**2020 Online KT Conference:**

**Social Media Strategies for Knowledge Translation**

*Panel: Using Facebook to Impact the Knowledge of Evidence-Based Employment Practices by Individuals with Traumatic Brain Injury*

Katherine Inge

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>> KATHLEEN MURPHY: We are going to be joined for the next few minutes, about a half an hour, by Chika Agbassi. Patricia Heyn and Irene Ward. Chika is a of research methodologist with the program in evidence-based care at the McMaster University in Canada, specifically that is in Hamilton, Ontario. She works with other experts as a guideline development specialist and like all of our reactors, she has experienced developing clinical practice guidelines and working on endorsing, updating or adapting and adopting existing guidelines.

Patricia Heyn joins us for the Cochrane US network, the University of Colorado affiliate center. She is an associate professor of physical medicine and rehabilitation at University of Colorado’s Anschutz Medical Campus. Her research focuses on the effects of exercise on people with Alzheimer's. She is also involved with developing clinical practice guidelines. She is a fellow of the gerontological society of America, and the American Congress Rehabilitation Medicine also known as ACRM which in 2018 selected her for its Women in Rehabilitation Science Award for her excellence in Rehabilitation Sciences. She is an associate editor for a variety of journals in that field.

Irene Ward works is Research Coordinator for the Brain Injury program and she works at the Kessler Institute for Rehabilitation and is a doctoral trained physical therapist and a clinical assistant professor at the department of physical medicine and rehabilitation at Rutgers University’s New Jersey Medical School and the Seton Hall University school of medical sciences. She’s board-certified clinical specialist in neurological Physical Therapy ‑‑ the clinical guidelines keeps coming up specifically for the academy of neurologic physical therapy for the American physical therapy association. So, we do have questions that Chika, Patricia and Irene have specifically prepared. But I do want to address some of the questions that have come in from the audience.

So Katty, let's start with you and if others have additional information to address these questions that would be great as well. First one is does anyone have references about what percentage of people with disabilities from rural areas or underserved populations have as far as using Facebook or social media? Is this really a tool that they gravitate towards?

>> KATHERINE INGE: I don't have that off the top of my head. We have been discussing that more and more at the office related to rural areas and internet access simply because of the social isolation that we are all experiencing right now. And seeing innovative things that people are doing. Schools that are parking school buses with Wi-Fi in areas for students to access the internet. I know in Virginia; they are trying to do more in that area about bringing high speed internet to rural areas in Virginia. That is not really an answer to your question, but it is most certainly an issue and a concern. I don't know whether any of the panel would like to address that at all?

>> IRENE WARD: I don't think I have anything additional to that. But I have a follow up question if we have time. Thinking a little about how Facebook is an excellent resource and probably helps solve some accessibility issues but may also present other accessibility issues. The question about do people in rural areas who maybe have less access to Wi-Fi and things like that resonates as well. I don't have an answer, but for of a question for that.

>> KATHERINE INGE: I think one of the things I didn't mention as far as implications for future research, I did mention at recruiting participants getting VR services or supported employment services certainly for I think about individuals for instance, intellectual disabilities. Pairing that person with a mentor where they are so that they can take advantage of Facebook certainly is something to consider for individuals that have accommodation needs is important to consider. We didn't have anyone in this particular group that expressed any accommodation needs.

We did have tech support available for people who needed assistance during the group. They couldn't figure out how to join the group. I did have tech support available if people had questions. And that was provided as part of study.

>> KATHLEEN MURPHY: This is sort of related it’s from Jess Chaiken many of you may know here from the National Rehabilitation Information Center, NIDILRR grantees are familiar with that site, we call it NARIC. She was wondering related to this. This doesn't necessarily mean rural, but if people don't have reliable access to the internet whether it's because they are lower income or rural, just kind of elaborating on this issue of what do you do when you can't use the internet other than trying to provide internet, have you found that multi‑pronged reach is important, Katty I know you did a bunch of research over the years.

