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A Qualitative Analysis of Attitude, Knowledge, and Interest in Research of People with Parkinson’s Disease and their Care Partners in an Accessible Research Education Program

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Abstract

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Background and Objectives: People with Parkinson’s disease (PWP) and care partners (CP) have unique perspectives regarding research and the research process. TeleDREAMS was an eight-week research advocacy training program designed to increase understanding of, and participation in, clinical research by older adults, including those from underrepresented groups.

Methods: A qualitative evaluation was conducted to explore the themes resulting from weekly phone call conversations with participants, both PWP (n=32) and CP (n=17), in an eight-week telehealth educational intervention. All participants were assessed for clinical characteristics and demographics (Mean age PWP = 68.06 ± 8.3, Mean age CP = 66.68 ± 6.4). Qualitative data were derived from 365 thirty-minute semi-structured interviews. The calls were conducted by telephone between participants and study staff to gauge progress, motivation, and information retention after each module of the educational program. These interviews were thematically analyzed using inductive and deductive methods.

Results: Thematic analysis revealed eight salient themes. Participants expressed varying beliefs and attitudes towards clinical research, the research process, and participation in research, encompassed in the themes, “Understanding the Importance of Advocacy,” “Becoming Cognizant of Past Advocacy Experiences,” and “Research Participation.” There were also unexpected themes, including “Knowledge Acquisition Sometimes Diverged from Module Intention,” “Learning from Example,” “Community Engagement,” and “New Awareness of Ethnic Disparity.”

Conclusion: This study provides insight for increasing research participation of hard-to-reach and underrepresented participants. Phone call interviews are an accessible, adaptable method that is effective in gathering the needs, opinions, and attitudes of older adults. Further studies are needed to identify additional barriers to PWP and CP participation in research. This qualitative model and its results can be used for improving future iterations of TeleDREAMS and similar telehealth educational programs.

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INTRODUCTION

Hard-to-reach participants, including older adults from racial and ethnic minority groups and those with low incomes, are critically underrepresented in research.[1] Fostering trust of the research process in these communities and creating lasting partnerships, through training underserved health ambassadors, are successful methods for engaging underserved participants in research.[2]

Parkinson's disease (PD) is a progressive neurodegenerative disorder that is characterized by both motor impairments and non-motor symptoms. Rigidity, bradykinesia, tremors and postural instability are common motor symptoms, while cognitive changes, apathy, and mood disorders are non-motor symptoms.[3] The range of symptoms, rate of progression, and detection of symptoms vary for different individuals.[4]

Older adults with PD and their care partners may fall into one or more NIH-designated U.S. health disparity populations that include various ethnicities, socioeconomically disadvantaged populations, underserved rural populations, and sexual and gender minorities.[5] Engaging and retaining individuals who are a part of health disparate populations presents many challenges. Some of these issues may be addressed through timely, transparent recruitment strategies that help ensure participant retention.[6]

TeleDREAMS was an eight-week educational telehealth program for adults with Parkinson's disease (PWP) and their care partners (CP), and included participants from diverse racial, ethnic, and socioeconomic backgrounds. TeleDREAMS was a research advocacy program that aimed to educate older adults on the research process and role of participation in research. TeleDREAMS also sought to increase participation among PWP and CP who are critically underrepresented in research. TeleDREAMS built on the successful two-part, in-person

Developing a Research participation Enhancement and Advocacy training program for diverse Seniors (DREAMS[7,8,9,10]). While the previous program, DREAMS, was delivered in-person, TeleDREAMS was implemented via distance-learning. Weekly phone call interviews with participants gauged progress, motivation, and information retention in TeleDREAMS.

PURPOSE

The purpose of this study is to examine the effects of the eight TeleDREAMS educational modules on beliefs and attitudes towards clinical research, the research process, and participation in research in older adults with PD and their care partners. This was accomplished through a qualitative thematic analysis of weekly phone call interviews conducted over the course of the program's eight-week duration.

HYPOTHESES

Through these series of interviews, we anticipated varied responses from participants about what they learned and gained from the modules; we expected that some concepts would be readily adopted, while others would be more difficult to process. From the interview questions directly, we expected to learn what educational content participants found interesting or new, how they were able to use the module's content in their daily lives, what topics they might have already known about, which supplemental materials they relied on, and any suggestions they could make about the modules' contents.

Beyond finding participant responses closely aligned with interview questions, we expected to see an increase in knowledge of clinical research opportunities and research processes, an increase in the willingness to participate in clinical research and an increase in positive attitudes toward research and participation in research. Moreover, we expected these core ideas would evolve to become increasingly apparent in participant responses. We predicted a difference in responses between PWP and CP. More specifically, we anticipated an increase in the understanding of the role of advocacy among care partners, an increase in understanding of how disparities in target populations impact research outcomes, and how the roles of advocacy differ between CP and PWP.

METHODS

Emory University Institutional Review Board reviewed and approved the Tele-DREAMS protocol; all subjects provided informed consent before participating in study activities.

Participant Recruitment

With the help of previous partnerships from DREAMS (DREAMS Team[11]) and Patient Stakeholder Advisors, a total of 51 adults who were either people with Parkinson's disease (PWP) or care partners (CP) of people with Parkinson's were recruited and enrolled for the TeleDREAMS study (Table 1). Strong efforts were made to recruit individuals from historically underserved backgrounds, such as ethnic minorities, poor or isolated individuals, and individuals with low health literacy. Participants were recruited at local community centers and events, within community outreach programs at Emory's Center of Health and Aging, at local churches, and at Parkinson's community events.

Two care partners were excluded from the original sample (n=19) because they received different methods of content delivery than the rest of the TeleDREAMS participants. A subsequent version of this research advocacy training program was designed so that participants received audio recordings of the educational content, in addition to physical binders. The two excluded CP received this new method of content delivery.

CPs were originally selected for inclusion in this study because of their integral role in PWP care. It has been recommended that CPs be incorporated in informing policy, education, and research concerning the health care of their care recipients.[12]

Participants were expected to comprehend written English and to participate in a weekly, thirty-minute phone call interview with the study team. Distance learning and one-on-one accountability through phone call interviews allowed for participation of rural and mobility-limited individuals. Free transportation to in-person pre and post-test assessments was provided to decrease some barriers to participation.

