

Article

Considering Material Culture in Assessing Assistive Devices: “Breaking up the Rhythm”

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Abstract: This paper reports on a project that looked at the meaning stroke survivors assigned to assistive devices. Material culture theory served as a framework to help stroke survivors explicitly consider [dis]ability as a discursive object with a socially constructed meaning that influenced how they thought about themselves with impairment. Material culture theory informed the design (taking and talking to their peers about photos of anything that assisted) and analysis of the meaning of the assistive devices project. In our analysis of the narratives, survivors assigned three types of meanings to the assistive devices: markers of progress, symbolic objects of disability, and the possibility of independent participation. Notably, the meaning of assistive devices as progress, [dis]ability, and [poss]ability was equally evident as participants talked about mobility, everyday activities, and services. We discuss how considering [dis]ability as a discursive object in the situation might have enabled stroke survivors to participate.

Keywords: disability; material culture; stroke; assistive devices

1. Introduction

We live in a material culture [1]. Peoples’ clothing, furniture, transportation, music, art, and technology are chosen to perform a wide range of practical functions, but they also express an individual’s desired identity, as well as the individual’s position and class in society [2,3]. Objects have symbolic authority: “it is difficult to imagine a king without a throne, a judge without a bench . . . they are literally clothed with the vestment of the positions (p. 15)” [4]. As well, the meaning of all material and discursive objects are continually being created discursively through interactions [5]. In other words, the meaning of the king and the judge has changed with time and as the culture has changed. Meaning (material, social, cultural, linguistic) is a process, not a static product [1,5]. Accordingly, [dis]ability is constantly being defined through the bodily, social, and material cultural experiences of persons within their contexts [6,7].

External objects such as assistive devices can become vestments of self-image for people with bodily impairments ([dis]abilities). Assistive devices are the products, tools, or devices that facilitate participation in desired activities [8,9]. At their best, specialized assistive devices should increase ability by increasing independence, improving quality of life, and reducing the physical and attitudinal barriers between people with and without impairments [10,11]. Correspondingly, assistive devices can contribute to [dis]ability by setting people apart from others and making them feel different [12,13]. People with impairments are subjected to disabling societal attitudes that view them as less valuable,

lazy, and/or objects of pity [14,15]. Assistive devices can become part of a person's self-image, in effect increasing embarrassment, their felt stigma, and exerting a negative impact on one's self-image [16,17].

While participation may be demanding or even impossible without assistive devices [18], consumers will abandon assistive devices prescribed by health professionals. Abandonment or non-use rates range from 30% in a study of 227 people with a variety of impairments [19] to 76.7% of 126 adults with neurological, lower extremity orthopedic, or complex medical conditions discharged from inpatient-rehabilitation [20]. Abandonment has been attributed to changes in needs (recovery or additional impairment), devices that are not suited to needs (heavy, awkward) [17,21,22] or because the device draws unwanted attention or increases stigma [16]. Only the person using assistive devices can estimate the capacity of those assistive devices to enhance their ability or increase disability.

Consumer involvement, *i.e.*, actively seeking consumers' experience and opinions, is recommended as the route to a better match between assistive technology and users [18–20,23]. Consumers are more likely to use assistive devices if: (1) their opinion is included in the selection of their devices; (2) the device is easy to obtain, reliable, comfortable, and easy to use; (3) the device contributes to personally meaningful activity or self-image; and (4) the device continues to meet consumers' needs [19,23]. When people with disabilities are given the opportunity to assess their own needs and determine what assistive devices would work best for them, they are less likely to abandon their assistive devices. Involving people in the design, selection, and evaluation of adaptive devices can also be empowering [9]. Health literacy (knowledge about condition, treatments), self-confidence, ability to communicate, and participation in society (activities outside the home, *e.g.*, volunteering) all increase when people are engaged [24–26].

The purpose of this paper is to report on employing material culture theory as a framework to help stroke survivors explicitly consider [dis]ability as a discursive object with socially constructed meaning that influences how they think about themselves with impairment. Discursive objects, *i.e.*, words in conversations or texts, have cultural meanings that make a particular response contingently relevant in the situation [27]. Frequently, stroke survivors are unaware of the constructedness of this meaning and the possibilities of thinking about themselves and their environmental contexts in other ways. In specific terms, we report on a project that looked at the meaning stroke survivors assigned to assistive devices. The paper is organized into four sections. First, we situate this meaning of the assistive devices project into the "Getting on With the Rest of Your Life after a Stroke" intervention. Second, we describe material culture as an approach to enable stroke survivors to clearly understand how the meaning they attach to [dis]ability has consequences for how they "got on" with their post-stroke lives. Third, we proceed with the study's methodology; report on the project in which participants discussed the meanings they attach to assistive devices; and outline participants' evaluations of the project. Finally, we discuss how considering [dis]ability as a discursive object in the situation might have enabled stroke survivors to participate.

