



# 30

## We Tell Our Own Stories: Older Adults as Expert Researchers

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*Working alongside older adults as partners gives me great hope for our community and clinical and research practices moving forward. I have found older adults to be excellent co-investigators and co-creators. They share so generously from their lived experiences, and when empowered to innovate, they come up with brilliant ideas. As we explore methods with more inclusive potential, we can address the complex problems facing our world today. On a personal note, the work is fulfilling and inspiring in ways I never could have imagined during the early stages of my career. I am ever humbled by the willingness of my older adult partners to ask hard questions, to share the sometimes messy, painful parts of life, and to engage in deep inquiry.*

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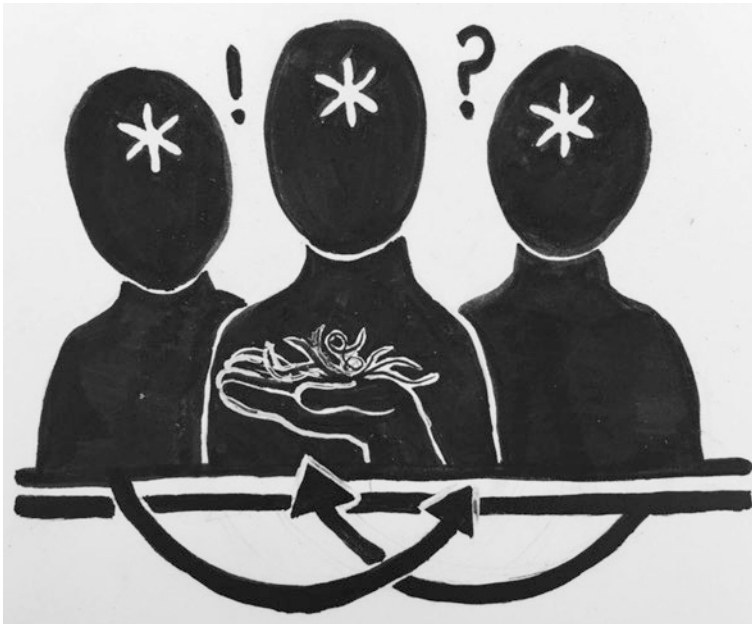
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**Fig. 30.1** Communication mural. The mural was painted on unstretched canvas and then stretched and hung when complete, in order to enable more people to participate



**Fig. 30.2** Traditional research dynamics. In traditional research methods, the researcher holds the methods tightly. The researcher has the initial ideas, asks the questions, and receives recognition for the produced knowledge. The research subjects provide data, but do not receive anything back. The barrier between researcher and research subjects is strong; the relationship is unidirectional



**Fig. 30.3** Participatory research dynamics. In this model of research, the researcher and participants are on the same level; they share in the inquiry, findings, and knowledge creation. The researcher offers methods with an open hand. Data and knowledge flow in an omnidirectional manner between stakeholders

## Research and Older Adults

Older adults are categorized as a ‘vulnerable population’ by many institutional research boards or other research subject protection laws; this classification can be viewed as a protective measure ensuring extra precautions, or it can be viewed as paternalistic and infantilizing (Kwan & Walsh, 2018). Characterizing older adults as vulnerable strips them of their power and wisdom—eliminating the possibility that they have valuable information to contribute and reinforcing the problematic power structure of traditional research methods. The ‘vulnerable population’ lens spills out beyond the research context into clinical and community contexts as well; older adults are shut away, left out, and protected to the point of being silenced.

When elders are empowered to serve as co-researchers, as in the Amplified Elders (Partridge, 2016) study described in this chapter, and involved in telling their own stories (Bergman, 2017; Houpt et al., 2016; Mcleod & Ricketts, 2013), they have a great deal to contribute to their communities and to society. The lived experiences of older adults are important when trying to address issues of ageism (Applewhite, 2016; Levy & Macdonald, 2016) and aging experience; though historically considered to be more favorable in collectivist cultures, a recent meta-analysis revealed more nuanced attitudes incorporating traditions as well as economic and demographic realities (North & Fiske, 2015). When considering how to approach and transform elder care practices, the realities of shifting care contexts (Schoenborn et al., 2013; World Economic Forum, 2012) and workforce availability (Parks, 2010; Poo & Conrad, 2015) require innovative practices on the individual and collective levels. Technology can provide solutions, but the troubling adoption of robotic care and personal devices without careful consideration (Parks, 2010; Sparrow, 2016) imposes limiting and dehumanizing practices on older adults.

