actually actively navigating through providing for example, in the Decision Support Study providing the decision aid. In all of these studies the community health workers are supported an oncology nurse, so that is an important component and we certainly built in some of those interactions into the training.
	The other unique aspect of the project is that in all of these studies again, we're focusing not just on patients, but we're focusing really on patient and support person dyads. So there is this idea that the support persons can also be doing a significant portion of the navigation and developing training that would be appropriate for community health workers in these settings, provided us the opportunity to also provide training to the support persons.
	This was what we perceived an early stage in the development of that aspect of all of these projects.
Rachel:	One of the important outcomes of the overall research is an appreciation for the collaborative relationship between these community health workers, who are long-term residents of these local communities within which the supportive work is ongoing, and the research team and really making those community health workers full members of the research team and building that partnership, so that we could have a sustainable program of support in the future.
	They would also take away from the training skills and knowledge that they could then use to also help support members of their local community who weren't necessarily involved in any of these supportive interventions, but their other friends and family members and contacts in the future.
Jennifer:	Another component is that the training itself originated in prior descriptive work that we had done focus groups with, because all of these interventions occur in different settings.
	Some are located in Baltimore. Others are such as this training were centralized in rural Virginia, because that's where we perceived the greatest immediate need for training and the earlier focus groups we conducted with urban and rural African-American cancer survivors.
	We did talk to them about some of the characteristics. The familiarity with community health worker interventions, which was actually very low, their awareness of these individuals, but after having described the role to them, what they perceived these individuals in these types of roles could do for them.

Jennifer:	An interesting aspect of the work is that, as Rachel was talking in terms of sustainability of the intervention, one of the things I often hear in working with the dyads that we're navigating is that patients or the support persons will often say when we describe the intervention and the role of the community health worker nurse team that's going to be helping to navigate them.

I often hear, "Well, that's really work that I think I could see myself doing," or "I think I would really enjoy doing that kind of work." I think particularly because we're working in a rural community setting of the project that we're in right now.

Darius:	If you could, in the spirit of going beyond the manuscript and beyond what you have written in this paper, talk a little bit about that relationship between the CHW, the oncology nurse and maybe what you needed to do in terms of training and ongoing monitoring with that relationship.

Rachel:	I think this is one of the real innovations of this overall study plan that Jennifer has designed, because certainly there has been a lot of work with CHWs in other areas of illness management and support and the relationship between the oncology nurses, which for example I'm one of the oncology nurses working in this larger ongoing navigation study.

I work very closely with community health workers, one in particular, and she and I are really a team. One of the things that we bring to that relationship is a respect for the unique knowledge that each of us has and what we can offer to the dyads that are being navigated.

So, this community health worker, she is just a phenomenal representative of the study in the community and as a long-term resident of that community, who has built a lot of contacts up over the years and acquired a lot of knowledge about resources and the local culture and has a real sensitivity to the kinds of challenges that some of these dyads are facing.

She has that as a filter for all of her interactions with the persons who then subsequently are being navigated through the study and she has regular contact with those individuals on at least a biweekly basis. Then she and I have both formal and informal communication strategies that are constantly evolving as we develop this relationship.

So, one of the formal strategies if of course, the entire research team, not just the senior researchers like Jennifer, who is the principal investigator, but also the community health worker or lay health workers involved in the study have regular conference calls and meetings to give reports and check in with each other to hear about new resources or issues that the community health workers have become aware of or issues that the oncology nurses or other experts on the team are aware of, so that they can have an exchange of knowledge within those team meetings.

Then the community health workers who were hired for the study learned how to track their interactions and the kinds of support that they're providing in a software tool that is shared across the study—a data management software tool that they have become proficient in through the training that we have done collectively. So that provides another window onto their activities.

Rachel: Some of our interactions with the actual participants in the study, be it the survivors themselves, who are receiving treatment or the support persons, who are also enrolled. Occasionally, those will happen together, where the nurse and the community health worker will, as a team respond to the challenges that those individuals are expressing.

In other cases, the community health worker has developed a real rapport with those individuals and they feel comfortable with that person, because they recognize their knowledge and the fact that they are a resource they can trust who has an awareness of their community and the issues they may be facing.