2. The "Getting On" Intervention

The goal of the "Getting on With the Rest of Your Life after a Stroke" research was to determine if stroke survivors' community integration could be optimized through the provision of a structured program providing opportunities for physical activity, leisure, and social interaction. Hereafter, we use "Getting On" as the program name, as that was what our participants called it. The program was designed as a three-phased program similar to stages of flight: Lift-off, Gaining Altitude, and Full Flight. Each phase was the length of a typical community based course: 10 weeks. Participants began by setting personal goals they could achieve within the in-house exercise program, group learning projects, and individual leisure (Lift-off). Then, participants explored self-development projects in the community in addition to the ongoing in-house activities (Gaining Altitude). The Full Flight phase gave these participants time to consolidate ongoing goal setting and accomplishments in-house and in the community. It was expected that survivors' goals would become more complex in each stage of the program (see Figure 1, Study Plan).

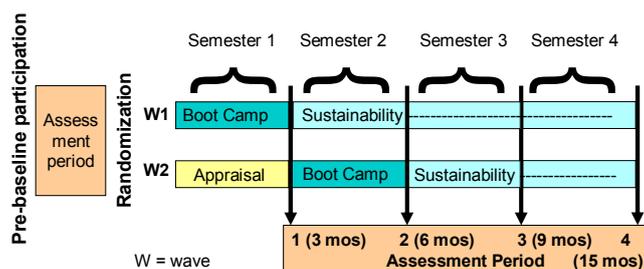


Figure 1. Study plan.

“Mission Possible” was the name given to the goal setting leisure/learning/social component of the intervention. In Lift Off, participants were put on a “Mission” to formulate personal goals that could be staged into a series of realistic projects that survivors could meet by developing internal resources and existing community-based resources. Program leaders were charged with developing daily and weekly group leisure/learning/social projects that would develop stroke survivors’ skills to set and achieve their own goals. Rather than utilizing the typical expert professional lecture approach, program leaders were expected to adopt a life coach or mentoring approach. Program leaders were to support survivors to find their passions, set goals, and take action to achieve their objectives. The “Getting On” Program received ethical approval from McGill University. The benefits of the entire year-long program are reported elsewhere [28]. Participants’ names used in this report are pseudonyms.

3. Taking a Concrete Approach to Project Learning: Material Culture

After survivors had completed the consent forms, group leaders met individually with each survivor to learn about their interests, goals, and the facilitators and barriers they had encountered in reaching their goals. As we compared notes in the first of our weekly planning meetings, we realized that our participants were firmly focused on their [dis]abilities rather than their abilities. To illustrate, Marvin explained: “I would like to play golf, but I can’t do that until I can use my left arm,” and Dee also said she could not participate in activities until she could walk. We decided that if we were going to coach participants’ self-efficacy to achieve their goals, the group learning projects would need to concretely shift participants’ understanding of impairment and [dis]ability. We decided to use the pragmatics of material culture [2] in designing some of our daily and weekly projects. According to Dant [2], “everyday interactions with material objects are dependent on us making sense of what they mean and what actions will be effective in transforming them to suit our purposes.” We wanted our participants to understand social and cultural [dis]ablement as a concrete object with meaning to which they were reacting.

[Dis]ability Discourses as Material Culture [Objects]

Material culture is concerned with how humans derive cultural meaning and value from tangible objects [5,29]. Culture exists in human minds and is shared by people in interactions. Thus, cultural meanings continually unfold during interaction with an object and are contingent on specific interactive circumstances [1,2]. Changes in society’s values and beliefs are therefore likely to be reflected in changes to meaning of disability, as well as in changes to design of objects such as homes or wheelchairs [1,5]. Although individual meanings of [dis]ability have consequences for how people (with and without bodily impairments) make sense of what is going on and then act, meaning is generally understood to be a mental rather than a physical phenomenon. James Deetz [30], however, argued that the meaning in spoken words can be understood as material culture objects in a “gaseous state” (p. 36), *i.e.*, in a different form (e.g., ice, water, steam). That is because the meaning that people attach to words like ability, able-bodied, or disability are real in their consequences. Disability is a discursive

