Empowering
Partnerships
Preparing People with Dementia to Partner with Researchers

Evaluation of Livewell Training for Stakeholders and Researchers

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Summary: Overall, people living with dementia (PLWD), care partners (CPs), and researcher attitudes towards people with ADRD improved as a result of the training as measured by the Dementia Attitudes Scale. Also, both stakeholders and researchers found the training very helpful and to be a positive experience. Some of the researchers suggested all research should be conducted from this perspective

People Living with Dementia (PLWD)

PLWD Attitudes about People with ADRD

PLWD's attitudes about People with ADRD did not improve significantly over time.

PLWD	Pre-Attitudes – M(SEM)	Post-Attitudes – M(SEM)	Statistics
Comfort subscale	4.1(.11)	3.9(.12)	F(1,17)=1.6, p=.23
Knowledge subscale	6.2(.12)	6.3(.14)	F(1,14)=.09, p=.77
Total score	5.2(.08)	5.1(.09)	F(1,14)=.18, p=.68

PLWD's attitudes about people with ADRD increased the most about feeling it is rewarding to work with people with ADRD, being comfortable touching people with ADRD, and believing that people with ADRD like having familiar things nearby. Their attitudes decreased the most about thinking it is important to know the past history of people with ADRD, imagining caring for someone with ADRD, and feeling frustrated because they don't know how to help someone with ADRD.

PEOPLE LIVING WITH DEMENTIA	**% agree (N=9) PLWD Pre**	**% agree (N=9) PLWD Post**	**Change in % from baseline**
01. It is rewarding to work with people who have ADRD.	73	100	27%
05. I am comfortable touching people with ADRD.	82	100	18%
10. People with ADRD like having familiar things nearby.	82	100	18%
12. It is possible to enjoy interacting with people with ADRD.	82	100	18%
14. People with ADRD can enjoy life.	82	100	18%
15. People with ADRD can feel when others are kind to them.	82	100	18%
18. I admire the coping skills of people with ADRD.	82	100	18%
13. I feel relaxed around people with ADRD.	73	100	17%
19. We can do a lot now to improve the lives of people with ADRD.	73	86	13%
07. Every person with ADRD has different needs.	91	100	9%
04. I feel confident around people with ADRD.	82	89	7%
09. I would avoid an agitated person with ADRD.	27	33	6%
06. I feel uncomfortable being around people with ADRD.[a]	9	11	2%

03. People with ADRD can be creative.	100	100	0%
20. Difficult behaviors may be a form of communication for people with ADRD.	73	71	-2%
08. I am not very familiar with ADRD.	27	11	-16%
02. I am afraid of people with ADRD.	18	0	-18%
16. I feel frustrated because I do not know how to help people with ADRD.	27	0	-27%
17. I cannot imagine caring for someone with ADRD.	36	0	-36%
11. It is important to know the past history of people with ADRD.	73	43	-40%

PLWD Evaluations of the Training

In the training evaluations, PLWD' views improved the most about believing they can understand research. They were least confident that they had learned about research.

PEOPLE LIVING WITH DEMENTIA	**% yes (N=11) PLWD Pre**	**% yes (N=10) PLWD Post**	**Change in % from baseline**
03. I believe I can understand researchers(pre)/I understand researchers(post)	64	80	16%
01. I am comfortable with talking to researchers. (pre&post)	91	100	9%
04. I believe I will be able to share my experiences and views(pre)/ I was able to share my experiences or views(post)	91	100	9%
05. I trust that researchers will listen to me(pre)/Researchers listened to me(post)	91	100	9%
07. I trust researchers can use our input (pre&post)	91	90	-1%
02. I believe I can learn about research(pre)/I have learned about research(post)	100	90	-10%
06. I felt heard (post)		100	
08. I valued socializing with the group(post)		100	
09. I was satisfied with the training experiences(post)		100	
10. I would recommend this training experience to others(post)		100	

PLWD indicated that they enjoyed most communicating with the group, the varied backgrounds of the people in the group, and learning about the research process.

What did you enjoy the most about the Empowering Partnerships Experience? (PLWD)
Communicating and participating with others who also had Alzheimer's disease and their partners as well as professionals in the field and old friends from Livewell
Everything
Study design
The camaraderie with researchers, staff, and other people like me with dementia
The number of persons with so many backgrounds coming together making
Working with the people learning the process of how a researcher gets their info

PLWD indicated that they wouldn't change anything about the experience.

What would you have changed about the Empowering Partnerships Experience? (PLWD)
Nothing (stated by 4 participants)

PLWD said they thought that everyone reached out to them, that it was better than they thought (very interesting and touching), everyone's ideas were heard, and that the session reduced and addressed "stigma".

Please provide any additional comments you might have about the Empowering Partnerships Experience (PLWD)
Everyone reached out to me and to everyone making it a relaxing, accepting environment which is very important to someone who is living with dementia as I am
It was better than I thought very interesting and touching
It was social, it was informative, all rolled together, everyone's ideas were heard and put in as part of the process
Reduces and addresses "stigma"

Care Partners (CP)

Care Partners' (CP) Attitudes about People with ADRD

Care Partners' attitudes about People with ADRD did not improve significantly over time.