In those cases, the interactions between the community health worker and the participants are more one on one with the oncology nurse there as an extra level of support, who checks in with the participant on at least a monthly basis, but also has this ongoing and constant dialogue with the community health workers and as they identify issues or challenges, can bring that oncology and clinical knowledge and perspective to their situations as well.

So there is expert guidance that's been translated by this community health worker to the individuals who are receiving it in a format that feels comfortable for them.

Jennifer: I would add to that is when you were talking about how did this kind of translate into the training? We looked at this really early in terms of planning this sort of train the trainer curriculum and how to deliver it. So the curriculum includes things like well, first of all it was really developed by our community health workers.

It was really community health workers, some of the research staff and the nurses who are actually all still working on the project, including myself. The nurses, themselves represent different areas of oncology expertise. So we're sort of helping to train each other. There is some peer training that goes on among the nurses and the community health workers.

The community health workers train us in terms of the resources. They're actively looking for resources in the community that I think the nurses are helping to provide support in terms of oncology, understanding oncology nursing. Some of that's included in the curriculum.

Ongoing issues between the study team, when we have our biweekly meetings, where we discuss issues that have come up in the nurse community health worker interactions. Rachel calls me a senior person on the team, but I actually navigate as an oncology nurse.

I have a community health worker that I work with and she and I discuss regularly issues that are coming up. She sometimes asks me questions. She is very well versed in the resources and helping patients and families in the community, but sometimes she has oncology-specific questions, and hearing these kinds of issues, "is this something that is normal? Should we be addressing this?"

In terms of the nurse community health worker partnerships, we definitely recognize that it's the community health worker who has the most contact, but the nurses in

Jennifer:	the community health worker super trainers helped deliver the initial training. We all informed the curriculum and I think we keep that training ongoing again at this peer level, where the nurses are there to support the patients and the support persons in the study.
	They're there to support the community health workers. So that the community health workers know that if there are any issues that come up that they perceive are diagnosis or treatment related, that they have questions about that they know that they can talk to us and some of the navigation calls are actually done with the nurse and the community health worker together.
	Some of that's intervention validity, but sometimes it's just to show the equality of and the importance of both members of the team and demonstrating that to the patients and the support persons through the navigation.
	Then again, there is a fair amount of nurse-to-nurse expertise, because all of us do represent different areas of oncology and certainly the number of changes that we deal with in terms of cancer therapies staying abreast of those, we really help each other.
Rachel:	In terms of the tool kit, for the study and what is provided to the participants who are being navigated, the community health workers like the one that I have been working with most closely have really brought an incredible amount of knowledge and had a lot of input into the development of that resource toolbox in ways of where they have knowledge from their time there that would have been perhaps very difficult, if not impossible, for a team who was simply helicoptering in who was not established in the community in the same way that they have been to achieve. That has been really invaluable in terms of their partnership throughout the process.
Jennifer:	Another example in terms of the ongoing nature of the work is we do site visits, not so much to check up on the work, but to provide support and I think make contact. The community health workers direct that, so we do have community health workers who are not actively navigating patients in the study who went through the training.
	Their level is really at the community engagement level, and they continue to be active in terms of finding new agencies and when we're getting ready to make a visit from Hopkins down to Central Virginia, they tell us where we need to go and we go there together.
	They'll come with us and they are the ones, who are talking about the study, but they want for us to be there to talk about some of the research related issues and potential partnerships with local community agencies.
	They really direct a lot of our community engagement in terms of we may have suggestions, but I think a lot of these site visits are really I think focused on where the community health workers think that we need to be and what we need to be doing and who we need to be speaking with and engaging with in the community.
Darius:	You talk about the manuscript in two phases: Phase one focusing on the CHW training and phase two, you say going forward with community support persons, who are going to be receiving the next round of training and you talk about how the original CHWs that are trained are going to become the new super trainers.

Darius:

The support persons are going to be trained on how to provide navigational systems to a friend or family member with cancer. I'd be interested in hearing a little bit more about why you feel that that model is the right model to use moving forward in terms of having the support person doing more of the navigation instead of a community health worker and also to talk a little bit about how are you going to monitor that, if it is support persons instead of community health workers?