object in which people's interpretive understandings (meanings, expectations, beliefs, motives) are cultural resources that provide them with ways of making sense of their situation [2]. The ways in which [dis]ability is socially constructed and acts culturally to pattern knowledge and behaviors is largely obscured from stroke survivors for two reasons. First, meaningful interaction involves making sense of what symbols, objects, and peoples' words and actions mean [2], but, as a result of stroke, many survivors have difficulty understanding and formulating symbolic communications. It is more common for stroke survivors to misinterpret abstract ideas than to misconstrue concrete objects. Second, pre-stroke, many survivors may have held the dominant cultural view of bodily impairments as deviant, an individual abnormality in need of medical treatment [15]. Our participants, for example, were generally unaware of the American social model of [dis]ability, which frames [dis]ability as a civil right. From the perspective of this model, disability stems from the failure of the structured social environment to adapt to a disabled person's needs and aspirations. In the second week of our program, we introduced the [dis]ability models as concrete ways of thinking about what caused [dis]ability and ability. One program leader shared how thinking about external resources changed how she approached her dyslexia (difficulty with writing). It was not the case that the impairment was in her brain and that, unless it could be fixed, she would never be able to write: The ideas were there—she could write—but would need to have someone edit her writing. Participants discussed each [dis]ability model and how using each one might change their approach to goals. Participants decided that, by combining both models flexibly, they could look at changing the impairment, the activity, and the environment. Since the cultural meaning of [dis]ability refers to mental and symbolic objects, rather than physical ones, the characteristics of this meaning must be observed or abstracted from audio recordings, which is what we undertake in this paper.

4. The Meaning of Assistive Devices Project

In this group learning project, twenty-three people (10 men; 13 women), six months to fourteen years post-stroke, who were participating in the Getting On program were given disposable cameras to take photos of "anything" that assisted them to "get on" with their life after stroke. Stroke survivors ranged from 23 to 78 years of age (mean 54.87 years). Twenty-one were discharged from in-patient rehabilitation programs. They spent two months to one year in hospital and rehabilitation. Two had been discharged home after the diagnosis of mild stroke. Participants had a range of cognitive, communicative, and physical [dis]abilities as well as many skills and abilities. Prior to stroke, they had owned their own businesses ($n = 3$); had been employed as accountants, executives, engineers, secretaries, and tradespeople ($n = 15$); or had retired from an occupation ($n = 5$).

The photos were developed and printed. At four group meetings (2 h per session), participants were asked to describe their selection, modification, and use of the objects in their photos. Program leaders specifically asked participants to speak to, and ask questions about, how they mediated their lives as well as reliability, comfort, ease of use, safety, and durability because these are the main factors related to satisfaction with devices as well as abandonment [9,31]. The use of photos is also a material culture approach. Various described as "photo-voice," "photo-elicitation," or "visual narratives," participant-generated photography is used to document and elicit what is important to the person taking the photo [32,33]. In this project, photographs acted as a communicative bridge, a different way to get stroke survivors to think (and talk) about assistive devices. Pictures were concrete representations of the object (assistive devices) for participants to talk about and their peers to see. The sessions were digitally recorded. At the end of the project, participants asked to complete an evaluation form asking if the project was useful, fun, and what they learned (see Section 4.2.4 for a description). Data were extracted from the photos, digital recordings, and participants' evaluation of the project.

4.1. Data Analysis

All qualitative data collected (photos, audio tapes, and project evaluation) were analyzed using thematic content analysis [34] to understand the cultural meaning our participants attached to assistive devices as objects. The digitally recorded group sessions (8 h) were transcribed and verified. Photos, transcriptions, and participants' project evaluations were imported into NVivo 9 for efficient data management. Analysis was deductive, beginning with participants' descriptions of their selection, what motivated them to take the picture, their experience of the assistive devices, how the device made them feel, and the meaning they attached to it. We looked for whether they described the device as evidence of being disabled, a symbol of recovery, the end of recovery, a goal reached, or a new goal.