Table 1. Demographic Characteristics PWP vs. CP

		Total	**PWP**	**CP**
n		51	32 (62.75)	19 (37.25)
Age (year)		67.55 ± 7.6	68.06 ± 8.3	66.68 ± 6.4
Education (year)		16.33 ± 2.5	16.06 ± 2.8	16.82 ± 1.7
BMI		27.25 ± 6.2	26.45 ± 5.8	28.61 ± 6.8
Composite Physical Function		19.74 ± 5.4	17.88 ± 5.9	23.06 ± 1.4
Sex				
	Men	28 (54.9)	22 (68.8)	6 (31.6)
	Women	23 (45.1)	10 (31.2)	13 (68.4)
Race				
	Asian	3 (5.9)	1 (3.1)	2 (10.5)
	Black	11 (21.6)	7 (21.9)	4 (21.1)
	Hispanic or Latino	2 (3.9)	1 (3.1)	1 (5.3)
	White	35 (68.6)	23 (71.9)	12 (63.2)
House Type				
	House/apartment/condominium	49 (96.1)	31 (96.9)	18 (94.7)
	Senior housing (independent)	2 (3.9)	1 (3.1)	1 (5.3)
Leave House				
	1-2 times/week	8 (16)	7 (21.9)	1 (5.6)
	3-4 times/week	12 (24)	8 (25)	4 (22.2)
	Every day	29 (58)	16 (50)	13 (72.2)
	Less than once/week	1 (2)	1 (3.1)	0 (0)
Use of Assitive Device				
	NO	35 (70)	17 (53.1)	18 (100)
	Sometimes	8 (16)	8 (25)	0 (0)
	Yes	7 (14)	7 (21.9)	0 (0)

Table 1. Participant Baseline Characteristics. Values are presented as Mean± SD for continuous variables, and n (%) for categorical variables.

Overview of the TeleDREAMS Program

An educational binder was distributed to TeleDREAMS program participants that contained eight separate weekly modules. Participants were expected to independently read the corresponding module for each week. To ensure accessibility for all participants, the weekly modules were approximately 20-30 pages long and were written at an eighth-grade reading level. In addition, optional supplemental videos and related web-based resources were provided in footnotes with which participants could engage. The educational material contained modules on understanding clinical research, health topics of relevance to PWP, and health disparities (Table 2).

Table 2. Module Topics in TeleDREAMS Educational Content

Week	Topic	Week	Topic
1	Introduction to Research Advocacy	5	Aging and Clinical Research
2	Research Nuts and Bolts	6	Informed Consent – Understanding the Issues and Health Literacy
3	Ethics and Aging Research	7	Effective Advocacy in the Clinical Research Process
4	Understanding and Interpreting Clinical Trials for Patient Advocates	8	Engaging Diverse Communities in Research and Getting Started as a Research Advocate

Data Collection

Data were collected from 32 PWP and 17 CP. At the end of each weekly module, study participants were involved in 30-minute phone calls with research staff to ascertain progress and discuss each completed lesson. The interview-like telephone calls always started by asking participants if they had read the weekly content and the following questions mirrored those used for the original DREAMS Program small group discussions. Participants were asked what they learned, what content they found interesting or new, what content they might be able to use in their daily lives, what topics they might have previously known about, and which supplemental materials they relied on (Appendix A). Participants were also asked for suggestions on what content they believed should have been included. Accessible phone-based communication ensured participants had the ability to provide feedback on the educational modules without traveling to a different site and without major technological concerns.

Data Analysis

Field notes were taken during each weekly phone call. The field notes were analyzed using NVivo 12 and NVivo (Release 1.3.2) software. The data were coded by the first author using both deductive and inductive coding techniques. The coded data were then thematically analyzed and key themes were identified. Themes were verified and reviewed by the second and senior authors. The eight salient themes that were most inclusive of participant responses have been considered and identified.

RESULTS

Participant Characteristics

As indicated in Table 1, PWP average age was M = 68.06, SD = 8.3, while CP average age was M = 66.68, SD = 6.4. It is important to note that the demographic and clinical characteristics for this sample were diverse, as the sample contains individuals with comorbidities. Composite physical function scores are out of 24 where higher scores are representative of less risk for loss of function. On average, composite physical function was higher for CP (M = 23.06, SD = 1.4) compared to PWP (M= 17.88, SF = 5.9). Male participants accounted for 68.8% of total PWP, compared to 31.2% for female participants. In addition, male participants accounted for 31.6% of total CP, compared to 68.4% for female participants. The total sample size for this study contained 54.9% male participants and 45.1% female participants. Both PWP and CP in this sample also suffered from additional comorbidities that included high blood pressure, heart problems, diabetes, depression, arthritis (or rheumatism), asthma (or other breathing problems), osteoporosis, cancer, stroke, vertigo (or other inner ear problems) and some participants had past joint replacements.

Qualitative Findings

The eight most salient themes extracted from CP and PWP responses were: (1) Understanding the Importance of Advocacy, (2) Becoming Cognizant of Past Advocacy Experiences, (3) Community Engagement, (4) New Awareness of Ethnic Disparity, (5) Learning from Example, (6) Knowledge Acquisition Sometimes Diverged from the Module Intention, (7) Recognizing Patient Autonomy, and (8) Research Participation. The percentage of total, PWP, and CP responses that were coded and analyzed to each of the eight most salient themes are

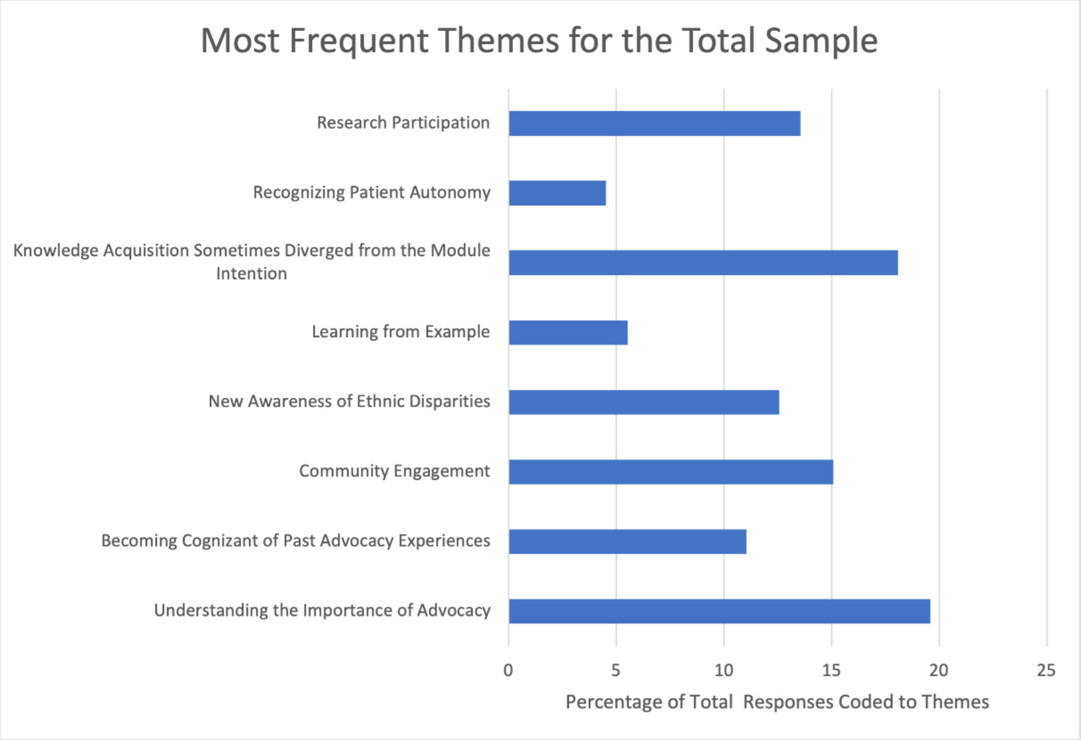

Figure 1. This histogram represents the percentage of 199 total responses that were coded and analyzed to each of the eight most salient themes. Data resulted from a total of 365, 30-minute phone call interviews placed by staff and conducted every week over the eight-week program for all participants in the sample, including PWP (n = 32) and CP (n = 17).

shown in detail in Figs. 1-3. Additionally, percentage coverage of each theme by participant have been produced (Appendix B).