How are you monitoring whether or not the support persons are really communicating the right messages and doing the monitoring in the way that you deem would be the most effective?

Jennifer:

I would have to say we're not quite at that phase yet in the study, but I think I can certainly address the rationale. The rationale behind this I think really innovative concept went back to the focus groups that I had referred to initially with the survivors, who when we described the role of the community health worker definitely perceived some utility with the role.

Particularly this older population affected by known health disparities and we definitely saw this in our rural population in particular, but again, overtones of it in the urban groups as well was the fact that when we asked them what are some of the key characteristics of people in this role, one of the early things they identified almost across the board was trust and the focus on relationship.

As a study team we explored that—we realized it's not necessarily easy to do that, particularly at the time of diagnosis, because we're doing some other studies as well, looking at minority accrual to clinical trials and one of the things we're hearing is this is just a really tough time for people.

At the time of diagnosis, they're almost being assaulted by so much information, so many places to go that the idea, I think, of forming a new trusting relationship with individuals is….it's just almost tips the scale in terms of they're not sure they can handle doing that at that time.

I think what we decided is what's easier? Is it easier to try to build this trusting relationship during this extremely difficult time or is it potentially easier to provide training within relationships that are already built, where there is a trusting relationship and providing not just training, but also support.

The way that we originally conceptualized the project and the way that we're going forward is looking again just as the community health worker, we don't just sort of throw them into this environment of navigation and providing support without having someone to support them in terms of the role of the oncology nurse, but the support person, who honestly is already I think in our current health care system relegated to a lot of navigation activities.

When we talk to support persons in our current study, they are doing a significant amount of navigation already. The difference being they're just doing it with no support or training and very few resources.

Jennifer:	Thinking about trying to formalize the support that they have from the community health worker, who is working with a cohort of dyads that we could build on this existing relationship of trust. So that's where we conceptualized the project.
	I think one of the challenges that we're finding as we are moving past Phase One and looking at Phase Two is that not surprisingly, we are finding that the support persons are the people who are significantly overburdened.
	Certainly, there are issues that the patients face that when we look at availability, when we look at real burden, it's the support persons who may have the least amount of availability. Who may have the greatest I think number of tasks that they're already trying to balance.
	That's going to be a challenge for us, but certain things we are doing passively, so in terms of our navigation specific to the support persons we do talk to them through this process as navigation resources that we can provide to them, as they support the patients in the study.
	We do have the training curriculum that we've put on our study website so that they have access to that information as being part of the study. So again, because we had developed so much of this is as self-study modules, we do have that opportunity to kind of learn from the phase one and provide some of that information.
	Then again, this sort of cadre of ongoing resources that we're providing in terms of navigation for the community health workers, but that information is also made available to the support persons, as well as the patients.
Darius:	One of the things that you talk about in the manuscript regarding the training for the community health workers is the approach you took and specifically, you talked a lot about the training via online modalities and I think that in this age of scarce resources for doing research and for doing training I think a lot of folks are looking for cost-effective approaches for training research staff.
	Could you talk a little bit about some of the lessons learned from the online training that you conducted and maybe speak to other researchers who are thinking about using online training, both in terms of the strengths and limitations that you think are present, particularly as they relate to training community health workers?
Jennifer:	One of the things that we envisioned as we were thinking about long-term sustainability we were also thinking about trying to create some capacity for the phase two of the projects. So thinking about where we could build in some flexibility realizing already, but I think coming to realize that even more, as we're delivering the intervention now that support persons are extremely burdened.
	We were thinking about a way that the training could take place at a pace where individuals could find it comfortable for them with suggestions. Obviously, we say it's a 2-day self-study, but the truth is, is some of it even in the training I think some people took—had the ability to sort of break that down and take a little bit longer to go through what would be 2 full days of self-study.

Jennifer: Trying to build in those resources thinking ahead to the next phase of the project really helped us in terms of thinking through sustainability and then I think the other issue was we actually did ask the trainees how would you prefer to have this training delivered, because we at that time, again not knowing what to expect per se, with this rural group of people who were interested in the community health worker role and interested in receiving training.