Attempting to solve the problems of increased care acuity, decreased workforce, and longer lifespan using traditional methods, we cut key stakeholders out of the conversation. Ethical, person-centered practices and revolutionary or perhaps even disruptive strategies create opportunities for transforming our communities. We need to stop silencing older adults and create spaces where their voices are heard and their requests are met with action.

## Interrogating Traditional Research Methods

The criticism and reimagining of research is part of a larger conversation about the “need to resist colonialist, sterile research impulses” (Ellis et al., 2011) of past practices. The recent reconsideration of the ubiquitous ‘Word Gap’ research in education where the research methodology, presence of the researcher, and underlying assumptions may have had a significant impact on the study outcome (Baugh, 2017; Gilkerson et al., 2017; Sperry et al., 2018) is just one example of heavily circulated research that did not stand up to a more nuanced investigation. While there is certainly a place for traditional methods in the spectrum of social science research, the history of categorizing certain methods as more valid, accurate, truthful, useful, or worthwhile has led to a narrow understanding of human life. We need to ‘destabilize’ (Fine, 2018, p. 6) past practice to create space for other ways of knowing.

*Participatory research with older adults.* As I worked to develop my research ideas early in my doctoral program, I knew I wanted to work with something related to the field of aging. My clinical experience was filled with so many rich anecdotes and case studies I wanted to better understand. I came into the program full of drive and fire to ‘prove’ the efficacy of art therapy with this population through a large, quantitative study. Through the process of writing papers and critiquing past practices, the themes bubbling to the surface were about agency, voice, and expertise—themes far more difficult to quantify and suggesting alternative research methods. Some of the questions I was thinking about were as follows: How are the older adult participants considered by the researchers? What accommodations were made to account for those who may not be able to express themselves through conventional research tools? Who is qualified to speak about the experience of aging?

I also thought about my experiences working with older adults each day; I had a different level of access and connection than an outside researcher would. Instead of a liability or negatively biasing influence, I came to see myself as an embedded ethnographer. Over time, this shifted to a true sharing of the documentation and inquiry process with the older adults I spent each day with.

## Amplified Elders Study

As a result of critical analysis of existing practices, reviewing the literature, and an ethical commitment to empowering older adults, my dissertation study involved participatory art-based inquiry (Partridge, 2016). The study was

designed to take a holistic look at communication in elder care settings—both in the moment and by tapping into the knowledge of the older adults—how can they inform and teach through their ideas about communication? The following sections will cover the research study with a focus on the challenges to traditional methods and ways to inspire new thinking about research.

*Research questions.* The Amplified Elders study operated under the assumption that older adults have important knowledge to share about their experiences, needs, and preferences in communication. This assumption placed the older adults in a more empowered role than traditional work with elders; instead of framing aging as a problem with implications for communication practice, this research framed aging as an asset providing a window into longitudinal experiences of communication. The study inquired into the capability of digital art images to express communication experiences and the use of community mural-making as data synthesis.

*Methodology.* This study was open to older adults in assisted living, skilled nursing, and memory care in four buildings in California operated by a non-profit organization. Staff, volunteers, and family members were also able to participate. Participants were invited to create an image about their communication experiences and answer a series of semi-structured interview questions. The questions covered their experiences of communication, asked them to define both good and bad communication, asked them about their experiences of communication in the elder care setting, and asked them about their belief in art or visual images as a form of communication. Older adult participants in one of the assisted living communities were also invited to participate in data analysis and in creating a mural as a visual summary of the results.