Theme 1: Understanding the Importance of Advocacy

Throughout the eight-week program, participants appeared to understand the importance, role, and responsibilities of advocates in research. Many participants recognized the universal role of advocates; the phrase “anybody can be an advocate” was reiterated word-for-word at least four different times. Though many participants were previously familiar with celebrity TV advocates before the program’s start, some participants were unaware that members of their communities, including themselves, could serve as advocates. Upon participation in TeleDREAMS, a 64-year-old White female care partner responded that she, “didn't know that you needed everyday advocates,” while a 54-year-old Black female care partner said, “outside of just celebrities, it [advocacy] can be a community effort.” The responsibilities of advocates were then detailed through different actions. A 74-year-old White male PWP described advocates as people who, “stand up and make their voices heard,” and went on to say, “advocates come from different point[s] of view, especially between patient and caregiver”. Lastly, a 59-year-old White female PWP reported that she learned, “how important the advocacy program is to get people included in research and clinical trials and how a person like me can be an advocate and help facilitate that.”

In addition to learning about the role and responsibilities of advocates, participants drew conclusions on the long-term effects of advocacy in healthcare. A 62-year-old Asian female CP noted the impact on the relationship between advocates and researchers, reporting, “…advocacy can diminish the communication gap between participants and researchers.” The same 62-year-old Asian female CP also noted, “advocacy can help to bridge the gap of under-served populations in research and healthcare” by helping patients learn more about the impact of chronic illnesses on patients and their families. A 68-year-old White male CP extended advocacy to a broader scale, saying, “An advocate can come in so many different forms. Anyone can become an advocate. If you support something or someone, you can become an advocate.”

Still, a 57-year-old White male PWP identified a unique difficulty with becoming an advocate, stating, “Being an advocate for other people looks like a really good thing. I try to do that in my community. With PD, it is hard to get motivated. So many people withdraw, but even though you have PD, you have to keep going.” A 69-year-old White male PWP expressed his fear of inadequacy because of health concerns to be an effective PD advocate, saying, “I'm worried I'm not a good advocate because I don't speak or remember well.”

Overall, these responses demonstrate that learning about advocacy encouraged some participants to pursue advocacy. A 61-year-old Asian male CP said,

> “I am excited about advocating for myself and people you meet to get others involved in research and research advocacy, because that's what my wife and I do and will continue to do. It gives us hope that people are dedicated to get others involved in research.”

A 64-year-old White female CP even determined best next steps for her own advocacy efforts by saying, “I need to learn more about PD and more of the scientific part of PD if I am going to be an effective advocate. I am a retired attorney so being an advocate isn't new to me. I understand some of the things advocates can do, but you have to be well informed to be effective.”

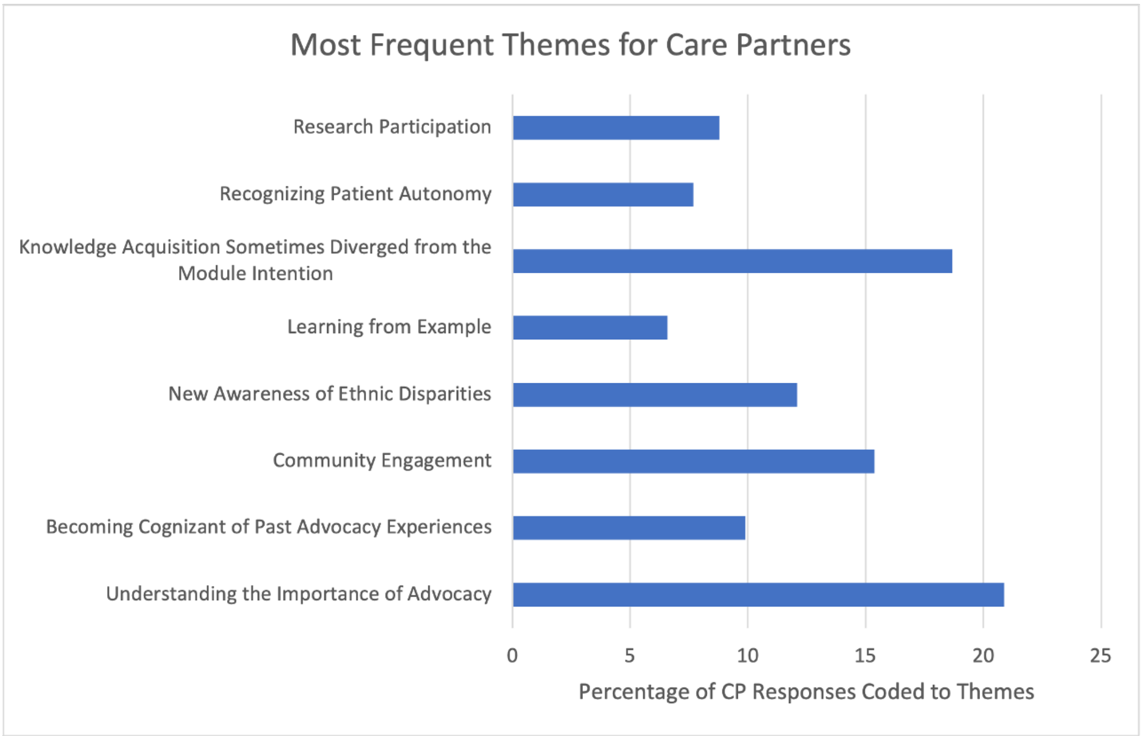

Figure 2. This histogram represents the percentage of 91 CP responses that were coded and analyzed to each of the eight most salient themes. Data resulted from a total of 122, 30-minute phone call interviews placed by staff and conducted every week over the eight-week program for CP in the sample (n = 17).

