



Contesting Health Policy: Toward a Utopian Vision of Community-based Rehabilitation for Brain Injury

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University



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Outline

Describe the brain injury policy landscape

Challenging outdated rehabilitation paradigms

- **Developing new outcome measures**
- **Exploring lived experience with brain injury**

Discussion

- **Community-based solutions**
- **Who is being left out?**

Conclusion



Some Statistics

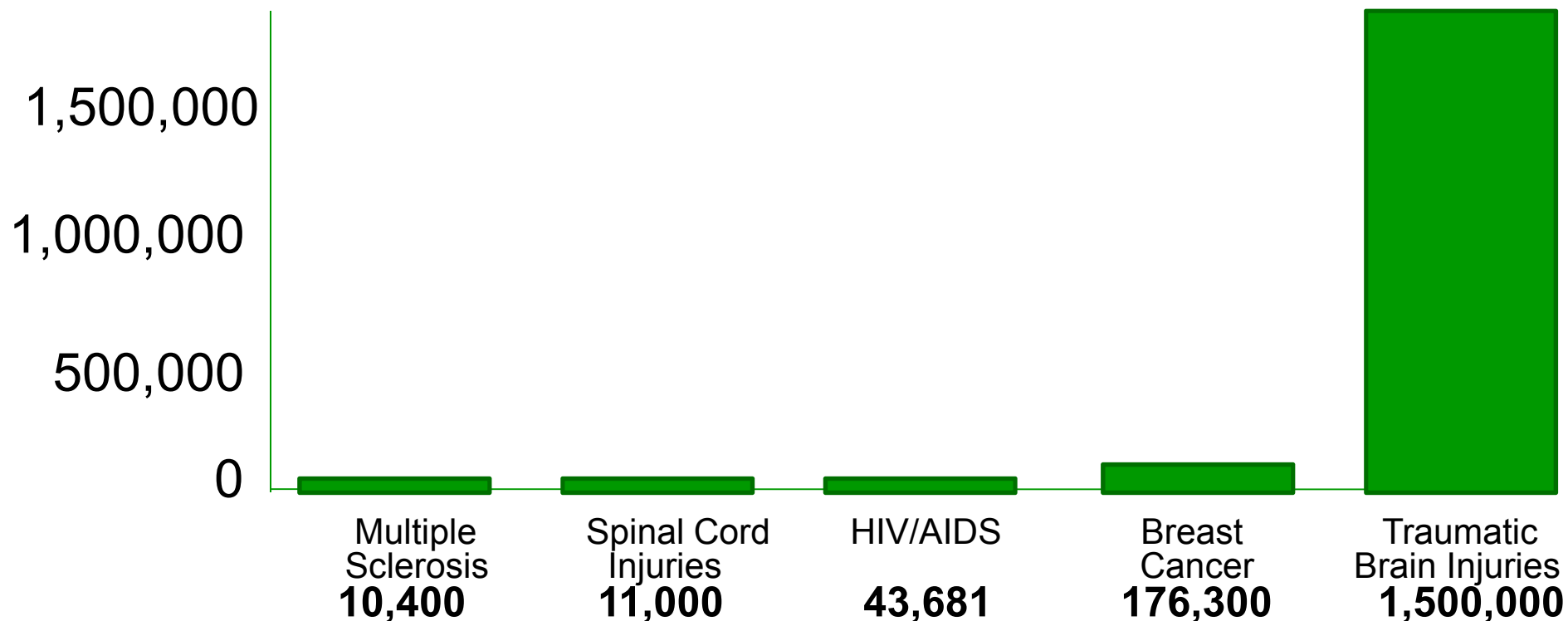
- 650 brain disorders¹
- Affect 50 million Americans per year¹
- Account for more long-term healthcare costs and hospitalizations than all other diseases combined²
- Disorder symptoms can be cognitive, emotional, behavioral, and physical

1 – Boyle 2001

2 – Arlinghaus, Shoaib, and Price 2005



Annual Incidence of TBI in US



- **50,000** will die annually as a result of TBI
- **80,000** annually experience the onset of long-term disabilities following TBI
- **5,300,000** Americans currently live with a disability as a result of a TBI

* Centers for Disease Control. "Traumatic Brain Injury in the United States: A Report to Congress." www: Centers for Disease Control, (January 16, 2001)



Rehabilitation

Is intended to help people to

- return to optimal effectiveness in daily living¹
- reach and maintain their optimal functional levels²