In total, there were 240 photos. Almost half (46%) of the photos and objects related to mobility, a third (33%) were connected to everyday activities, and 21% were related to services. The photos of mobility equipment included devices to assist with: walking (canes, ankle-foot orthoses [AFO], Walk Aide, walkers), personal mobility for non-walkers or slow walkers (wheelchairs/scooters), and accessing their community (licenses, left footed gas pedals, spinner steering wheel knobs, cars, Disabled Adult Transit Service bus, vans). There were two types of daily living assistive devices in the photos: (1) those designed for people with disabilities and (2) off-the-shelf products. Photographs of products designed specifically to assist with activities of daily living included accessible showers and bathtubs, bath lifts, large number phones, spoons with large grips, card shufflers, one handed cutting boards, and Dycem. Off-the-shelf items included kitchen devices (Mixmaster, can openers, meat-slicer, ulu knife), computers, and cell phones. Participants grouped photographs of walking and art groups, exercise facilities (private gyms, YMCA, Steadward Centre), Driveable (driving assessment service), and restaurant meals into the services category themselves.

4.2. Meaning Assigned to Assistive Devices

The majority of the objects in the photos were clearly designed to provide assistance (95%), but there were a few photos of objects that remained mysterious until participants described why they had taken the photo. Whether the device or its use was obvious or not, the meaning of the assistive device only became clear as participants talked about it. As Rom Harré [35] proposed, it is only through the narrative and storyline in which they are embedded that objects have meaning: "an object is transformed from a piece of stuff definable independently of any storyline into a social object by its embedment in a narrative" (p. 25). In our analysis of the narratives, survivors assigned three types of meanings to the assistive devices: markers of progress, symbolic objects of disability, and possibility of independent participation. Notably, the meaning of assistive devices as progress, [dis]ability, and [poss]ability was equally evident as participants talked about mobility, everyday activities, and services.

4.2.1. Markers of Progress

Participants' narratives of acquiring new assistive devices and being able to abandon them quickly demonstrated the theme of assistive devices as markers of progress. Early after stroke, participants highlighted how obtaining each new device and being able to abandon that device enabled them to see their progress towards returning as closely to their pre-stroke lives as possible. They described how canes, ankle foot orthoses, and walkers enabled them to walk faster and further with less fear of falling. Mobility devices increased their ability to participate in activities at home and in their communities. Sam's description of his walker was typical of the mobility narratives, highlighting the independence of first steps with a walker.

Over the next couple of days I improved in my walking with this miracle walker. I was permitted to walk without the therapist or the therapy attendant holding on to a gaitbelt placed around my waist. Boy did I ever feel great when that occurred. I felt so free and independent. The fact that I could only walk inside the department, which was pretty

small, and that they kept a pretty close eye on me didn't bother me. I WAS WALKING without anyone's help and that was good enough for me (46-year-old male).

Likewise, Sam's comment about his progress being better than expected related to being able to abandon an assistive device: "about a week before I went home, I had progressed from a quad cane to a regular cane. I made much better progress than I was supposed to."

Until Aaron started to talk about his photo which showed a stone path leading to a gate (See Figure 2), it wasn't clear that it also concerned assistive devices as markers of progress towards independent mobility: "My goal was to be functional in my old world. My balance was so bad that at first I could only dream of walking on that rough path and out the gate." He explained that his daughter would not allow him to use the backyard for fear he would fall:

I waited until she went to work and then I would practice. First, I had to use my cane, because as I stepped from stone to stone, I would almost topple over. But I kept at it. It took months before I finally had the confidence to go up the steps to the field. I got my balance back on those stones. I gave the cane away so I couldn't take a picture of it.



Figure 2. The stony path to balance.

As Sam and Aaron's cases suggest, survivors didn't just celebrate the freedom attached to the devices, they accepted assistive devices with the explicit goal of abandoning them. They referred to "ditching" devices or "graduating" from one assistive device to another, for example, from wheelchairs to canes or walkers. Lacey's narrative about pictures of her quad cane illustrated how she set and achieved goals to abandon assistive devices: "I graduated from this quad cane. Then my goal was to walk for a quarter mile without a cane. Mission accomplished." She held up her driver's license: "All of those were steps toward my driving license. Now, I go anywhere I want."

In telling stories of such progress, most survivors placed special emphasis on devices that assisted with daily activities. They noted how devices prescribed by health professionals (accessible showers, Dycem) and off-the-shelf devices (can openers, computers, cell phones) enabled them to "take back" their own care and "make life more normal." Survivors were relieved at how these assistive devices enable them to reduce the care burden on their families. Illustratively, Carol showed pictures of an accessible shower and then a bath lift: "When we had these installed, I started to take back my day. I didn't need [husband's name] to help me into the bath" (Photo—Figure 3). As she elaborated on Carol's positioning of devices as symbols of progress to independence, Susan's narrative reinforced that she saw progress in how accessible environments and assistive devices reduced the burden on her husband:

We built a new house with accessible showers and kitchen so I went from needing help with everything to doing most things by myself. I felt like such heavy load on my husband. I am not back at work. We went from two incomes to one, but I do all the cooking and

cleaning now. It has taken me a long time to do the things I wanted to do. You will see; I found lots things that work with one hand.