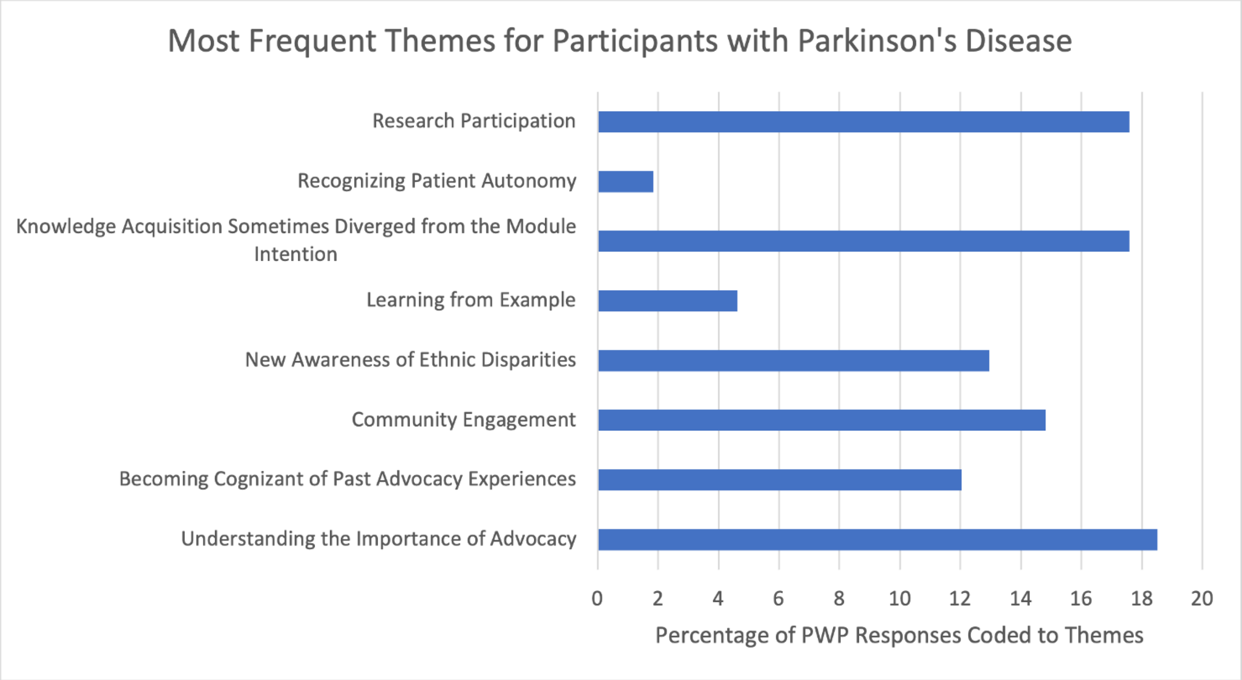

Figure 3. This histogram represents the percentages of 108 PWP responses that were coded and analyzed to the eight most salient themes. Data resulted from a total of 243, 30-minute phone call interviews placed by staff and conducted every week over the eight-week program for PWP in the sample (n = 32).

Theme 2: Becoming Cognizant of Past Advocacy Experiences

Over the course of eight weeks, participants not only came to understand the foundations of advocacy, but also began recognizing their own previous experiences in which they were unaware they were serving as advocates in their communities. Once provided with the formal definition of advocacy, many participants realized they had unknowingly participated in advocacy during their lifetimes. Participants frequently mentioned support groups as means of advocacy. A 77-year-old White female PWP said, “I realized I was doing things and didn't realize it. Hopefully things I have done in the past have helped people come into research.” A 59-year-old White female PWP saw this moment of realization as encouragement for future participation when she said, “It just makes me excited to continue to participate. And to know, I've been an advocate all along but didn't realize that.”

The educational modules brought to mind similarly encouraging experiences for other participants. A 77-year-old White female PWP revealed decades of advocacy experience, saying,

> “Going through this course has made me aware of all that I have done and continue to do. I am very open about PD and I try to encourage people to attend support groups. I have been an advocate for at least eight years.”

A 77-year-old White female CP even recognized that her spouse had previously engaged in advocacy efforts, saying,

> “My husband, in his support group, brought in a speaker, who is a yoga instructor. The yoga instructor talked about how yoga can be therapeutic for those with PD. This is one way advocates can help the community. Bringing resources to their community. and among those resources is research.”

Theme 3: Community Engagement

Many participants expressed interest in becoming more engaged in their communities in capacities that were distinct from research participation. Learning about certain facts or studies referenced in the educational modules often inspired participants to become more engaged with preexisting community programs. A 69-year-old White female CP described how her cancer support group is, “always interested in a better healthcare model,” and upon learning about various healthcare systems around the world, she realized she could now, “contribute to the conversations,” and, “will share this information with [their] peers.” A 68-year-old Black female CP even planned on trying dance lessons with her spouse, saying, “dancing has a positive effect on people with PD and stroke, spinal cord injury, so me and my husband are talking about dancing lessons. It improves balance.” A 57-year-old White male PWP had hopes of spreading information about Parkinson’s disease and had already done so with his church, stating, “I talked to my church group a little bit and tried to explain to them, and they enjoyed it.”

A few participants expressed interest in planning and leading entirely new programs for their communities. Fitness groups were referenced by multiple participants, with a 74-year-old White male PWP hoping to create, “some kind of studying and exercise at local recreation places that would sponsor those kinds of events,” while a 61-year-old Asian male CP detailed plans he had already generated, saying, “I am going to help start a PD boxing group in different parts of Mississippi. I have a meeting with prospects tomorrow.” A 68-year-old Hispanic/Latina female CP compared PD care in the United States to PD care in the South American country Colombia, saying, “There is research, clinical trials, and support groups in the US. There is everything here, but nothing in Colombia. Everyone with PD goes to the same doctor because he is the only physician that specializes in it.” This participant then expressed a desire to change her community in Columbia, stating, “I would like to collaborate with researchers and organizations because people with PD are abandoned there.”

Still, not all participants were inspired to become more involved in their communities and a 69-year-old White male CP noted he was actually, “pulling back from doing stuff,” and, “looking for ways to be less involved,” but they, “might move in that direction again.” Interestingly, learning about the historical exclusion of older adults in research led one patient to recognize his own lack of engagement, which he then perceived as a flaw. The 76-year-old White male CP said, “old people are excluded for convenience’s sake. Older people can isolate themselves, which is kind of what I'm doing, which isn't a good thing.”

Theme 4: New Awareness of Ethnic Disparity

Most participants seemed to understand the ethnic disparity that exists in both healthcare and research. Participants who were not aware of these disparities prior to the beginning of the program frequently expressed a degree of shock. A 61-year-old White female CP recalled, “I was surprised about the gaps with Latinos and African Americans in research. I did not realize that a larger percentage of Hispanics die from cancer, but few are in the cancer studies.” Other participants felt compelled to make a change in these, “dismal results” through outreach efforts. A 62-year-old White male PWP said,

> “I would like to help with the strategy to help overcome that obstacle [participation in research] and get people in those hard-to-find segments...the minorities for example, and the groups that are underrepresented. I think that is a big deal! We shouldn't have those kinds of issues.”