Goals may be compensation or recovery

Involves three phases: acute, subacute, and chronic³

Access limited to 1-3 years post-injury – many receive little to no cognitive rehabilitation⁴

1- Burton 2000; 2- Raskin 2011; 3- IOM 2011; 4- Cope, Mayer, Cervelli 2005



Evidence for Cognitive Rehabilitation = Weak

Problems include:

- Small sample sizes
- Lack of standardization of variables and definitions
- Lack of representative samples

In addition:

- Cognitive rehab as measured by clinical tests does not have real world value from funder (or patient!) perspectives



Challenging Outdated Paradigms

- 1998 NIH Consensus Conference
- 2006 position statement of the BIAA
- 2011 review by members of ACRM's BI-ISIG¹

To date: Much research focuses on technologies, providers, and costs related to providing services³

Need evidence of health-related improvements that show transfer to function in day-to-day living⁴

1- Cicerone et al 2011; 2- Prigatano 2000; 3- NIH 1998; 4- Raskin 2011



Standardizing Outcome Measurement

- 32 separate outcome instruments are housed on COMBI website (funded by CDC)
- Federal interest in streamlining instruments (NIH & NIDRR)¹
- Individuals with BI are participating in challenge (as encouraged by WHO, NIDRR & PCORI, & some clinicians²)
- New instruments: May generate evidence across small sample sizes & reduce the 17-year (!) delay from bench to bedside for RCT evidence³

1- Carlozzi et al 2011; 2- Prigatano 2000; 3- Duncan 2011



Health-Related QOL Issues for TBI¹

Function Domain	Participant Rating	Clinician Rating
Emotional	50%	34%
Social	23%	26%
Physical	14%	17%
Cognitive	11%	13%

- Used CBPR approach to review instruments and identify issues
- Domains parallel symptom domains – and echo interest of BCBS
- Current instruments do not capture complexity of HRQOL in TBI
- TBI-targeted item banks are needed – esp. on emotional & social function in community