>> KATHLEEN MURPHY: That is the bio you gave us.

>> KATHERINE INGE: But I always say I'm not done yet. You know, I don't know whether I have any ‑‑ I think this is one strategy. You know, it's offered as a strategy that has potential for ‑‑ I hope this doesn't sound like a cop out answer to this question. You know, for me, it's one strategy for people who do have access to the internet. It's not ‑‑ you know, it's not just like everybody is going to want to read a fact sheet or not everybody is going to want to sit in on a presentation. I think this adds a strategy to our tool kit. That doesn't mean that we should not be concerned about the people that don't have access to this because clearly, I already started out in the beginning talking about the social isolation feature of disabilities to begin with. So, I don't really think I have an answer other than to say, it’s certainly not going to be a strategy for all.

>> KATHLEEN MURPHY: Lauren Smith from the RTC rural which is another NIDILRR funded project, is noting this isn't directly related but we developed a website called telecomtool box. She puts the link in the chat box as a resource for rehabilitation counselors and consumers to use different online platforms to communicate and online career development. Note, we stopped updating the website in 2018 so some of the information about social media platforms may be outdated as you know these things do move quickly.

This might be a good time to say to Chika, I know you have been involved in recruiting people to help develop clinical practice guidelines. Are there any strategies that worked well or not for you as far as reaching hard to reach populations?

>> CHIKA AGBASSI: Thank you for that question. I will start with saying that when it comes to guideline development everything is knowledge translation. So, most of the times we don't work with the patients, the primary people. So, we work with evidence and resynthesize it. But even at that, my role as a methodologist and guideline specialist working with the program, we work on mainly cancer topics. So, my department, the program and evidence‑based care has been around for about 25 years now. And in these 25 years, we have developed established contacts and channels of communication. We target users and target audience. So that makes our work a lot easier, like I said.

It's not always going to medically retrieve that language. We don't go to the patients because it's a higher level of expertise that all of the patients might not have. And even when we need the patients in our system of connections and channels, we still have a pool of patients and a pool of experts that we can reach out to any time we need to develop any guideline. So, most of the time we don't use social media because of those systems that we have already established. But I can see from today's presentation the usefulness of Facebook and social media in this area. So, it is something that will be looked at.

>> KATHLEEN MURPHY: Sure. And Patricia Heyn is pointing out too, it may be different platforms are good for reaching different people. If you want younger generations Instagram or Twitter may be a better way to reach out. I have also seen increasing use of cell phones. Even though not everybody has internet, throughout the world almost everyone has a cell phone. That is an area to explore. I personally don't have experience with, but I have seen it in other studies.

So, talking about the different platforms, one reason we are talking about how different demographic groups sometimes gravitate towards one or the other. And I think, Patricia Heyn may be able to comment about the importance of having a peer mentor. Like the Facebook group participants, the moderator in Katty's group was Jay who was a TBI survivor. That shared experience was what the participants liked best about the group. This relates to the importance of having stakeholders as collaborators in a research study. So, kind of speaking or off of what Chika was talking about, how have you involved stakeholders in your research projects or when developing clinical practice guidelines.

>>PATRICIA HEYN: Definitely. Thank you for the comment. It of is so important to develop their trust. So, by including the stakeholders, you not only are giving opportunity to hear what are the real issues and how we can accommodate and facilitate and acknowledge the technical expertise and their understanding that we can use, but also to gain the trust of the relationship.

In terms of our projects, we have projects that have different goals. Depending on the project and the stakeholders focus, we definitely include them in the process since the beginning. Sometimes if the knowledge is not well‑established, if there is an area that needs more we do a focus group and start to develop that even before starting the project or developing the protocol to include the stakeholders. To define the different knowledge and expertise including the population, the stakeholders, the patients, consumers at a different phase. You may need to approach different consumers like the patient, the person who has the condition from the professional who works to serve the person. So you might have to do more of that multi-disciplinary context of including all the different stakeholders in the process. To develop their trust in a way that the knowledge would be useful and will help you and partner with you in making that knowledge accessible and also to promote and disseminate among their own groups.