We were willing to travel down to them. We were willing to have them, to pay for them—we had some funding thanks to the National Institute for Nursing Research to pay them to come up, you know we had some limited travel funds to have them come up to here to Hopkins.

We really wanted to know how did they want to receive the training, and we had some options for that. Overwhelmingly, they actually wanted to stay in place in the community, receive the training. They were willing to come to a central location, that being the School of Nursing at the University of Virginia.

The opportunity to receive training from a place like Hopkins to interact with community health workers, who had been engaged in this kind of work, the nurses who were going to be involved in the work and who had familiarity with the patient population and with the issues that they perceived being of interest, those were incentives for them to participate in the training.

It was a little bit of a technological hurdle for us in some ways and there certainly are some lessons learned that I think Rachel is going to share.

Rachel: There were both challenges and sort of unexpected benefits building beyond just the considerations that had been taken for their time and preferences. Of course, this being a rural population as well, travel is a consideration, not just time spent in training. It's not always just a matter of popping down the street.

It was nice to have the training conducted in a very central location with the majority being done at person's homes or wherever they wanted to access the information and then the in class training day being at this central location that was certainly much closer for individuals than traveling up all the way to a place like Hopkins in Maryland.

There were some challenges inherent and particularly with regards to issues like computer literacy. Again, we didn't really know going in just what the comfort level would be and, again, people were given some options in terms of how they wished to receive the materials. In some cases, in fact, I think in all cases we did send a paper and pen or hardcopy version when someone wanted it in addition to providing access to the online modules.

That did create a thought process for us for planning for the future in terms of doing some maybe more in depth assessment of comfort with technology and computer literacy ahead of the training itself, as well as the potential for one of the benefits we found from this being building the skills of the individuals involved.

Rachel: Some of our community health workers, at least in one case, one had never had an e-mail address, but they opened an e-mail account for the first time. They had this new functionality that they could use for communication, not just with us, but in their personal life.

Many of them did express that they appreciated this opportunity to gain a little better comfort and fluency with some of these technological tools and another added benefit of making it a self-study module, particularly one that's available online from any access point that you might have is that as new community health workers and staff have joined the study, that training had been built and is there and is able to be disseminated and built upon for future work.

While we did have to do some one on one work with some individuals to help facilitate their access to the training online and then in terms of follow-up with some of the evaluation tools that we had also provided online, in the end it was an experience that many felt was new for them, but also sort of exciting and different and overall enjoyable.

Jennifer: I think one of the lessons learned for me, in terms of directing the project, was that because people indicate that they want a certain level of training or they want training delivered in a certain way, we shouldn't naturally assume that that means they have a lot of comfort.

Sometimes, as Rachel points out, it's capacity building. People want to stretch themselves and that's why they are participating in the training. They want to learn new things. So the fact that they wanted to do self-study, they wanted to have some online content delivered, they wanted to do this distance kind of interactive training doesn't mean that they'd ever done it before or they even felt very comfortable with it.

What we originally thought going in was that, there is a lot more comfort and experience here and capacity than we would have expected, when in reality I think we really had the range.

We had some people who really flew through the online modules and had no difficulty with this online environment, and others who talked about the fact that it was intimidating, but they found it empowering to have had some expertise.

Then a few people, who just had some technological difficulties, not because of no skill, but just the kind of technical errors that happen to all of us and maybe a little bit of frustration I think, but fairly low levels, because again, we had options to opt out of that.

Offering hardcopy opportunities as well, so that if there was failure in the online environment they knew that they could fall back on that.

The other really important component of the training was something that required a little bit of capacity on both sides and that was an interactive video format, where we actually got to see them in the classroom there. They got to see us and we got to interact.

The lesson learned there is something that we knew, just from other trainings or just teaching classes was helpful for us. That was to have the IT staff standing by to make sure that there weren't connection difficulties, because when you get a group of people together, that's resource intensive and having some IT support on both sides is really important.

Jennifer: I think the training actually went very smoothly, but I can think of just a single glitch, where we certainly needed people to be there.

Darius: We're almost out of time, but I wanted to give you the opportunity to add any other comments about the work described and the manuscript that you think would be important for our readers to hear about or describe any other thoughts related to moving this work forward.