1- Carlozzi et al 2011



A Closer Look at These Domains- Photovoice with Individuals with Brain Injury

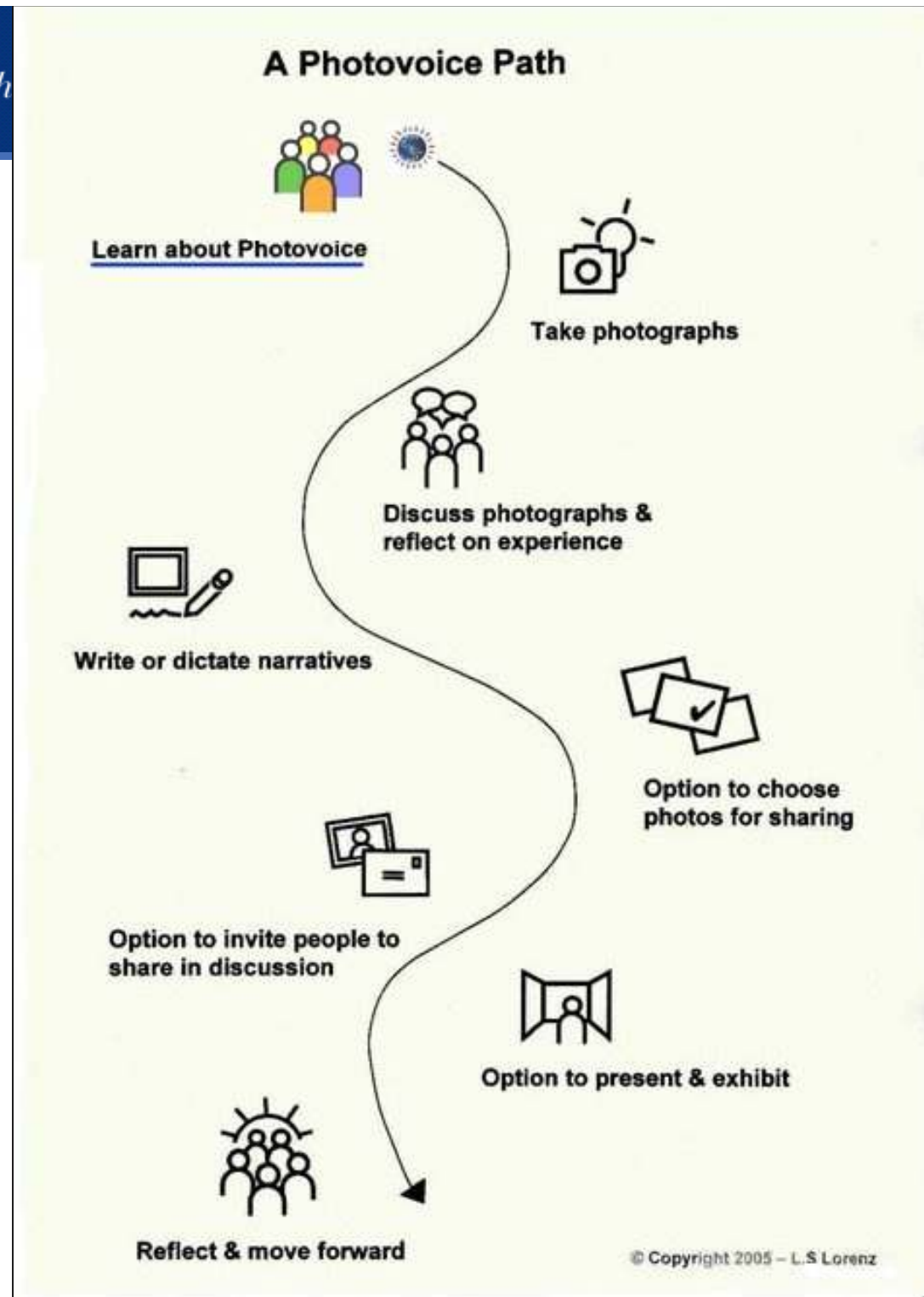


Participants: 8 members of a brain injury survivor support group supported by BIA-MA; & 2 BI co-facilitators

A Photovoice Path

Ask people to represent their lives, point of view and experience using photographs and narratives^{1,2}