>> KATHLEEN MURPHY: Thank you, Patricia. Getting back to, you know, this issue of differential access to the platform. Lauren Smith is commenting she doesn't know of any rural disability focused references or stats on social media use, but the P research center usually has interesting stats this link has social media, internet broadband and mobile technology among different groups but not people with or without disability. Robin Brant noted there is also information about the digital divide. And CDC is using cell phone numbers to contact people to participate in surveys. So, Irene, you work specifically with people with traumatic brain injury just like we heard in this talk. So what is your approach to tailoring and varying information strategies for people with TBI when you are developing clinical practice guidelines or other kinds of documents?

>> IRENE WARD: My comment on that is it's interesting to hear some of the similarities that in terms of our approach and including basically patients or family members in some of the cases specifically in guideline development.

There are ways we included people. The stakeholder or patient or family member. One was generally in terms of identifying the topic is typically done through identifying the need through the clinician. Speaking more specifically about the academy of neuro PT. There is usually something directed from practice, there’s a need identified through practice. But once that topic of a rough idea gets shaped, in one case at least ‑‑ I guess we are newer to the CPG area. We have about four now out. And a few more in development. But in one of them they involve stakeholders during development stage. What is it about the outcomes in which therapists are doing during your sessions, what are the outcomes that you care about when seeing a physical therapist and what are those domains? That helped shape the scope of that CPG. In terms of the one I was part of I can speak in more detail of some of the things we did to engage the stakeholders.

We brought them in once the document was written, but not out yet for public comment for their review. These documents are huge. There is a lot of information in them. All of our reviewers needed a little bit of a guided tour on what we were asking their input on. For the patient stakeholder, we wanted to know what they thought in terms of feasibility. So, if the evidence says that this is the intervention to do, what would their take on that in terms of willingness. To start the conversation about engaging the patient in that decision making of treatment and what would be some of the issues, the feasibility issues on their part in terms of the intensity of that session or the frequency of that session?

We engaged stakeholders in that level. It's really been about identifying the scope in some cases. Certainly, in the review process. We talked a little more about having that become more evident earlier on. Not just in the review process for earlier on and reaching out professional organizations where people are members, like the brain injury alliance of New Jersey, where I'm located. People are active members and speaking this information and providing information. That is one way we try to engage people. Also, think about how we can do that better to engage people in terms of guideline development.

>> KATHLEEN MURPHY: Yes. I know we have Patricia here from the Cochrane Collaboration which is an organization that shepherds systemic reviews. So, I know they have a group on aging that has also attended some sessions where they try to get input into what should be the outcomes that are included in a systemic review itself so that even as you are synthesizing the information, that would be then fed into that patient provider conversation that you are talking about from the get go we are getting that consumer involvement. We do have a question from M Rose or Irene. How did you deal with privacy issues regarding those clinical guidelines? Was it acceptable for the organization to have that information in a public access site like Facebook?

>> IRENE WARD: I'm not sure I'm understanding the privacy question? The review for private in the sense they were not posted. When we had somebody review it whether it was another health professional, other stakeholder from another discipline or former stakeholder patient those were private. Sort of how a journal would do it. We sent them the manuscript, whatever their preference was electronically. They can submit a survey as a guided review or they can write on it and submit it back to us in whatever format they wanted. Those reviews were not public. I'm not sure if that is covering the privacy question?

>> KATHLEEN MURPHY: I think so. Okay. So, they weren't posting. That does raise another issue I have heard for presentations for the America with Disabilities network conferences. This is why Katherine you had maybe a closed group. As people engage in disability-oriented communities on social media, they may in effect, be disclosing. This can come up. I don't know if they are supposed to do that but many checkout social media profiles of applicants.