Another participant, a 64-year-old White female CP, recognized she was not from an underrepresented group but that “there are areas that [she] probably can reach out to populations that are somewhat diverse, and you can always find people to help translate." A 77-year-old White female CP appreciated the inclusion of ethnic disparities in the modules because of her personal connection to the content. This female CP said,

> "Diversity matters a lot to me, and I am so happy that a section was dedicated to it. I was head of a children's school and one of my missions was to improve diversity in the school…I was very happy to see that diversity also plays a very large role in research and research advocacy."

Theme 5: Learning from Example

Participants seemed to benefit the most from the example-based pedagogical approach that TeleDREAMS achieved. Personal stories and experiences helped participants relate to the educational content and often allowed them to draw similarities to their own lives. A 68-year-old White male CP said,

> "I enjoyed the example of advocates sharing their opinions and giving a more specialized opinion to the research team. They have first-hand knowledge and can contribute to the research. I liked the personal touch of listening to the advocates and their personal experiences."

Many other participants expressed how they enjoyed the example stories and experiences, with a 77-year-old White female CP stating, "There were also a lot of interesting statements and testimonials from other advocates. I enjoyed reading them." Another participant, a 68-year-old Hispanic/Latina female CP, followed along the same line and said, "I like the examples. It was very interesting to hear about the research they are doing in other parts." A 63-year-old White male PWP found these personal stories, "useful to pass along," perhaps signaling his decision to implement the personal stories into their own discussions about PD and research. Even for a 69-

year-old White male PWP who struggled with cognitive impairment and was unable to recall the examples in detail, the presence of personal stories in the weekly modules had a profound impact, although he acknowledged having memory impairment was a problem for him. This male PWP said, "it [the module] gives real life examples of the types of studies and so forth, and…there's something related to having a real-life example, but my memory is so bad, I'm not sure it will help me."

Theme 6: Knowledge Acquisition Sometimes Diverged from the Module Intention

Each week, participants engaged with a different module that centered around a new topic related to advocacy, research participation, and the research process. Though each week had its own unique learning objectives, participants acquired different knowledge about the same topics. We observed that what participants actually learned from specific weekly modules sometimes differed from the module creators' intended goal.

Weeks 1-3:

Responses from the first three weeks concerning advocacy, research "nuts and bolts", and ethics largely suggest that participants acquired knowledge congruent with each module's goals. Quotes from the first three weeks include:

> From week 1, Advocacy: "I learned what advocacy is and to understand what PD advocates do in research and the different types of projects and possible things ones could get involved with." (77-year-old White female CP)
>
> From week 2, Research Nuts and Bolts: "I learned that there are all types of research. Basic vs. you know...and I like it when you're actually monitoring a specific group of people. I enjoyed learning about the research." (66-year-old White female PWP)

> From week 3, Ethics: “I knew there are a lot of ethical practices in place to prevent unethical studies.” (64-year-old White female CP)
>
> From week 3, Ethics: “The ethical issues were powerful stories,” and said, “They knocked me off my chair. The Tuskegee was cruelty. That really stuck out to me it was on Americans! Information was kept from them for 30 years.” (68-year-old White male PWP)

Week 4: Understanding and Interpreting Clinical Trials for Patient Advocates

During the fourth week, focused on interpreting clinical trials, participants appeared to not only understand clinical research, but also an appreciation for learning about how to read research papers. A 74-year-old White male PWP said,

> “[learning] how to read a research paper was interesting, because most people will just read the snapshot before they read the paper. and I thought it was an excellent way to read it... to read the introduction and pick the key questions in your mind and see if you can see any bias in it. You hear all those studies like mypillow.com it guarantees. Who pays for their research is the question I have! The statistics show... so and so... but who pays to show that research?"

Week 5: Aging and Clinical Research

Most participants were able to relate week five’s topic on aging to their own personal experiences with aging. A 76-year-old White female PWP said that she,

> “learned that everyone goes through losing some of their abilities to see and hear as they get older and I always thought I could just go to a doctor to get those fixed but might just have to be happy with the way it is”.

Others were surprised at the definition of age discrimination. A participant in the program, a 74-year-old White male PWP, said he, “didn't know ageism is a word,” while a 61-year-old Asian male CP said, “I’m 62 and I never thought about age discrimination and awareness. Never thought about age discrimination but now I know to be aware of it and pay attention about that.” A 74-year-old White Male PWP appreciated information about exercising related to aging, saying,

> “The benefits of exercise stuck out to me as well as the benefits of mental exercise. Because I have Parkinson's it is important to see how fast I can do calculations like 143 minus 7. My wife has been doing that for many years now.”

Week 6: Informed Consent and Health Literacy

Most participants appear to have gained an understanding of health literacy by the end of the week. A 77-year-old White female CP said, “The notion of health literacy, and other kinds of literacy, feels like it helps people make appropriate decisions about healthcare based on information.” A 59-year-old White female PWP noted,

> “I learned that I thought I had good health literacy, and I hope I do. After reading the definitions I kind of questioned myself. Especially when I read that small percent of people have good literacy. You had to understand a lot of insurance to qualify as good. Maybe I'm only adequate.”

The other goal for the module was to teach about informed consent. A 60-year-old White male PWP said, “I found the information about the consent laws in GA very informative, i.e. directives and such.” Another participant seemed to grasp the importance of informed consent. This 58-year-old White female PWP said, “For someone who has a minimal amount of education, [I] can see how it would be very difficult. [I] would be concerned if it was someone in [my] family and the doctor would just gloss over the informed consent process.”

Participants reported learning specifically about health insurance models and advanced directives more frequently than health literacy or the broader topic of informed consent. This is an example of a surprising finding that differed from the module's intended goal. A 61-year-old Asian male CP, in particular, noted,

> "I learned about health care systems around the world and how the US is more like a hybrid system. It's more like a a-la-carte. I didn't think about how Medicare and veterans and the different patients access different types of systems instead of one system like in other countries."

Another participant, a 64-year-old White female CP, reflected this sentiment when she said,

> "I didn't know what the different models of health care were called, and the US is totally out of sync with everyone and that was interesting to learn. I did know that they spend almost 2x as much on health care... I did know the Medicare stuff because I have to go on a supplement policy this year."

Week 7: Advocacy in Clinical Research

Though expectations of the seventh week were focused on understanding advocacy within clinical research, it appears that participants were intrigued by the collaborative role an advocate can play in research. For instance, a 59-year-old White female PWP described this, "collaborative aspect of the research," saying,

> "I don't know why it was new, because I've done research before. I still think that reading this it feels more like a collaboration of equals. We need them [researchers], they need us [patients], as opposed to the researchers having all the knowledge and power."