Care Partner	Pre-Attitudes – M(SEM)	Post-Attitudes – M(SEM)	Statistics
Comfort subscale	4.0(.08)	4.0(.09)	F(1,13)=.07, p=.80
Knowledge subscale	6.4(.08)	6.5(.10)	F(1,12)=.64, p=.44
Total score	5.2(.07)	5.2(.08)	F(1,12)=.00, p=.99

CP attitudes about people with ADRD increased the most related to feeling confident around people with ADRD, avoiding an agitated person with ADRD, finding it rewarding to work with people with ADRD, and feeling relaxed around people with ADRD. Their attitudes decreased the most about feeling frustrated about not knowing how to help people with ADRD, thinking it is important to know the past history of people with ADRD, thinking there is a lot we can do to improve the lives of people with ADRD.

CAREPARTNERS	**% agree (N=11) CP Pre**	**% agree (N=7) CP Post**	**% change**
04. I feel confident around people with ADRD.	78	100	22%
09. I would avoid an agitated person with ADRD.	22	43	21%
01. It is rewarding to work with people who have ADRD.	89	100	11%
13. I feel relaxed around people with ADRD.	89	100	11%
08. I am not very familiar with ADRD.	22	29	7%
02. I am afraid of people with ADRD.	0	0	0
03. People with ADRD can be creative.	100	100	0

07. Every person with ADRD has different needs.	100	100	0
10. People with ADRD like having familiar things nearby.	100	100	0
12. It is possible to enjoy interacting with people with ADRD.	100	100	0
14. People with ADRD can enjoy life.	100	100	0
15. People with ADRD can feel when others are kind to them.	100	100	0
18. I admire the coping skills of people with ADRD.	100	100	0
20. Difficult behaviors may be a form of communication for people with ADRD.	100	100	0
05. I am comfortable touching people with ADRD.	89	86	-3%
06. I feel uncomfortable being around people with ADRD.[a]	11	0	-11%
17. I cannot imagine caring for someone with ADRD.	11	0	-11%
19. We can do a lot now to improve the lives of people with ADRD.	100	83	-17%
11. It is important to know the past history of people with ADRD.	78	57	-21%
16. I feel frustrated because I do not know how to help people with ADRD.	44	14	-30%

Care Partner (CP) Evaluations of the Training

In the training evaluations, care partners' views increased the most about feeling that researchers listened to them. They decreased the most about understanding researchers.

CAREPARTNERS	**% yes (N=9) CP Pre**	**% yes (N=7) CP Post**	**% change**
05. I trust that researchers will listen to me(pre)/Researchers listened to me(post)	78	100	22%
07. I trust researchers can use our input (pre&post)	89	100	11%
01. I am comfortable with talking to researchers. (pre&post)	100	100	0
04. I believe I will be able to share my experiences and views(pre)/ I was able to share my experiences or views(post)	100	100	0
02. I believe I can learn about research(pre)/I have learned about research(post)	89	86	-3%
03. I believe I can understand researchers(pre)/I understand researchers(post)	78	71	-7%
06. I felt heard (post)		100	
08. I valued socializing with the group(post)		100	
09. I was satisfied with the training experiences(post)		100	
10. I would recommend this training experience to others(post)		100	

Care Partners indicated that they felt that everyone was given the opportunity to be heard, they enjoyed the collaborations, and enjoyed the satisfaction of completing the project.

What did you enjoy the most about the Empowering Partnerships Experience? (CP)
Anyone who had anything to say at any time was given the opportunity to be heard

Collaborative interactions (2)
Exercises I-II
Learning how the whole process works
That I was able to express how it was to me to be a care partner to tell how I feel
The satisfaction of completing the project

Care partners indicated that they would have wanted more information prior to the training, less information about clinical trials on Day 2, skipping the Briggs Stratton personality test, and less background noise.

What would you have changed about the Empowering Partnerships Experience? (CP)
As important and well-deserved as the information on clinical trials was a lunch time on Day 2, the amount of time inhibited my "getting going" again on the major focus of the day
Much less of the Briggs Stratton personality test - it was difficult for this crowd to complete and not that interesting or useful
Nothing (stated by 2 participants)
Provided more information prior to training to allow time to prepare
The only thing I would change is announce to participants to try to hold down the noise since I am hard of hearing and background noise makes it hard to concentrate

Care partners said they thought they enjoyed the mix of individuals, the compassion of enthusiasm of the participations, Day 2, and the commitment from everyone.

Please provide any additional comments you might have about the Empowering Partnerships Experience (CP)
Enjoyed the mix of individuals and ability to engage throughout the 2 day event
I was extremely impressed by the compassion and enthusiasm of the entire group of participants
Second day particularly good - we had a great team and participation from all
The commitment from everyone involved was amazing
Well done

RESEARCHERS

Researcher Attitudes about People with ADRD

Researchers' attitudes about People with ADRD did not improve significantly over time.