Figure 3. Independence through a walk-in shower.

Barb's description about the picture of her cutting board and Ulu knife (Figure 4) was illustrative of assistive devices as progress to "make life normal" as well as how assistive devices could facilitate her independence and reduce the burden on her family:

I had nothing. I felt like I couldn't do anything with one hand. Like how do you peel a potato or cut a tomato? I was looking all over for some stainless steel nails for a cutting board. We couldn't find any, so the OT gave me a couple so I could start doing some stuff myself. She was awesome. Then I found the ulu knife, so at least I could make a tomato sandwich. Small thing, but life started to become normal with a tomato sandwich.



Figure 4. Life started to become normal with an ulu knife and nails in a cutting board.

When Barb did not talk about the Dycem, Sam did: "The Dycem there, it is really useful for anyone. I use it to stick anything down: mixing bowls, plates, even soup bowls." The phrase "useful for anyone" offered an opportunity for the group to talk about off-the-shelf products. Participants appreciated the normality and esthetics that the devices they found on store shelves offered. One-handed participants were particularly enthused by battery-operated can openers after Mike brought his in so others could try it: "It is so easy to use and anybody would like to use it" (Mary) and "look at the nice design, it just fits into my hand" (Jacqui) (See Figure 5). Along with ease of use, participants discussed how off-the-shelf devices enabled them to do daily activities independently: "Once my mother gave me the Mixmaster, I could cook or bake almost everything I want, even my own bread" (Sam). John's story about the meat slicer was also about progress in taking back his male role:

The men in our family always carved the meat at the table. I tried electric knives, but I really couldn't cut with one hand. My wife had to do it. Then I came on the meat slicer. I just get boneless roasts or turkey and voila! I can cut meat again.



Figure 5. Finding tools for use with only one hand: Battery operated can opener.

When participants shared their pictures of computers, iPads, and smart phones, the group was almost unanimous about how they enabled them to progress. They were less isolated because of email, Facebook, and messaging, as well as more knowledgeable through the information available on the Internet. Rich explained that since he had a cell phone, less concern about his independence was progress:

I always worried that I would get lost or I would fall and so did my family. Then I got the cellphone. I started by walking to Safeway to get groceries. It was just a couple of blocks, but I knew I could call if I was in trouble. Now I walk everywhere.

In categorizing their pictures into the services category, our participants also recognized that support from other people and supportive environmental contexts facilitated their abilities and sense of belonging in addition to marking their progress. The narratives of photographs of services such as walking and art groups demonstrated the evolution from doing activities at home to doing activities with others. Sally found encouragement to progress at an art group for people with brain injuries. She took photos of three of her brightly colored paintings: "I couldn't paint before my stroke. I learned at the [name of program]. We are all brain-injured and we all have problems, but everyone there inspires you to do more" (Painting in Figure 6).



Figure 6. Learning about new abilities: painting.

Gary said he found that that same sense of belonging at the Steadward Center. The Steadward Centre is an exercise facility at the University of Alberta exclusively for people with disabilities. He

marked progress in new friendships as well as improvements in function: “We go on on the same days and you make friends. We go for coffee and now sometimes to a movie. We all get fitter.”

4.2.2. Symbolic Objects of Disability

Participants recognized how assistive devices labeled them as [dis]abled to others, but also that having to use assistive devices reminded them of their bodily impairments and forced them to abandon the possibility of complete recovery. Many of our participants had associated assistive devices with older people or for someone disabled at birth; they had never thought of themselves as someone that might need a wheelchair or a cane. While they recognized that assistive devices increased their ability to do the things they wanted to do, they also had to come to terms with their recovery slowing or the end of recovery with the possibility of ongoing bodily impairment. Survivors also acknowledged that prescribed assistive devices looked awkward and clunky. They perceived that people without disabilities avoided them because they were disabled or assumed they were incapable, in part because of their assistive devices.

Participants thought that mobility devices shouted disability. Helen began by explaining that wheelchairs were almost exactly the same as they had been when she was a student nurse and continued with how her sense of self was affected:

I need this old black wheelchair whenever I go out, but it screams different. People won't look at me. I didn't realize what being in a wheelchair does to your sense of self until I had to use this one.