*Use of technology.* This study utilized a relatively new, immersive computer system, the Sprout by Hewlett Packard. It was loaned to the researcher's university with no strings attached, just a curiosity about how it could be used as an art-making tool in art therapy. The tool, a touch-based system involving both scanning and mark-making capability, enabled a larger number of participants to express themselves. The tool does not require holding a paintbrush or marker and it may paradoxically seem less intimidating than traditional art tools. Artists and non-artists participated in this study and only one or two of the sixty participants made any statements about not being creative or artistic.

*Art-based methods.* Art-based methods using a technology tool created a more equal meeting ground for participants; Delbanco (2011) described the ways art and image making is a human drive that does not decrease with advancing age. The simple, touch-activated system eliminated the need for cognitive tracking of multiple steps while maintaining the tactile stimulation

of physical art making; though no paint was involved, using fingers to make marks stimulates the participants similar to the expressive, emotive properties of finger painting (Hinz, 2009; Lusebrink, 2004, 2010). The resulting images, whether the participant could verbally supplement their image or not, contained a great deal of insight into communication preferences and experiences.

*Researcher reflexive process.* Throughout the research process, the researcher engaged in a reflexive art process, similar to the directive given to individual participants. The researcher utilized the digital art tool to create an image after every individual interaction, representing herself, the participant(s), and the communication as she perceived it. These images served two purposes in the study. The first was to create a visual record of the communication experience within the research process itself—an in situ measurement of interaction. The second was to bracket her creative biases and excitement about the technology. The tool can allow for expressive mark making, but most participants chose to limit their use of color and marks. Creating and exploring with the tool between data collection sessions lessened the impulse to suggest participants to use more colors or create more complex images. Making her own images allowed the researcher to maintain an open, receiving stance toward the images created by participants.

*Results.* The results of this study confirmed the hypotheses; participants were able to use digitally created images to express their communication experiences and were able to provide important insight into communication in the elder care settings. The research revealed an interesting distinction between the elder participants and the younger staff or family participants; older adults tended to create images with positive messages and to reflect positive experiences of communication, while younger people more often created images referencing elder decline and the need to adapt communication to address the decline. In the verbal interviews, older adults tended to give metaphoric or abstract examples, while staff and family members shared specific communication experiences with individual people. The majority of participants across all categories reported an improvement in their communication over their lifespan. Because of the participatory nature of the study design data concentrated into several emergent themes beyond the specific questions about communication: power, technology, and simplicity.

*Emergent themes.* Several interesting themes surfaced in the verbal and art-based data from individual and group processes during the research. The first emergent theme was about power, specifically as it pertains to culture, ethnicity, language use, and discrimination. Participants discussed the way these issues impact communication along with their individual experiences of racism, ageism, and discrimination. The existence of bias and discrimination can

impact the oppressed person's communication; one resident described the racism she faced and how it caused difficulty in her interpersonal communication: "I don't know what it was about me but it just didn't go right. The reason I see is racism. Because I am Mexican, they thought I couldn't have a good mind" (Amplified Voices participant). She described struggling to understand for many years and then coming to realize the problem was with the other person. They related their past experiences to the current political and social climate and worried aloud that if things do not change, the research findings would be the same in five years if the process was replicated. In addition to life-long discrimination, participants discussed experiences of age-related bias. Ageism and the use of elderspeak (Kemper & Harden, 1999; Lubinski, 2010; O'Connor & St. Pierre, 2004; Williams et al., 2003) often inspired participants to mimic the negative communication they witnessed, using voice intonation and gesture as they described their experiences. One elder described how she needed to understand the context to avoid misjudging her peers:

So even though [peer]'s manner seemed overbearing to us from what we could hear at the next table it really had a purpose that we didn't understand until long afterwards...I judged her as having bad or unsuccessful communication, and being bossy and overbearing with her finger in every pie. But it's from the point of view. Point of view makes a big difference. (Amplified Voices participant)

Many participants spoke to this idea—considering point of view or learning to think about other peoples' perspectives while communicating. Related to ageism and the care environment, many older adults discussed the different power dynamics in the care relationship; they expressed gratitude for good care while also acknowledging that their care needs often meant they were reliant upon or at the mercy of their care providers or family.