Week 8: Recognizing Diverse Communities and Becoming an Advocate

In week 8, when learning more about advocacy and recognizing diverse communities in research, most participants took away an understanding of barriers to research. Overall, participants used the term “barrier” in the context of research participant limitations, eleven different times. A 58-year-old White male PWP said,

> “It [the module] kind of lays out ways we can become more involved and barriers. I recognize and notice a difference in the population of people I see and experience. I am trying to figure out how barriers apply to the PD community I am in.”

Theme 7: Recognizing Patient Autonomy

Though not explicitly discussed in the weekly educational modules, recognizing patient autonomy was identified in the personal stories of autonomy and the desires of care partners to promote the autonomy of care recipient. A 60-year-old White female CP, revealed that her participation in research studies has led her to, “want[s] others to realize they have a voice when others feel that they don't.” A 61-year-old Asian male CP said, "people need ownership of their healthcare. You have the responsibility to take care of your health." This same participant illustrated how he, “[has] ownership,” in his decision to use a spreadsheet to track his medical history that he presents to his healthcare professionals as a supplement to his patient charts. A 64-year-old Black female CP recalled instances where she recognized her husband’s autonomy, saying, “You don't need to let everything slide. Sometimes you need to let him [her husband] deal with people himself.” Field notes reveal an 80-year-old White female PWP found learning about health insurance, “was interesting because she [participant] could relate to insurance. She usually let someone else do it for her, so it was new for her to learn.”

Theme 8: Research Participation

Overall, it appears that learning about different types of studies and the research process may have fostered interest in scientific topics among program participants. A 68-year-old Hispanic/Latina female CP felt it was her, “social responsibility to help find a cure for Parkinson's disease,” while others were interested in topics like genetic research and cerebrospinal fluid analysis. Beyond interest in research topics, participants conveyed skills that they gained from the program that benefit their participation in research. For instance, a 58-year-old White male PWP recalled, “I was actually interviewing for a clinical trial and what they are doing makes a lot more sense. I am learning a lot more than I am able to explain.” A 68-year-old Hispanic/Latina female CP felt, “motivated…to participate in clinical trials,” after stating, “This study gave me some tools to ask researchers about getting results.” Many other participants expressed similar interest in both participating in research and recruiting their community members to participate as well. A 60-year-old White female CP began, “telling people that they should try to participate in more clinical studies because of how informational the readings are and that it is a great fulfilling experience.”

A 66-year-old White female PWP illustrated her interest in participating in research by saying, “For example, I want a cure, and I'm thinking, I never thought of looking into other research resources. You can't just stop at one page and not continue. I want to look into more and get in touch with researchers at Emory.” A 77-year-old White female PWP revealed that TeleDREAMS helped to, “refocus [her] into trying to prioritize what is the most important,” and to her, participating in a, “clinical trial or study…is very important.” Some participants even seemed to understand the importance of research for future generations. One of these participants, an 81-year-old White male PWP noted, “Just participating in the trials might help my condition (exercise, drugs), but they are not designed to benefit me. They are designed to help the future."

DISCUSSION

General Findings

TeleDREAMS combined distance-learning and phone-based assessments with the intention to create an accessible approach to promote research advocacy for older adults dealing with PD. Information gathered from these phone calls is important in analyzing the needs, opinions, and attitudes towards research participation in a group of individuals, some of whom are underrepresented in research. Additionally, the diverse demographic and clinical characteristics of the CP and PWP in this study may have shaped participants' responses to TeleDREAMS. The presence of comorbidities in study participants and experiences unique to PWP and CP likely influenced participants' responses as well.

While TeleDREAMS appeared to increase interest in community engagement, research participation, and advocacy roles, participant responses to two specific questions – "What did you learn?" and "Did anything stick out as particularly interesting or new information for you?" – reveal that responses may have remained relatively constant across the eight weeks (Fig. 5).

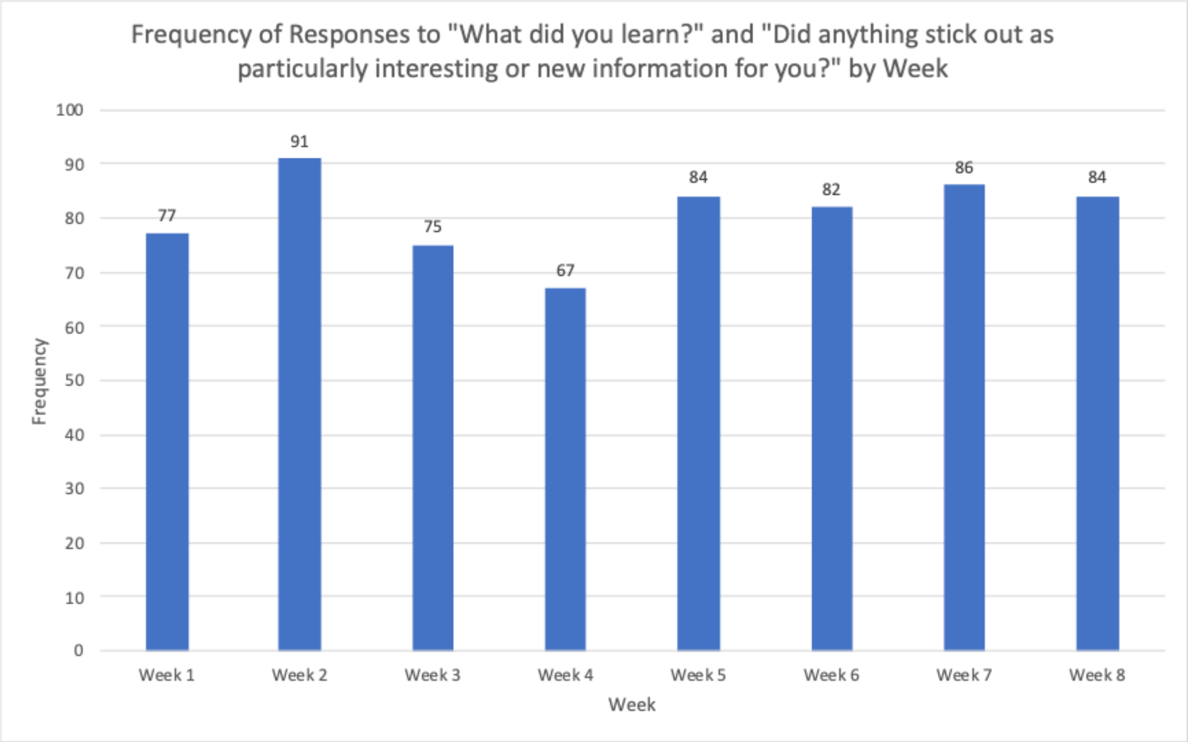

Figure 5. This histogram represents the frequency of participant responses to the questions "What did you learn?" and "Did anything stick out as particularly interesting or new information to you?" specific to the topic and goals of each week. Data resulted from a total of 716 participant responses to these questions over the eight-week program. Responses that did not fall under the weekly topic but reported new information learned (n=70) were still coded to this total. See Table 2 for the topic that coincides with each week.