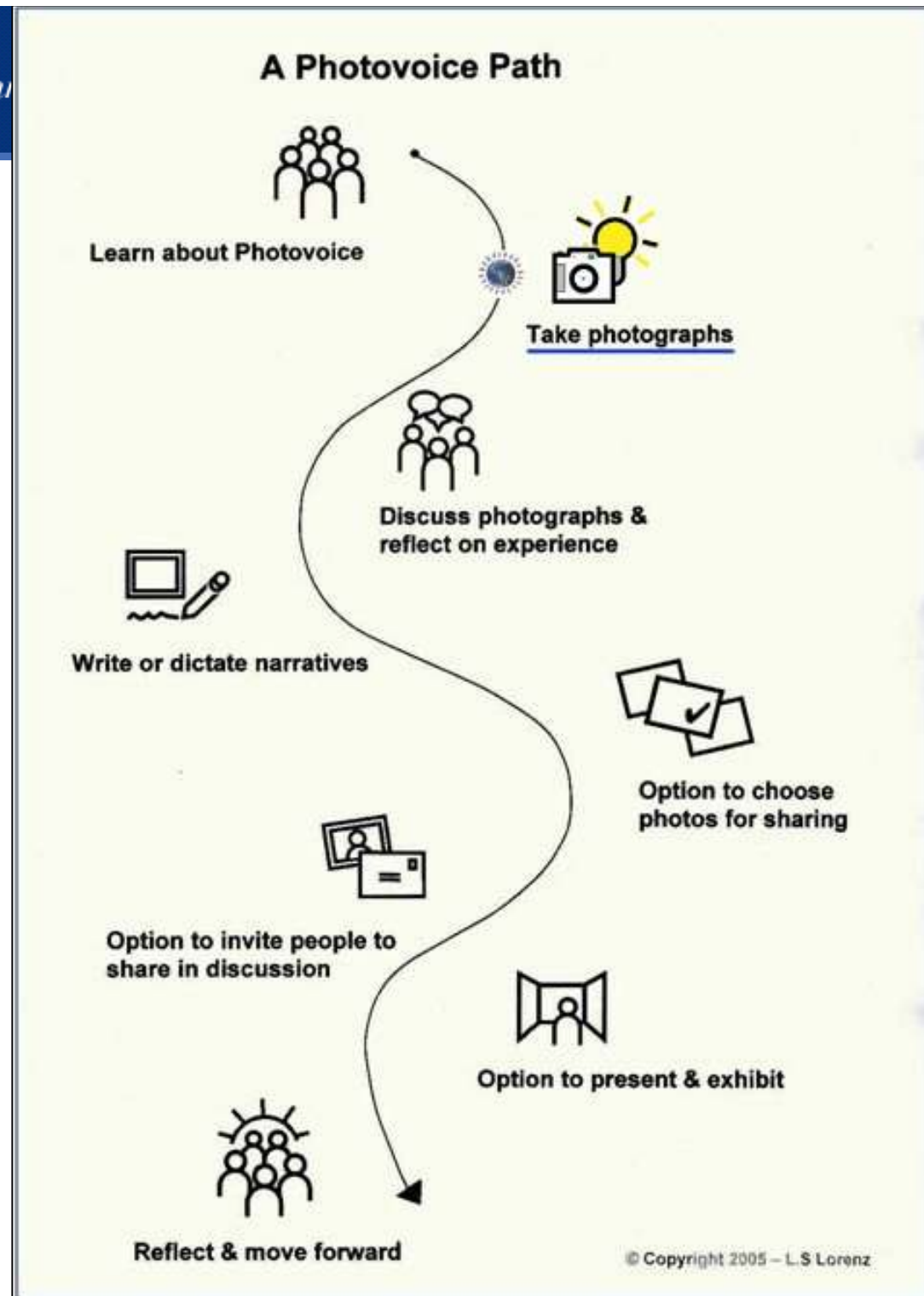
1- Wang & Burris, 1997; Lorenz 2010



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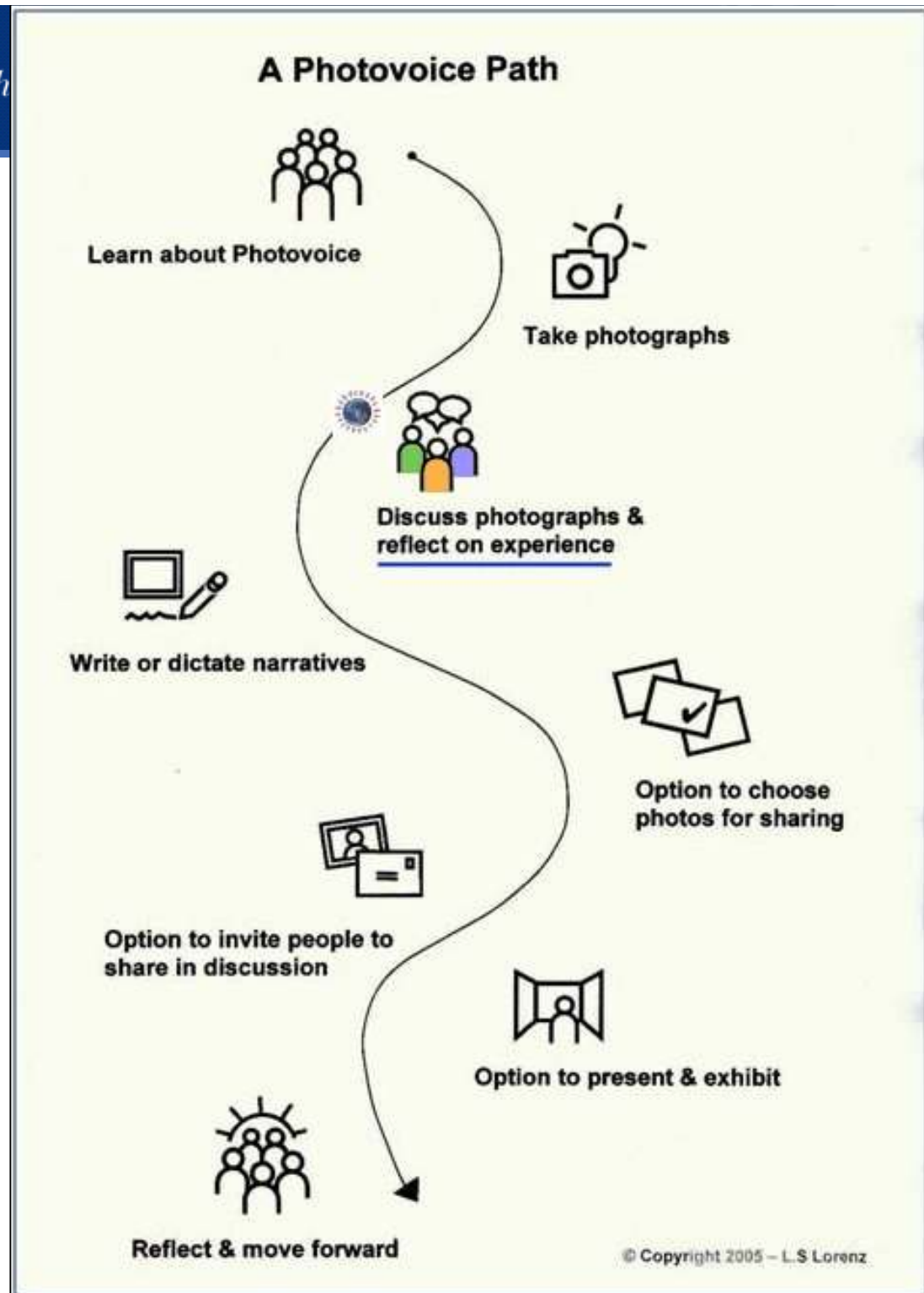