She went on to say that even her ankle foot orthosis made her look sloppy:

I have to get shoes one size larger, then this one is too big on my good foot. Sloppy, looks horrible.

Zoe noted how the walker enabled her to become independent and then echoed Heather's perception of mobility devices as symbols of stigma and disability: “There I was trying to maneuver the aisles in Walmart in that old granny walker. It just screamed old and disabled.” She went on to say that, although she wanted to abandon it, she just couldn't regain enough balance to walk safely without it: “The real kicker comes when you have to admit that it's going to be a permanent fixture.” Dee, who used an electric wheelchair, added that admitting she was going to be in a wheelchair felt like declaring defeat: “It was like saying that's the end, I will never walk.” She then noted that people didn't know how to treat a person using a wheelchair: “Any wheelchair and you get treated differently. Like the first time I went shopping in this wheelchair, the store clerks just avoided me. It was like I was invisible.”

Barry elucidated on how services saw him as a symbol of disability. He described how people in restaurants saw someone who was old and disabled rather than him, personally:

When they see me coming in my scooter, they see an old man, and old people are not valuable to them.

He went on to explain how he thought economics and time mediated his perception of waiters' assessment of him:

Well sure they're in a hurry to get me seated and get their tip and me out so they can get the next people seated. It's the rhythm and I am breaking up the rhythm. The manager wants to get as many seatings as possible and if I'm walking slowly it's ruining their rhythm.

Joan and Sarah told stories of how community exercise services symbolized disability. Joan felt excluded in two ways. First, she was told that she was not disabled enough to qualify for the Steadward Centre and then felt that other women excluded her at a women's only gym: “The other women don't really talk to me. I don't think they know what to say to me.” For Sarah, the gym door symbolized disability:

The door wasn't even accessible at [name of fitness facility]. It was heavy and with my cane, my gym bag, and only this hand, I couldn't open it. My 80-year-old mother had to come to open it . . . The door says only young able-bodied people.

Zoe talked about "purchasing errors" that made devices to assist with daily living into symbols of disability. She bought pots and pans and then realized once she opened the box that they had handles on both sides:

A small purchasing error. Must have just slipped my mind that I only had a left hand, [laugh] but at least I could return them. Funny how I didn't see that from the picture in the catalogue.

Jacqui laughed and then recounted how her purchasing error remained an enduring mistake. After seeing an ad on TV, she ordered a walk-in bathtub. She discovered that "the bar was in the wrong place for this hand," so she needed her husband's assistance to get into it and then discovered it took a long time to drain: "I was so cold by the time it drained . . . I used it once. So there it sits, reminding me every time I go past it."

4.2.3. Possibility of Independent Participation

Some of our participants described how the meaning of assistive devices shifted from symbols of disability to devices that created the [poss]ability of independent participation. With time, some participants said they managed to focus on what they wanted to do (ability) rather than what they could not do ([dis]ability). They focused on how an assistive device would enable them to meet their larger goals of participating in personally meaningful activities rather than concentrating on recovering from impairments to be able to participate.

Sarah had taken a picture of her manual and electric wheelchair side by side (See Figure 7). She explained how she had to think differently about mobility: "My goal was to walk, but the therapist insisted I would need a wheelchair when I got home." She worked to learn to walk quickly enough so that she could abandon the wheelchair and her quad cane, but she could not walk far enough to do what she wanted to do, especially when she ventured into the community. She found the manual wheelchair frustrating: "There I was in the shopping mall, trying to maneuver my manual wheelchair with one good leg and one arm and I realized something had to change." She described how difficult it was to think that she would never be able to walk the way she wanted, and then spoke about coming to regard the electric wheelchair for how it increases her ability, rather than seeing it as a symbol of the end of recovery:

I came home and cried. My husband said I just didn't want to be realistic. It took me a long time to choose this model. Now I use it to go everywhere, the mall, to the gym. I still work at walking at the gym, but when I use my electric wheelchair, I go shopping.



Figure 7. Symbol of disability to an enabler of ability.

Dave reinforced Sarah's experience by telling almost the same story. In his case, making his own meals was the trigger for buying a scooter:

I bought the same type of manual wheelchair as Sarah for the same reason. The OT wanted me to get an electric wheelchair, but come hell or high water I was going to walk everywhere. And then last summer I decided that I wanted to be able to go to [Safeway] to buy groceries. I was using Meals-on-Wheels, but it was expensive and I thought I could cook for myself. So I decided to get a scooter. I would never have been able to walk far enough or fast enough to get around the store. I gave up my dreams of walking like I did before stroke, but I regained my life. I gave up Meals-on-Wheels. I get my own groceries and make my own meals.