Care Partner	Pre-Attitudes – M(SEM)	Post-Attitudes – M(SEM)	Statistics
Comfort subscale	3.9(.09)	3.7(.11)	F(1,16)=1.6, p=.23
Knowledge subscale	6.5(.06)	6.5(.07)	F(1,15)=.06, p=.82
Total score	5.2(.07)	5.1(.08)	F(1,15)=.65, p=.43

Researchers' attitudes about people with ADRD changed the most regarding liking having familiar things nearby, being comfortable talking with people with ADRD, and being familiar with ADRD.

RESEARCHERS	Researcher % agree (N=11) Pre	Researcher % agree (N=8) Post	% change
4. I feel confident around people with ADRD.	91%	100%	9%
1. It is rewarding to work with people who have ADRD.	100%	100%	0%
3. People with ADRD can be creative.	100%	100%	0%
6. I feel uncomfortable being around people with ADRD.[a]	0%	0%	0%
12. It is possible to enjoy interacting with people with ADRD.	100%	100%	0%
13. I feel relaxed around people with ADRD.	100%	100%	0%
14. People with ADRD can enjoy life.	100%	100%	0%
15. People with ADRD can feel when others are kind to them.	100%	100%	0%
18. I admire the coping skills of people with ADRD.	100%	100%	0%
19. We can do a lot now to improve the lives of people with ADRD.	100%	100%	0%
7. Every person with ADRD has different needs.	100%	100%	0%
20. Difficult behaviors may be a form of communication for people with ADRD.	89%	89%	0%
17. I cannot imagine caring for someone with ADRD.	20%	13%	-7%
2. I am afraid of people with ADRD.	9%	0%	-9%
11. It is important to know the past history of people with ADRD.	100%	88%	-12%
9. I would avoid an agitated person with ADRD.	27%	13%	-14%
8. I am not very familiar with ADRD.	18%	0%	-18%
5. I am comfortable touching people with ADRD.	100%	75%	-25%
10. People with ADRD like having familiar things nearby.	91%	63%	-28%
16. I feel frustrated because I do not know how to help people with ADRD.	60%	25%	-35%

<u>Researchers' Training Evaluations</u>

In the post-training evaluation, researchers said they learned important things from stakeholders, that they enjoyed the training experience, and would recommend the experience to others. They were least confident about whether they communicated ideas in a way that stakeholders could understand.

POST TRAINING EVALUTION FOR RESEARCHERS	% yes (N=9)
4. I have learned something about varied views of research (persons living with dementia and caregivers)	100%
5. I believe I will be able to use what I learn from persons living with dementia and carepartners to improve my research.	100%
6. I valued socializing with the group	100%
7. I was satisfied with the training experiences.	100%
8. I would recommend this training experience to others.	100%
1. I am comfortable interacting with persons living with dementia	89%
2. I believe I understood what persons living with dementia had to say.	89%
3. I believe I communicated ideas in a way that persons living with dementia could understand.	67%

Researchers indicated their enjoyed learning from people with ADRD and their care partners, designing the research project, and the overall experience.

What did you enjoy the most about the Empowering Partnerships Experience?
Collaboration with persons living with disease, care partners, researchers and livewell made me realize how important it is to stay connected
Designing the research project. Networking
Empowerment strategies used
Hearing from the people living with dementia
I enjoyed being an information seeker and learning from both people living with dementia and their care partners about what matters most to them
I have never experienced something like this before - the trust, generosity and enthusiasm were remarkable. This is such a valuable model for future research (and I will use it!!)
Interactive development of research plan based on priorities of people living w/dementia
Listening to the folks with dementia and their caregivers
Making social connections with people w/dementia, care partners and other researchers. Feeling more comfortable interacting with different audiences about research. Hearing what is important from persons with dementia

Researchers indicated they thought it was too noisy, that more time was needed for developing research questions, that Day 2 needed more material with collaborative context, and less content was needed, especially after lunch.

What would you have changed about the Empowering Partnerships Experience?
1) more quiet spaces for each group, 2) great change from day 1 to day 2 with this, 3) the days were long; might be nice to have shorter sessions
A bit more time for development of research questions
At times it seemed too much (fast, confusing, loud) for people with dementia to follow but maybe it was fine with them
Day 2 had several speakers with no collaborative element. I'd reduce the time spent on those activities
Nothing
Seriously - nothing - you have done an excellent job
Shorter podium presentations after lunch
The added breakout rooms day 2 were great - ideally one group/room. Also adding a bit more time for group discussions on day 1 would be good

Researchers said they thought this should be required for every research study and it was a very valuable experience especially for junior researchers.

Please provide any additional comments you might have about the Empowering Partnerships Experience
Importance of meaningful engagement by junior researchers who will be the leaders in the future
It was great!

Thanks for including me
This experience is everything to me personally and as a researcher - thank you!
This should be required for every research study (working with the community on a deep level) - Thank you! It was definitely worth the cross-country flight to attend
Wonderful experience!