Telehealth Educational Programs

Telehealth educational programs combined with phone-based assessments may be comparable or more effective than traditional in-person methods of educational programs.[13] Telehealth education appeared as a promising alternative to face-to-face health promotion and programming during the 2003 severe acute respiratory syndrome outbreak in Hong Kong.[14] Therefore, TeleDREAMS also may have the potential to improve educational outreach programs to older adults during similar public health crises, such as the SARS CoV-2 (COVID19) pandemic, in addition to its original purposes. Recent research has suggested that out of several technologies developed for older adult health education, printed material is most developed, but software-type technology and video technology are also effective and may also lead to autonomous learning.[15] Future iterations of TeleDREAMS may benefit from incorporating different technology.

Findings Related to Advocacy, Autonomy, Community Engagement, and Research Participation

The purpose of TeleDREAMS was to provide a research advocacy program that educated older adults on the research process and role of participation in research. TeleDREAMS also sought to increase participation among PWP and CP who are critically underrepresented in research. The themes, "Understanding the Importance of Advocacy" and "Becoming Cognizant of Past Advocacy Experiences" are critical in considering how older adults view research advocacy and the roles and responsibilities of advocates. These themes are the most important findings of this study as they show that the goals of TeleDREAMS were at least partially achieved. These themes reveal that participants learned about research advocacy and further, were able to apply what they learned to their personal experiences. The findings of "Recognizing Patient Autonomy" appears to inadvertently overlap with our findings on advocacy. For example, a 60-year-old White female CP stated she, "want[s] others to realize they have a voice when others feel that they don't." On the individual level, an autonomous individual needs both intentional and full understanding of their actions.[16] Both autonomy and advocacy require some degree of self-awareness and informed decision making. More research is needed to understand the overlap between patient advocacy and autonomy.

The identified themes, "Community Engagement" and "Research Participation" reveal that TeleDREAMS may have potential to improve older adults' participation in both research and community programs. These findings are consistent with previous studies that suggest "interactive advocacy training and health education may impact older adults' willingness to engage with the scientific community."[9]

Findings Related to the Education of Older Adults

Perhaps the most surprising finding from this study came from understanding learning preferences of older adults. We found that participants seemed to enjoy and learn best from personal stories and examples, which is consistent with previous research that advises that information presented should have personal meaning to older adults who are self-directed and self-regulated.[19] More research is needed to determine if older adults may better understand traditionally difficult content when it is present in a narrative format.

Though each weekly module was designed with its own learning goals, participants frequently reported learning about topics distinct from the module's intended objectives. This observation was identified in "Knowledge Acquisition Diverges from the Module Intention." Previous familiarity with topics may have influenced how participants acquired knowledge that diverged from the module's intention. During Week 6, for example, many participants claimed to have prior knowledge of health literacy and informed consent – the principal topics of the week. A 59-year-old White female PWP, who claimed she was familiar with the topic, still expressed deeper moments of understanding after completion of the module, saying,

> "…under the whole umbrella of health literacy, the concept was new, but the things underneath I was familiar with. The things to be health literate I knew about. I was familiar with informed consent. I had not linked research and informed consent and health and health informed consent. I hadn't seen them paralleled."

A recent study found that while healthy adults may be familiar with research subject protection measures, many are unfamiliar with the informed consent process. In the cited study, this was the case, even when most of the sample had been asked to participate in research before.[17] That study, accompanied by TeleDREAMS participants' expression of existing knowledge, might suggest there remain aspects of the research process that are unclear to many people.

TeleDREAMS Successes

Many participants enjoyed learning most from personal stories and example-based lessons, i.e., learning from others who have experienced similar issues. Most participants could relate the program's content to their own lives, and many found the content easy to share with others in their community. A 62-year-old Black male PWP said,

> "One of the things I learned over the eight weeks is that this program has been put together well. There hasn't been something that has not been covered. It is put together in a way that I can understand it. It is at home and gives you something to do, you can learn something and then pass it on. I also learned about clinical trials that are going on that aren't PD related. I learned about exercise classes and social things going on. I think it is well put together."

Overall, most participants appeared willing to participate in phone call interviews and several participants "looked forward" to upcoming modules. Some participants enjoyed the weekly phone call conversations themselves. A 63-year-old White male PWP said "I enjoyed the phone conversation today. I am looking forward to the second module." Weekly phone calls that coincided with each weekly module seem to be an effective method for holding participants accountable. Furthermore, dividing content into eight weekly modules may be beneficial for participants who have difficulty with cognitive functioning or completing tasks independently. A 68-year-old White male CP shared, "We set up a time an hour before you call, and it's good, relaxing and bonding time to spend together reading. It's also thought provoking."

Areas of Improvement

During the phone calls, participants provided direct feedback on areas of improvement. Participants suggested methods of summarizing information and reorganizing the structure within each module. For example, a 68-year-old White male CP said,

> "Maybe another suggestion is at the final page of the chapters, do key bullet points from the chapter. Then maybe at the end of the chapter, ask for volunteers and tell us what trials there are, and what they are researching and testing. Is there a research trial that you would recommend? You're educating us, but at the end of the chapter I was so overloaded."

A 63-year-old White male PWP, noted,

> "I found it to be direct. It was a lot of facts. In terms of completeness, I never had a feeling of something left out I do believe that it was a little ---and I will probably think this through---it was not organized the way I'm most comfortable reading technical material. It needs to start out with the very biggest concept. Identify what we're here for, and why we're doing this, and then successive drill downs. If you drill too quickly down, you lose people. And, I sort of got that feeling."

A 69-year-old White female CP reported that their spouse suggested using an index or glossary at the end of each module. Summarizing and organizing each weekly module through different methods may help participants feel less "overloaded" with information.

Even with conscious efforts to make the educational content accessible to a wide audience with varying literacy levels, some participants still struggled with what they called, "terminology and nomenclature," or "technical stuff." A 68-year-old White male CP said, "the jargon was kinda confusing and unnecessary," for their care recipient to understand. In addition to organizing each module and highlighting key terms, adjusting the content from an eighth grade reading level to a fifth-grade reading level may allow print material to be understood by more participants.[18]

Several participants requested more information about PD specifically. Participants were interested in resources related to PD research, symptom management, diagnoses, and preventative measures. This finding aligns with previous research that suggests patients are motivated by existing physical and emotional restrictions.[19] Lastly, participants requested more examples, personal stories, and testimonials, thus emphasizing our observation that they benefitted from, and enjoyed example-based learning.