Other participants provided examples of similar shifts in the ways they thought about devices for daily activities as possibilities rather than markers of disability. Sam explained that he had changed the way he thought about impairments, activities, and/or devices: "Now I think of myself as differently abled. When I go shopping, I look for anything that will make my day easier. There are lots of things, like getting egg poacher for the microwave or Mixmaster rather than a hand mixer that make activities easier."

Several participants thought the largest changes in how they thought about possibilities for independent participation came from services, particularly the group programs. By comparing themselves to others, seeing how their peers' perceived them, or realizing that an impairment like aphasia or having only the use of one hand did not hold a peer back, they too could try new activities. Ellen referred to the walking group and getting inspiration from a participant who was always positive despite having two severe strokes. Sarah referred to being asked to teach Sudoku to the "Getting On" group and then how she showed others how she tied her shoes with one hand: "In this group, I learned how much I could do. It has encouraged me to do more." For Gary, Dan's ability to get his driver's licence despite severe aphasia was an inspiration: "If he can, I think I can." He set getting his driver's licence as an achievable goal (See Figure 8: Gary's Truck).



Figure 8. Group mentoring: Driving is possible.

4.2.4. Project Evaluation

To ensure that projects met participants' goals, Getting On participants were asked to complete a five-question evaluation at the end of each project. There were two questions that asked participants to rate the usefulness and fun on a five-point Likert scale; two open-ended questions asking what they had learned personally and how it helped them; and suggestions for improvements (Appendix: Project Evaluation Questions).

Participants thought the project was very useful (mean 4.8; range 3–5) and they had fun (mean 4.9; range 4–5). Most said they learned more about the devices that were available and found some devices

that might be useful for them: “I got myself a new can opener” and “I am thinking about getting a scooter.” One mentioned learning about how they might find the funding for assistive devices: “I didn’t realize that a shower renovation could be an income tax deduction” and another was interested in the art group: “I am going with Sally to the art group meeting next week.” Two participants said they were more aware that there were ordinary objects that could make their activities easier: “I have asked my grandson to show me how to use my cell phone” and “I am looking in the appliance aisle now.”

Picture-taking was a success by group participants’ ratings. Participants thought it was fun to decide what pictures to take and to share their experiences with others in the group. Several indicated that it was easier to talk to the group when they had a picture to talk about. They thought that group members were more open and they learned more about them when they talked about their pictures. There were few suggestions on how to improve this project. One participant suggested doing this project at the beginning of the program and then having a second session later. Another participant suggested we let participants take photos in other projects.

5. Material Culture as a Framework to Understand the Meaning of [Dis]ability

In this project, we used material culture as a framework to understand the meaning of assistive devices to stroke survivors, as well as to facilitate stroke survivors’ understanding how the socially constructed meaning of [dis]ability could change how they approached goal-setting. Initially, our participants described regarding assistive devices as a means to an end. They were a temporary aid, useful as they recovered from impairments. When recovery slowed or plateaued, assistive devices became symbols of [dis]ability for survivors. Then, for some survivors (15 participants), the meaning of assistive devices shifted to symbols of [poss]ability. The electric wheelchairs and scooters that had symbolized the end of recovery and the need to accept impairments as permanent transformed into enabling objects. Survivors looked for assistive devices that would enable them to reach their larger participation goals. To get on with life after stroke, survivors need to consider all of the factors that will enable them to participate in personally meaningful activities, including how cultural contexts and built environments contribute to [dis]ability. The participants’ change in perspective was not based on a specific stage or length of time post-stroke (e.g., 6 months, 14 years), but rather on their becoming more open to different interpretations through the group processes and the material culture framework that made cultural interpretations visible.

We utilized a material culture framework in three ways. First, we specifically chose to help our stroke survivors understand how the social construction of [dis]ability shaped their perceptions of actions that were available to them. From a material culture standpoint, objects and symbols communicate meaning, shape experiences, and impel or constrain agency. On their entry to the Getting On program, our survivors either consciously or unconsciously adopted the medical/rehabilitation model cultural framework that their impairments were [dis]abling. Material culture renders visible how culture manifests in objects and symbols so that people can understand how cultural meanings shape their perceptions and behaviors [2,29]. We believe that, by introducing the American social model, which positions [dis]ability as a failure of the sociocultural environment to adapt to the disabled person’s needs and aspirations, we opened up [poss]abilities for our stroke survivors to continue to work at changing their perspectives on their impairments, but also to look for tools and environments that could augment their abilities. Second, we had participants take and talk about photos.