So, for example, if you were attending an event for this is the J Komen race and wearing your pink. Then it's out there and everybody knows you are a cancer survivor and what is the implication of that. I agree with M Rose. There are a lot of privacy considerations that need to be taken into account. I don't know if that has come up in anyone's work?

>> KATHERINE INGE: We are very concerned about confidentiality and that is why we chose the private group which was a secret group at the time. We did not want in any way for the individual essentially to disclose their disability on Facebook for sure. That is why we chose that. It was a research study and VCU are being certainly reviewed this day related to confidentiality.

>> KATHLEEN MURPHY: Absolutely. And thank you Patricia Heyn is putting in some information from the Cochrane Collaboration that is relevant. Patricia, do you want to explain what these are?

>>PATRICIA HEYN: These are some of the resources from the Cochrane. They are related to engagement or plain language. You know the information is useful about the vote to the target population. Things like good resources to add to the panel today.

>> KATHLEEN MURPHY: AIR in addition to this knowledge translation center houses PECORI patient centered outcomes research institute has developed robust resources for how to engage stakeholders in these kind of issues in developing clinical practice guidelines or making sure when there is a review or research product that plain language summary is not only developed and pushed out, but that it goes through cognitive testing so they will take the language and sit down with the target audience member and think through, you know, have them read it and explain is it really conveying the content that it intends to convey. Those are some good resources. Thank you, Patricia for that extra guideline as well.

One thing some of you also noted there may be an age correlation that Facebook users skew older versus Instagram and other platforms. Full disclosure, I'm a mother to teen age boys who are active on Instagram and TikTok which are visually oriented. So I wonder if anyone could just comment on that aspect of social media with respect to especially to disability. How do you see the pros and cons of more visually oriented trend in social media platforms universally? Have any of you tried to deal with that? No? Okay.

I can tell you that we did post in the agenda if Ann or Joann could put the link to the day one links we have in the chat then because there are some accessibility guidelines related to Facebook and Twitter as they would address some of that issue of how to handle posting on Facebook visually or any of these platforms. I haven't seen anything. I don't know how TikTok deals with accessibility, if at all. We have a comment from Sarah McDonald that notes institute for work and health is doing research on the school to work transition of youth with disabilities to better understand what helps and hinders sustained employment. Recruitment success through our own Instagram and Twitter

was limited –-

I think this does speak to what we have been noting that any one platform is going to have a particular audience and depending on where you want to go, you may need a multi-pronged outreach. Sarah says as researchers we don't have that audience in social media. Sarah, sorry, what audience? The youth. This is the link to the day one document we created. Ann just put it in there so you can look at that and put it in there in case it's useful for all of you.

Jess is pointing out, I think it will also depend on whether you are aiming for conversation, interaction or just distribution. Good point. We are talking about social media so the whole ‑‑ one of the premises is often you are engaging in interaction and creating a community. And, if that is your goal, great. But maybe it isn't. Maybe you are just trying to push out something and have more control over the whole conversation than you might have on a social media platform that is open to anyone.

Joann is pointing out having youth on CEC helps. I'm assuming CEC is some kind of advisory board or something. Childbright projects do this. If you can clarify what CEC is? Community Engagement Committee. Thank you.

So, does anyone else Patricia, Irene, Chika or Katherine is there anything you want to add. We are coming to the end of this session and about to go to break but we have a minute.

>> CHIKA AGBASSI: I think it's very important to define the audience from the start. Because when you define the audience, then you will know where to find your audience if it is in the social media or you can find other means or figure out other means strategically to reach your audience. Social media is good. The younger generations seem to use it more than elderly. But there is guideline development some topics would be mainly towards the elderly. So, going to social media for that would not yield anything. So, finding the audience and gaining their trust I think will be the key to a successful use of social media.

>> KATHLEEN MURPHY: Absolutely. Thank you, Chika. I think noting the importance of trust is a great way to this part of the afternoon. We are going to go to break. Thanks very much.