LIMITATIONS

We acknowledge some important limitations. Approximately 1/5 of all PD cases in the United Sates are diagnosed in non-Caucasian race/ethnicity groups. [20] Even though PWP in this study may have reflected national PD incidence (28.1% PWP from non-White racial/ethnic groups), difficulty recruiting more participants from each minority race/ethnicity group and other underserved backgrounds limits the generalizability of these findings. Individuals from racial and ethnic minority groups, lower SES, and even less, or low, education are historically hard to reach and recruit into studies. Future recruitment strategies should target these groups, ensuring that research findings can better reflect the diversity in our communities to potentially improve policies and practices that eliminate health disparities.[1]

Additionally, this analysis was limited by the inability to observe theme progressions, or evolution, over time. Our current findings suggest that participants increased interest in community engagement, research participation, and advocacy roles. While we can suggest that interest in these three areas may have evolved over time, and some themes are often bound to certain weekly topics, we are unable to determine when participants' views began to shift in a positive manner. It is also important to note that salient themes often coincided with the introduced topic for each weekly theme. Themes that recurred over several weeks, like "Understanding the Importance of Advocacy," "Community Engagement," and "Research Participation," would provide the most conclusive data on determining how and when participant responses evolved over time.

Another limitation of this study was that weekly phone call interviews were neither transcribed nor recorded. Without proper transcriptions, participants' responses may be incomplete. Furthermore, the field notes generated for each call were completed by different research staff who documented the calls in varying formats (direct quotations or summaries of participant responses). Deciphering whether field notes for a particular call involved responses that were direct quotations or summaries of participant responses occasionally made analysis of field notes confusing. Reworkings of TeleDREAMS will greatly benefit from recording and transcribing phone call interviews.

CONCLUSION

The direct feedback from participants, along with an expressed desire to participate in research and community programs, is promising. The data from this study supports previous research that suggests research advocacy training programs benefit research participation of older adults. The combined model of distance-learning and phone-based assessment is an accessible means of interacting with hard-to-reach participants. Future iterations of TeleDREAMS may benefit from incorporating ample personal stories, clearly identified terminology, and well-summarized modules. This qualitative model and its results are useful for designing similar telehealth educational programs to TeleDREAMS.

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APPENDIX A

Questions Asked by Study Staff to Participants During Weekly Phone Call Interviews

1. Have you read the Week <1,2,3, etc.> lesson?
2. Did you look at any extra information about this topic, such as websites/videos/supplemental materials?
3. What did you learn?
4. Did anything stick out as particularly interesting or new information for you?
5. What did you know about (topic) before reading this lesson?
6. Did you learn anything that you can use in your own life?
7. Was there anything else related to (topic) that you think should have been included in this week's module?
8. Do you have any other comments about this week's module or topic?

APPENDIX B

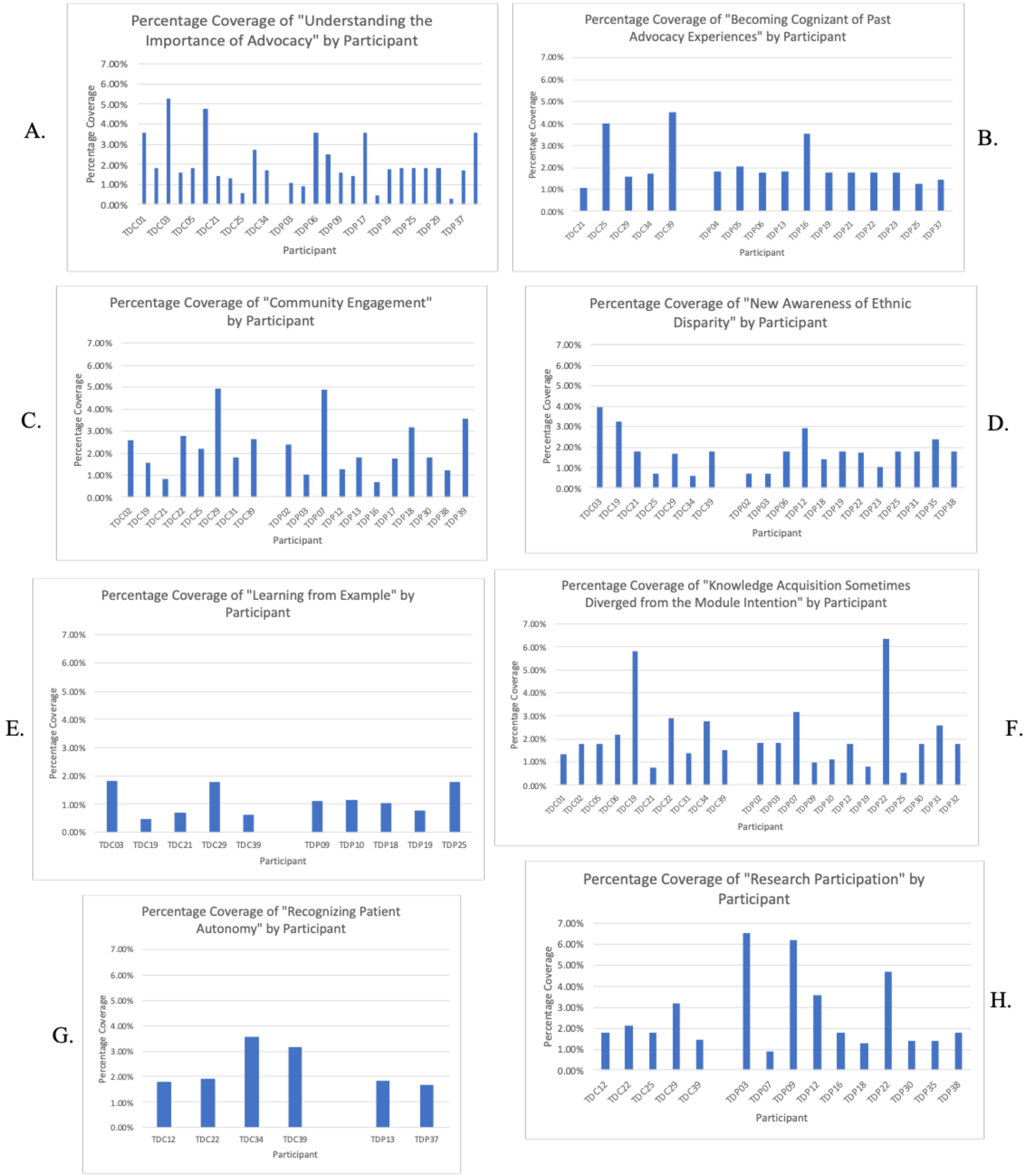

Figure 4. Histograms A-H of Percentage Coverage of Each of the Eight Most Salient Themes. These represent the percent coverage of each theme by individual participant. TDC bars indicate CP participants, while TDP bars indicate PWP participants.

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