Third, we used material culture as the means to understand the meaning participants attached to assistive devices. Within the medical model, assistive devices such as wheelchairs, canes, and walkers are assessed for their utility, but what assistive devices mean to users is rarely examined. [Dis]ability and assistive technology use are often treated as individual experiences, yet both occur in much larger cultural contexts. It was difficult for our participants to separate the symbolic/cultural significance of assistive devices as markers of disability from the affordance that they provided [2]. Barry, for example, referred to [dis]ability and assistive devices as “breaking up the rhythm” of normal restaurant service. Similarly, Heather’s narrative about wheelchairs being the same design as they were when she was a

student nurse drew attention to how her position had changed from the nurse pushing the wheelchair to the patient being pushed and thus lacking agency. She and others noted how people avoided looking at them or treated them differently when they were using wheelchairs, walkers, or other assistive devices. Just as the throne symbolically defines the king's identity, walkers, wheelchairs, and canes mediate stroke survivors' identities by drawing attention to survivors' differences [6,7]. Learning about the social construction of [dis]ability enabled many of our survivors to begin to understand that meaning they were attaching to dis[ability] and to devices.

5.1. Implications

There are implications for practice and research. It would be useful for professionals to probe for the meaning that stroke survivors attach to recommended assistive devices. As our participants told us, they were loath to adopt an electric wheelchair when it signified the end of recovery, but were happy with electric wheelchairs that catalyzed greater participation. We suggest that including material culture theory into the design and prescription of assistive devices would increase the consideration of the symbolic authority of assistive devices [10]. Health professionals could ask survivors about the meaning they assign to assistive devices.

Survivors' goals and assistive device needs should be assessed regularly after discharge. As they become more familiar with their environmental contexts, they may be more open to assistive devices that would increase participation. Although the best practice guidelines in most countries do recommend regular assessments, a British study found that about a third of survivors underused assistive devices because they were not aware of, or could not afford, the necessary assistive devices [36]. Additionally, survivors' participation goals may be overlooked by professionals who rarely evaluate stroke patients at home or in the community [12,36–39]. Our participants charged that, once discharged from hospital, it was difficult to learn which assistive devices would help them meet their goals and how to pay for them.

5.2. Strengths and Limitations

A strength of this "Getting On" group was the wide range of ages and abilities. Although stroke rates do rise sharply beginning at age 50, stroke is a condition of all ages [40]. To mirror the range of stroke survivors in the community, adults of all ages were included in the program. Participants were able to compare their situation to others as well as mentor and assist their fellow stroke survivors. Older adults mentored younger peers and *vice versa*. Those with greater limitations often inspired those with fewer impairments. Even those who were resistant to change sometimes motivated others to change. For example, when Marvin continued to refuse to try to play golf one-handed despite the opportunity to play with a one-handed player who usually breaks 100 because "he would look weird to his friends," Gary decided to try golf. Later he said the conversation with Marvin made him realize he was letting the worry about what other people thought restrict him.

Group self-selection may be a limitation. Participants volunteered to participate, so this group may have been more engaged and optimistic by nature. Those who were apathetic or less open to change may not have been as open to group processes or the usefulness of assistive devices. However, as noted earlier, the reason we chose to use a material culture framework that explicated how internalized assumptions about disability prevented survivors from participating was because so many of our participants believed that they could only accomplish meaningful activities if they recovered. Helping participants understand what they assumed about [dis]ability made them aware of their agency.

6. Conclusions

If we are to "break up the rhythm" of stroke survivors' inactivity, we need to understand the meaning survivors attach to disability and the assistive devices, projects, and programs that are meant to assist them. Our survivors intuitively understood that disability was a discursive object which

informed their actions and how other people treated them. Understanding disability as a discursive object helped to make the social construction explicit.

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Appendix: Project Evaluation Questions (Completed by Participants)

1. Was this project useful to you? (1) Not useful at all; (2) a little useful; (3) useful; (4) quite useful; and (5) very useful.
2. Was this project fun? (1) Not fun at all; (2) a little fun; (3) fun; (4) quite a lot of fun; and (5) lots of fun.
3. What did you learn from the project?
4. How did taking picture and sharing your experiences of “things that helped” help you?
5. What do you suggest we could do to make this project better for other stroke survivors?

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