A second emergent theme in the data was about technology; participants discussed both the benefits and risks of technology in human life, particularly in reference to communication. In the communication context, it came up most often as a concern; participants worried it was preventing good communication skills or increasing experiences of isolation. They specifically brought up tone of voice and eye contact as important aspects of communication negatively impacted by technology use. During the mural process, the focus was more on the potential benefits of technology as well as the novel experience of using new technology tools. One elder summarized this emergent theme: "We need technology, but not overdone" (Amplified Voices participant).



The third emergent theme, simplicity, came from data throughout the study. Participants laughed aloud when asked to describe good communication; they described it as simple or a basic skill. The older adults involved in the mural creation used simplicity as the editing lens for their design ideas, wanting to make their image as powerful and communicative as possible. One of the individual digital images from an older adult participant and her verbal description of her image exemplifies the use of simplicity in the communication context. She chose to represent the communication between her and her sister, also a resident in the community. Her sister had significant medical and cognitive limitations to verbal communication, but the participant did not identify those limitations as barriers to connection. She drew one line, connecting her figure to her sister: “Nothing is very complicated, I know that. It comes from my heart. Like if I’m saying it and it is going to her? I would draw it from my mouth to her heart” (Amplified Voices participant). The hands of her figure are reaching toward the sister figure, but are not fully extended. These types of small, simple details stood out to the elder co-researchers; they often commented on the importance of the little details like a hand reaching out or figures being tilted toward each other.

For all the emergent themes, the researcher noted them in the verbal and art-based data prior to meeting with the elder co-researchers. The researcher did not introduce the emergent themes to the elder co-researchers; they identified the same themes, often using similar words, without prior knowledge. This finding supports the importance of these emergent themes in understanding communication in elder care settings.

*Mural as data analysis and data communication.* The mural creation occurred over several weeks of work with older adult co-researchers. The initial phase involved a tour of local murals in the neighborhood, several discussion groups about the history and meaning of murals as sociopolitical and community statements. After the conclusion of all individual data collection, the co-researchers looked at all the individual digital images and discussed what they saw in the images. They sorted and re-sorted the images based on observations about figure proximity, tone of the communication, and gesture. As they discussed ways to create a mural about communication, they talked about wanting to teach through a positive message while addressing some of the emergent themes, especially rebalancing power and emphasizing simplicity. They decided to create a mural within a mural, with people communicating about the process of creating the mural—much like the experience they were currently involved in. Prior to finalizing their design, they wanted feedback from older adults in memory care. One of the memory care participants confirmed the success of the design:

I think the composition is fulfilled. It has to be taken slowly, but assuredly. You have to fight for every figure and form. I think it's doing a pretty good following of itself, rather than trying to attach something to it or trick into it. (Amplified Voices participant)

The image they designed and then painted on the large mural panel depicts two simple figures in a frame, communicating via touch, gesture, eye contact, and speech; their mouths are opened and up-turned to show the speech is positive and spoken aloud. In the foreground of the image, four silhouetted figures are communicating about the mural within a mural: two older adults on the right side and an elder in a wheelchair directing a young person standing on a ladder painting. As a final touch, they invited people to add their contribution to the mural by painting their hands and putting some hand-prints on the edge of the mural (Fig. 30.1).

Throughout the mural process, they demonstrated their interest in and commitment to understanding the research questions. They discussed their communication experiences in the moment and made observations about the way the design and painting process enabled them to engage in ongoing inquiry. Thought charts and graphs quantifying elements of the individual images were included in the final research document, the mural tells a more eloquent and holistic story about the research process and findings.

When the mural was complete, we held an event in the community to celebrate the conclusion of our inquiry and to honor the older adult co-researchers. During the event, we unveiled the mural and the co-researchers described each element and what it meant to them. They shared the relationship between their initial ideas and the group composition. They took ownership over the data communication, both in the image and in the presentation to their peers in the community. The mural continues to be a discussion point, and the co-researchers often refer to it in their daily conversations with each other.