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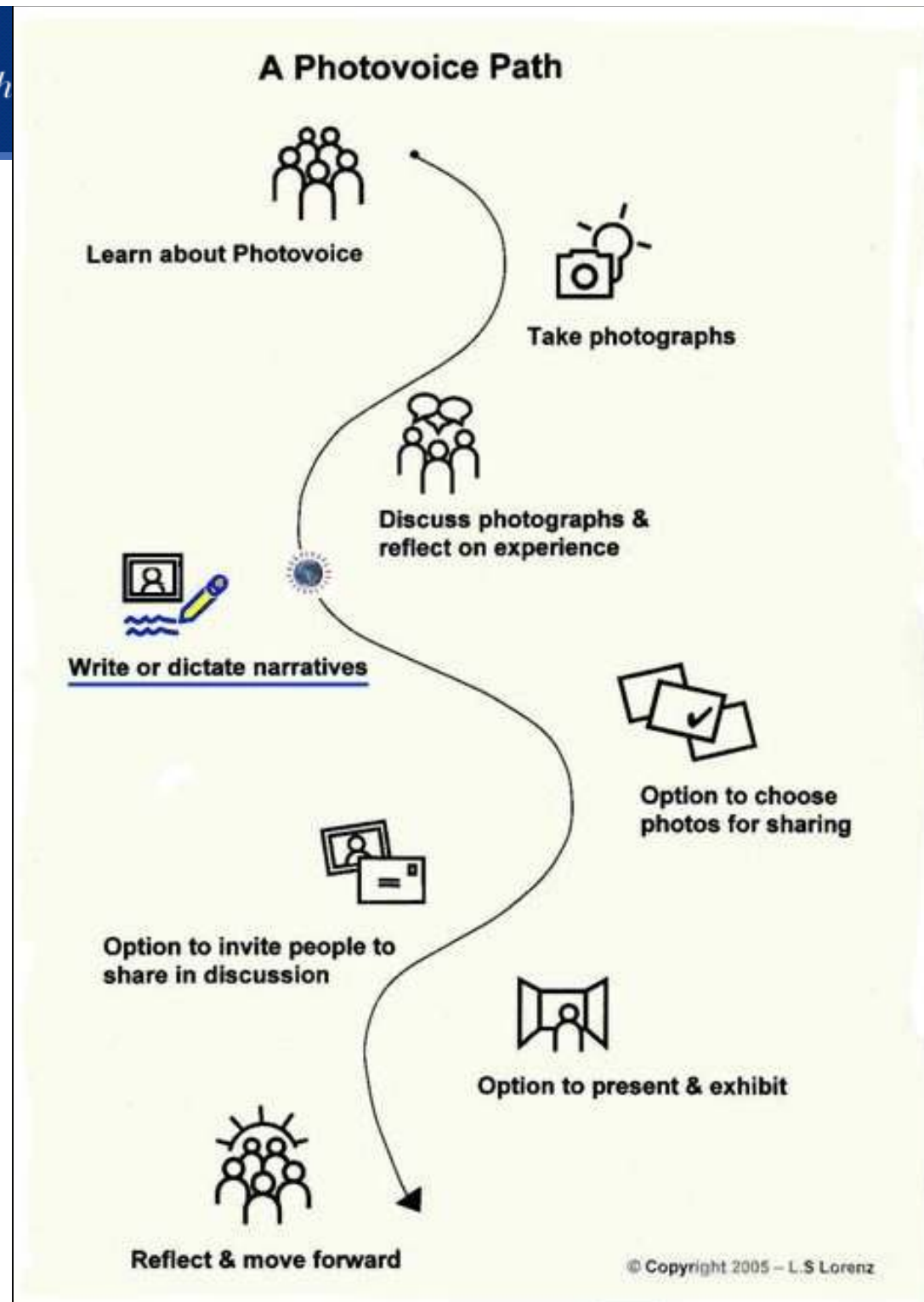
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