Rachel: One of the things that I've taken from this experience has been the fact that this really is an ongoing and very interactive process and very well planned in some ways, but also I think any time that you really are seeking to develop a project in partnership with other individuals you have to open to being flexible and to evolving over time.

We saw that even in the course of this training. For example, with the technology issues we just discussed, initially we had this online training, which people had indicated a desire to participate in, but as we encountered challenges or became aware of issues we had to then send hardcopies.

We had to adjust and are now using those lessons to develop and improve the next steps in terms of the support person training another component of the intervention and also just the dialogue.

We did some debriefing with each trainee at the end of the actual in classroom session, where a facilitator who was there at the School of Nursing in Virginia, who had actually been present throughout the in classroom session sat down with them and away from the eyes of the trainers at Hopkins talked with them about what they thought about the training.

What they thought was useful. What they thought could be improved and one of the themes that came out of the analysis of that transcript was that the community health workers trainees really appreciated the level of respect that they had been accorded. That they felt like they were really given a high level of attention.

That they had a say, when we said that we wanted their input and that this was going to be an intervention and a process that would be developed in partnership that that was something they perceived was happening and was exciting for them.

Particularly for a community, where we know there have been issues in terms of health disparities, issues in terms of when you look at the research literature not a whole lot from the perspective of these individuals, when we think about rural older adults— African-American older adults with cancer in particular and their support persons and then other member of the community touched by that.

They were very ready to go, as it were and they really seemed to be motivated by this desire to give back to their communities and that's probably not surprising, but and they were compensated as we mentioned in the article for their time, but it really each one of them brought a personal story about their reasons for wanting to participate in this process.

Rachel:

Even the trainees, who did not officially get hired on to the larger study going forward, have continued to serve as Jennifer was describing, as sort of ambassadors for the study within their communities and moving the work forward.

I think that was a just really heartening and I think also gave me an appreciation for just how important it is to develop those relationships and to really take the time to incorporate everyone's perspective, not just as preset plan that you come in with and then, intend to move forward on.

Jennifer:

I think Rachel's last statement says so much, because what I take away from this project or what I'd like for people to take away is the importance of having even something that we might think of well, you know we could easily sit around the table, just the study team and come up with a training.

This is a very long process. I mean, I think it took us certainly a lot longer than it took us to deliver the training to come up with a curriculum, to have conversations around the table, be meeting with the community health worker super trainers. To look at training, talk about the issues, talk about the larger project.

There was a lot that went into this and then, certainly just the training delivery, but I think the importance of having that whole process informed first of all, by as Rachel said everyone. By patients, who would be our target audience, essentially. By community health workers, who were working as community health workers, in terms of what did they perceive the training needs to be? How could we involve them in providing the training?

I think all members of the study team, I can honestly say even the CHW super trainers in talking to them they still express high levels of interest in the project and I think what I always hear from them is we want to stay involved in the project. They're not actually delivering the intervention, but I think that this level of investment is so important.

As Rachel said, the community health worker trainees, this is a group that is also I think very invested in the project. One of the things that we did as part of the training, where we were all together was we really went around and asked people what's your motivation for participating in the training today.

The other final points would be the importance of including some formal evaluation. Obviously, this piloted training that we did, five participants –it would have been really easy to say small numbers will just, you know maybe not worthwhile doing a formal evaluation, but I think that we perceived it was really important for us in going forward and planning the future phases and we wanted to have that feedback.

I really encourage people no matter the size. Sometimes we're all troubled by the size of our N, like is this too small? Is this project too small for us to think about evaluating it? I would encourage people to include formal evaluations wherever possible.

Finally, is the thinking through that is so important when you're working with any community level project—us giving back. What's a resource that you can leave in place?

Jennifer: What kind of skills, opportunities are you providing for everyone who is involved in the study, from the staff, the participants, people who are just helping you in terms of—we have people who are helping us on the study, who are not from a study staff, but they're invested and recognize the fact that we are trying to leave some resources in the community.

It's not just about delivering the intervention or sort of helicoptering in as rescuers. We are interested in partnerships, in sustainability, and even in the limited way that we can with pilot study resources, providing some kind of resource that people could take forward like having training that could be publicly available and easy to deliver continuously to different levels of people as they'd like to have it.