*Communicating research results.* Though they wanted to attend my dissertation defense, the distance and timing precluded this option. As a work-around, I did the same presentation for the residents in one of the assisted living buildings. Again, they surprised me. I assumed I would lose people to boredom and dozing off once the lights were dimmed and I started going through slides with charts and tables. Instead, it was a standing room only in our big community room. Their questions were insightful and they chattered excitedly to each other over some of the more interesting findings. All too often, participants in research are kept out of the final results, unless they go hunting for subsequent publications. For these co-researcher-participants,

seeing our findings formatted into a presentation with tables, bullet points, and charts signaled to them: you are part of something, you are creating knowledge.

After the research concluded, the older adult participants in one community had the opportunity to speak directly to stakeholders within the technology company who supplied the digital art tool we utilized. Instead of the usual practice, where the researcher or clinician translates for or operates as an intermediary, the participants spoke directly to people who were responsible for the piece of technology they used. With the exception of internally facilitated market research, consumers rarely have the opportunity to speak directly with the creators or providers of tools, services, or technology they consume. One resident expressed interest in serving as an ongoing test subject or in maintaining a connection with the tech developers: "I can tell you what it is like to bumble around with this thing." The elders felt strongly about talking to the technology industry directly, which is part of why we partnered with Hewlett Packard on a white paper and an article in their magazine (HP Development Company, 2016).

For my part, I hold very close to my heart the weight of presenting on behalf of my co-researchers. Though it is my name in conference proceedings, I remain mindful about describing it as 'our' research. I keep the participants updated when I apply to present at conferences, when those submissions are accepted, and provide updates about the conference proceedings afterward. We continue to discuss their ideas about what the research means and who they want to talk to next.

*Research implications.* This study was limited to the use of group and individual art therapy in care communities in one US state; participants self-selected or were referred by staff members to the study and may not be a representative sample, and not all participants were able to participate in all parts of the study; the researcher and participants were aware of the potential threats to validity and limitations of this study. The goal was less to achieve one generalizable data set, but rather to do a deep, rich exploration of the lived experience. This study incorporated several methods to ensure validity, most importantly, involving the elders in all aspects of the study, including discussion of emergent themes and study results. Their exact phrasing and language was utilized to illustrate different themes and findings from the study. The research results suggest a need for continued involvement of older adults in research. The study confirmed the elders' ability to provide rich data about their experiences and their ability to use a variety of participatory methods to communicate their experiences.

## Research Findings Informing Practice

The findings of the Amplified Voices study have informed the practices of the organization in support of the communities we serve. Efforts to address specific issues included explicitly addressing following up on requests as an expression of the company values. Emphasis on simple, human-to-human communication practices are implemented in our new employee training, regular staff meetings, and definitions of best practices. In response to their enthusiastic participation in this research and queries from student researchers, I developed a decision tree for future research projects; part of the decision tree includes explicit requirements that future researchers demonstrate an awareness about and methods to protect against ageist language and behavior in their writing, methods, and research protocols. It also ensures we prioritize our time and resources to focus on mutually beneficial partnerships. As we continue to engage with stakeholders in the technology field, we will be intentionally involving older adults in these conversations.

All too often, best practices are defined in contexts outside the lived experiences of the populations. The perceived necessity of large, quantitative data to secure funding and drive clinical and community work negates the wisdom of those who are immersed in the experience of that same population, either as a member or as a close ally. Best practice may not be measurable using traditional means to evaluate or quantify; empowering clinicians and clients to collaboratively study, design, implement, and evaluate best practice can result in more responsive, inclusive work.

The increasing accessibility of data and data collection tools means that many populations are no longer passive research subjects. The old model of a blank-slate research subject who passively receives the designed-on-high-research protocol no longer exists. This is not a failure or a shortcoming but a change to celebrate. The older adult participants fully embraced their new roles as researchers and, even two years post study conclusion, continue to refer to 'our' research and assume a confident posture when meeting student researchers or interacting with community groups. The elders have inspired new ways to think about research and the terms used. In a discussion about research gatekeepers, residents created a collaborative image about gatekeepers and concluded that the research gatekeeper is not always adversarial. One older adult mused aloud, "Maybe the gatekeeper is there to welcome us in."