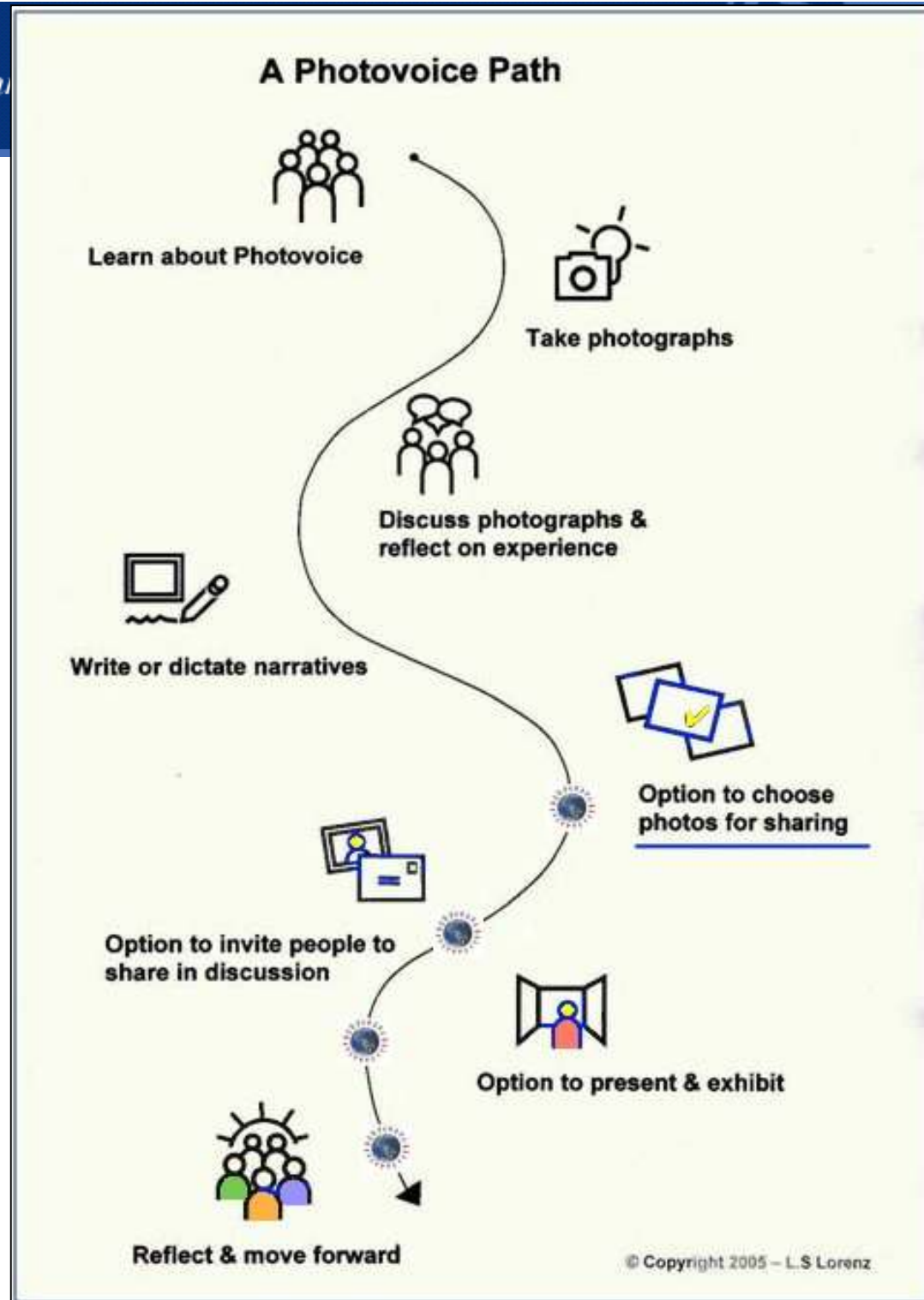
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Making Visible the Invisible: Using Photovoice to Understand Living with Brain Injury

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Abstract. Rehabilitation professionals have advocated for gaining an insider or patient perspective on living with disability, including brain injury, and facilitators and barriers to rehabilitation (Prigatano, 2000). Involving people with a disability in research about their lived experience may increase the relevancy of research to real-life situations (Rich et al., 2000) and provide an opportunity for those with a chronic condition to play a participant-expert role in the research process (Booth & Booth, 2003; Bruyere, 1993; Balcazar et al., 1998). Action research in the tradition of Kurt Lewin involves integrating science and practice in a dynamic group setting and emphasizes the combining of science and social practice (Adelman, 1993). For this study, carried out from September-November 2006, members of the 'Amazing' Brain Injury Survivor Support Group in Framingham, MA participated in a 10-week photovoice project (Wang, 1996), supported by BIA-MA and SHIP. The participating survivors took photographs of living with their brain injury, discussed them in a group, wrote narratives to accompany selected images, and prepared an exhibit to inform and educate policymakers, providers, and peers. Grouped under nine categories, including Chaos, Strategies, and Hope for the Future, the images and narratives convey these survivors' challenges and sense of mutual support as they work to accept their different abilities and move on with their lives.

Research Objective. To gain an understanding of lived experience with brain injury and the issues, concerns, and strengths of brain injury survivors living in the community, while providing an opportunity for survivors to reflect on their lives, use their brains, and employ a variety of cognitive skills.

Sample. The participants are members of the 'Amazing' Brain Injury Survivor Support Group, which meets twice a month at the MetroWest Wellness Center in Framingham, MA. Eight members volunteered to participate in the study. All are long-term survivors, having received their injuries between three and 31 years prior to the start of the project. Six are traumatic brain injury survivors, one had a malignant brain tumor, and another had a non-malignant brain tumor with co-occurring stroke.

Study Design. This was a participatory action research study using photovoice, a type of action research in which people represent their lives, points of view, and experience using photographs and narratives (Wang et al., 1996). Action research in the tradition of Kurt Lewin involves integrating science and social practice in a dynamic group setting (Adelman, 1993). The first author, a doctoral student with extensive photovoice experience, co-facilitated this project with her two co-authors: the support group founder and a group member with photovoice experience.

The photography and discussion phase lasted 10 weeks, from September to November 2006. Using disposable cameras with 27 exposures, the participants took photographs of living with brain injury from their perspective and discussed them together as a group. They wrote narratives for images that they selected for exhibit, and grouped their photographs and narratives into nine categories. They held a trial exhibit and reflected on their experience with this project. The group initiated an outreach phase in January 2007, and their efforts are ongoing.

Principle Findings. Taking photographs triggered participant reflection on their situation and what they wanted to convey to others about living with brain injury. Talking about their photographs with the group prompted deep discussions of emotional (and other) issues that had not surfaced during regular support group meetings. The participants' images and narratives convey their challenges and sense of mutual support as they work to accept their different abilities and move on with their lives. Study data indicate that from the perspective of these survivors, healing from brain injury is a gradual process that continues for years.

Conclusions. This research project provided the participating brain injury survivors an opportunity to play a participant-expert role in the research process (Balcazar et al., 1998; Bruyere, 1993). The outreach phase is providing new opportunities to use prior experience with communication, layout, and group dynamic skills in a supportive environment. Participating in this study became a meaningful experience for participants and facilitators alike.

Implications for Policy and Practice. Rehabilitation professionals have long advocated for gaining an insider or patient perspective on living with disability, including brain injury (Prigatano, 2000). Involving people with a disability in research about their lived experience may increase the relevancy of research to real-life situations (Rich et al., 2000).

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The Journey

It's a muddy, rutty, hands-and-knees crawl up to the first rung of the ladder that begins to make some semblance of sense—and then you get to begin to really struggle. The climb does not end and will not end... Sometimes weekly, and sometimes daily there is a new step to attempt to get to your "new self". You can't even ever hope to get back to your "old self". Oh wait! Maybe there will be a good view on this journey that I didn't expect.....



Lost Dreams

...this picture symbolizes what living with brain injury can be like...On an overcast day...I gazed up at the sky and took this picture through a tube...In the minds of many of us there are thoughts that we will never achieve some of the dreams we once held so dear...



Chaos

I feel chaos. I leave the dishes to be done later. I procrastinate...I make no time for completing my tasks...I watch cable television or daydream so I don't have to deal with what I should be doing. This is the piano that I should and would love to learn how to play. I must practice.



Challenges

...imagine yourself trying to run on ice...The faster you run, the more you get nowhere. These images parallel how each and every day of my life begins since I suffered my brain injury. I seem to spend a whole lot of time getting nothing accomplished.