Their interactions also opened the door for considering new and innovative ways to solve problems in their daily lives. An assisted living resident reached out through email with a technology solution to a broken statue outside the building:

Why can't we use a 3-D printer to make new "prayer hands" for our front yard Handless Mary? We could make several copies so as to have extras on hand ready to use when the next episode of vandalism occurs. Better yet, let's choose a petite old lady resident with the most worn, crooked, and gnarled hands to serve as the model. I believe the contrast of a young Mary with ancient, overworked prayer hands would be thought-provoking. I have a very capable consultant up my sleeve. (Personal Communication, October 31, 2017)

Her language demonstrates a subtle but evident empowerment; instead of asking 'could we' or 'is it possible to...' she put the workload back onto me—she knows this is possible and that it is a good solution. Her words are a challenge; she is asking me to prove her wrong. Another older adult shared her recent insight into the way that participating in research projects and creating visual images as a form of knowledge has shifted her daily thinking: "We're of the old school; I am still finding it hard to accept the background, but I am working on it. In each new image, I work on it." She described the way that looking at the full context instead of just the identified problem has assisted her with the struggles in her life. Her role as a researcher goes beyond the research context into her whole life. The experience of speaking back and speaking up has empowered the residents to voice their opinions in more effective and nuanced ways; they recently questioned a proposal for new chairs in the dining room by stating they do not want or need new chairs, they would rather see money go to other projects, and proposing a compromise of cleaning and reupholstering the existing chairs. They have reimagined themselves as problem-solvers and, more importantly, see themselves as equal stakeholders in their living environment. After several discussions about current events and their desire to get involved, they asked for assistance in establishing a group social media account in order to add their voices to the dialogue.

Increasingly, technology companies are proposing hardware and software solutions to the problem of aging. Their approaches often assume problems where they do not exist or assign importance to problems older adults are not concerned about. In a discussion group with older adults in assisted living, they repeatedly suggested that technology stakeholders come and ask about what their real problems are and also what they are excited about: "Why don't they make us better hearing aids and teeth? Those things impact us every day!" They were excited to try out some virtual reality headsets, but disappointed when use required removing their glasses; they correctly observed that the tool was not built with them in mind.

## The Future of Research

Though this chapter emphasizes the importance of participatory, inclusive research practices and questions traditional methods, these same traditional methods absolutely have a place in the greater universe of research. We need large, quantitative studies. We need to do replication studies and meta-analyses. We should continue working on developing and validating measures to use with different populations. However, when researchers are so attached to the methods they lose sight of the population or when the methods as theorized on paper are not relevant in the lived experience, we need to stop and question what we are doing and whether alternative methods would be better suited to the situation. In the worst-case scenario, participants have no power in the research process (Fig. 30.2). In the reimagined future, participants are involved stakeholders in the inquiry (Fig. 30.3).

Research needs in the field of art therapy are applicable to many fields of study in social science and community work. My deepest hope is that we can find some balance as a field. When we get too wrapped up in our fears of legitimacy or proving our merit, we miss the opportunity to celebrate the unique strengths our field brings to inquiry. I have witnessed students struggling to ‘prove’ not hypotheses but professionalism. The art therapy field is not alone in this fragmentation; Dweck (2017) identified some related problems in the field of psychology and called for a re-enriching of the field to ensure longevity and student interest. When we use our research as a means to justify our existence, we further marginalize the powerful work we do and we miss out on opportunities to bring the wisdom contained in the creative process. Our processes have the ability to empower, to illuminate, and to equalize. Art process with a focus on empowerment is “an emancipatory process in service of a collectively politicized movement towards global citizenship” (McLeod & Ricketts, 2013, p. 26). Our allegiances in research can do both—establish our legitimacy as scientific researchers as well as active collaborators in client empowerment. I urge students and professionals to recommit to research as an invitation into inquiry rather than a means to stake out territory.

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