Strategies

To compensate for my poor memory and organizational skills, I need to put labels on everything in my home. Where are my socks? Which of these is my schedule book? On which shelf did I put my Bible? These labels are necessary 3 years after my accident and probably for many years to come. It is painful to remind myself about all of the brain power which I lost at the time of my car accident.



My Advocacy Story

These are my counselors at Metro West Independent Living Center. They helped me to focus by bringing me to the statehouse to talk to my Senator and Representative.



Comfort and Support

With TBi certain parts of my life have added much comfort and support. God has blessed me with Teddy and Betty Blaine. They welcome me home with hugs and snuggles. We eat together, they sleep beside me and nuzzle their noses into my neck and face to gently wake me in the morning. They delight me with their personalities and antics. They warm my heart and comfort me. They make me smile and laugh. God has Blessed me with a little glimpse of heaven.



Acceptance

Whose grave is this? Surely it's not mine. This is not my fate, is it? I need to make the best of this situation, but how? It's all suddenly complicated...This was not my doing, nor my choice! I'm trying to be grateful. I need to accept this death of my "old self".



Hope for the Future

New identity. New passion of gardening. First baby step was planting in containers so as to not fall into dirt because of imbalance. My garden has progressed as my new life has. Now I not only can plant in the ground, I dig up grass and now have three perennial gardens.

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Brandeis Institute for Health Policy

- Nine themes, each with 4 or more photos
- Participants developed themes in collaboration with facilitators^{1,2}
- Describe long-term nature of BI healing
- Acceptance was an important if elusive goal¹
- Extensive outreach accomplished

1- Lorenz 2010; 2-Lorenz 2009



Emotional Health



...this picture symbolizes what living with brain injury can be like....On an overcast day...I gazed up at the sky and took this picture through a tube. ...In the minds of many of us there are thoughts that we will never achieve some of the dreams we once held so dear... (Brain Injury X-Posed: The Survivor's View 2007)



Social Health



Having Mark in my life helps me to avoid “meltdowns” ---episodes lasting hours during which I get severely confused, depressed and irrational. I can’t talk coherently, I take off some of my clothes in public, I feel like I want to die, etc.---by constantly and carefully observing my behavior and coaxing me back into reality whenever necessary---often several times a day. What Mark communicates to me at these times is honest and comforting: “Your brain was damaged in a car accident. It’s not your fault. You are still a good person. And I love you very much.” Living with brain injury without Mark is unthinkable. (Brain Injury X-Posed: The Survivor’s View, 2007)



Physical Health



This is the front steps of where I'm living. There are three stone steps. It makes it difficult to walk up them. Thank God there's a handrail. (Brain Injury X-Posed: The Survivor's View, 2007)



Cognitive Health



Using crossword and word searchers to reconnect pathways in the brain. (Brain Injury X-Posed: The Survivor's View, 2007)



Discussion

Participatory research findings provide evidence of “real world” lived experience with brain injury and rehabilitation

Data about lives are grounded in homes and communities, where most rehabilitation work takes place

For too long, policies have relied on now-outdated scientific and clinical attitudes and evidence that the adult brain has limited potential to heal and compensate after injury

For too long, policies have focused on attempts to measure and limit rather than encourage rehabilitation potential



Discussion cont.

I am part of a transdisciplinary group working to close the community-based rehabilitation gap for adults with brain injury in MetroWest Boston

3 small research studies under-way now

Also developing a pilot brain injury patient registry to understand -- do different services help? Do different living situations make a difference? What intersections and synergies exist between function and person-centered HR-QOL?

These data will contribute to greater understanding of BI outcomes over time and inform organizational, state, and federal investments in rehabilitation & supportive living



A Caution

The data and vision presented here is grounded in the experiences of middle-class white populations

Yet rates of TBI are highest in families with lowest SES and minority populations are at greater risk of injury

Up to 87% of individuals in prison may have a history of brain injury, and BI caused by violence may led to more persistent symptoms and greater levels of disability

Will findings from our studies have relevance for low SES groups? What could be done to improve BI outcomes for neglected individuals and populations?



Conclusion

It is unlikely that anyone living in the US – including all of us in this room – does not personally know someone living with brain injury

Our society may never be able to provide long-term rehabilitation over the long-term for every brain-injured individual who needs it

We can, however, rethink services and service delivery paradigms and challenge rehabilitation service limits

Perhaps most important, we can take action to foster communities of brain health – emotional, social, physical, and cognitive – with potential benefits for all



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