Proceedings of the 58th Hawaii International Conference on System Sciences | 2025

Born Twice: The Role of Social Media in Identity Redefinition After Sudden Disability

Lena Cavusoglu
Pacific University
lenacavusoglu@pacificu.edu

Nadzeya Sabatini
GUT-Gdansk University of Technology
Università della Svizzera Italiana
nadzeya.sabatini@usi.ch

Francesca Bonetti
HEC Montréal
francesca.bonetti@hec.ca

Stefania Borghini
Bocconi University
stefania.borghini@unibocconi.it

Russell W. Belk
York University
rbelk@schulich.yorku.ca

Abstract

From being attacked by a shark to being stricken by illness, people who acquire disabilities later in life have unique lived experiences. There is, however, a commonality that binds them: the loss of a former identity and a rebirth into another life. They may also struggle with self-acceptance as they shun societal stigmas and perceived deviance from cultural norms. Through a netnographic study, we examine how identities are redefined with the help of social media. We trace the journey of athletes, influencers, and others experiencing sudden disabilities as they transition from medical facilities to the comfort of their homes. We present the four critical phases toward acceptance of a disabled identity and show the role of social media as a transformative tool for navigating social exclusion and prejudice, as well as being a conduit for self-expression.

Keywords: transformative experiences, disabled self, netnography, social media, identity formation

1. Introduction

Meaningful and transformative experiences in a person's life are rarely selected or chosen but are instead compelled (Carel and Kidd, 2020). Liminal transitions, which are periods of transformative experiences, cause instability and ambiguity in a person's identity as they find themselves in an in-between state adjusting to new realities (Noble and Walker, 1997). Acquired physical disabilities are considered transformative experiences that occur at some point after birth and cover a wide range of impairments from temporary Bell's Palsy, which is a sudden weakness or paralysis in one side of the face, to amputation, vision or hearing loss, disfigurement, motor neuron disease, stroke, traumatic brain injury, multiple sclerosis, and cancers. As the body experiences dramatic changes, so too does an affected person's emotional state. Many feel a loss of identity as they transition from able-bodied to disabled (Upton and Han, 2003). These dramatic transformative experiences and the resulting liminal identity state necessitate a redefinition of the self-concept, social roles, and daily practices, both offline and online, that are the focus of our study.

Disabled people are devalued by society through *ableism* or the norm of being young, white, and able-bodied. Others face disability stigma and the expectation that they need to be "fixed" to approach this norm (Bogart and Dunn, 2019). In response to public and interpersonal stigma, disabled people may internalize failed ableism and derogate their self-concept (Dirth and Branscombe, 2018). They experience challenges in belonging and adjustment because society labels anyone who is disabled as "abnormal" or even monstrous (Cusforth, 1951). Thus, people with acquired disabilities carry not only the burden of their new physical challenges and outward appearance but also the normalcy expectation of society (Chan and Lempp, 2018). This normalcy expectation is akin to a blame-the-victim mentality, negatively affecting self-confidence and self-esteem (Farquhar, 1995). One method of protecting self-esteem in the face of ableism is to develop a positive disability identity (Bogart, Lundand and Rottenstein, 2018). This is achieved by accepting disability as an essential and valued part of the new self. It often includes finding solidarity with others, whether friends, family, or strangers who share aspects of their reconfigured identity. Along this journey social media can play multiple roles in reducing the distance among peers to reclaim normalcy and build agency (Parsloe 2015), plus providing support and practical advice (Tenderich et al, 2019; Lawless et al., 2022).

URI: https://hdl.handle.net/10125/109171
978-0-9981331-8-8

Given the relationship between expressive consumer goods, emotional empowerment, and self-confidence, the significance of expressive consumer goods for physically disabled consumers is even more critical (Entwistle and Wilson, 2001). Especially when identity is in flux, the newly disabled may use possessions such as customized wheelchairs, prosthetic limbs, mobility and hearing aids with unique colors, patterns, and designs, stylish adaptive clothing, and sports equipment that represent the self (Higgins, 2020; Higgin, Husemann and Zeyen, 2024) and help in the creation and reimagining of a positive disabled identity (Baumeister, 1999; Rosenberg, 1979). These goods can help to ease changes and transitions during liminal periods (Belk, 1988). But it can still be seen as partly bowing to ableism. That's where social media may come in.

Like expressive consumer goods, social media provides a dynamic platform for people to create and express their new identities, especially during transitional phases in their lives such as pregnancy, post-partum, and, of course, acquired disabilities (Argan, Argan, and Özer, 2016; Cavusoglu and Atik, 2023; Walker and Litchman, 2021). For physically disabled consumers, social media can serve as a powerful platform to challenge disability stereotypes and foster a sense of community and belonging. By sharing personal stories, challenges and achievements, emotions, and everyday experiences, users can redefine societal perceptions of disability and share and promote a more inclusive narrative (Parsloe, 2015). Furthermore, social media provides a space for visibility and representation, amplifies diverse voices, and thus enables disabled individuals to connect with others who share similar experiences to gain emotional support (Cavusoglu and Belk, 2024). The visual and interactive nature of social media further enhances the ability to present a positive and empowered disabled self (Södergren and Vallström, 2023). To pursue this possibility, this study aims to answer: How do people with adult-onset acquired physical disabilities and visible differences navigate the coping and acceptance process toward establishing a disabled identity using social media?

Our paper is designed to provide readers with an understanding of the often overlooked emotional and social impact of acquired physical injuries and describe the multiphase path toward acceptance of a new identity with the help of social media. We first explain the transformative experience of becoming disabled. We then discuss the role social media plays in self-expression and identity reconfiguration for people with disabilities. Following this, we detail our methodological approach, specifically our use of netnography. In our findings, we present a detailed account of the step-by-step processes through which those with acquired physical disabilities and visible differences navigate, cope, and establish a new identity despite the challenges they face. We conclude the paper by discussing our findings and their managerial and policy implications. Finally, we present the limitations of our study and suggest directions for future research.

2. Becoming disabled and building new identities on and off social media

While the psychological perspective on identity transformation focuses on individual coping mechanisms for dealing with being disabled, with a cultural perspective, "disability is not something a person *is*, but something a person *becomes*" (Moser, 2005, p. 668). This perspective lends itself to a deeper understanding of how disability is enacted in everyday life, how a new order of the normal is constructed, and how materialities are organized.

When a trauma such as an illness or an accident radically changes a person's life in a way that s/he did not choose (i.e., one of life's so-called unchosen transformative experiences), the sense of self and of being in the world must be dramatically reworked (Markovic, 2021). Personal plans, desires, habits, and many of the things that were meaningful prior to a disability are disrupted or even destroyed by external circumstances. New mundane and essential practices must be developed and learned. The process through which disabled people cope with this new situation is to rely on others like them, because they cannot rely on their pre-disability experiences, physical capabilities, and independence to shape their new self. The system of possibilities these people regularly relied upon to act and interpret their world is no longer available (Ratcliffe, 2019). Like many of us today, those we studied turned to the Internet and social media for hope, ideas, and social support.

At the beginning of the process, newly disabled people experience disruption caused by the mismatch between established practices, such as aspects of their identity tied to their previous lifestyle and their new precarious conditions. They must react by developing a new sense-making process and deploying their remaining practical capabilities. They also turn to social media to help make sense of their new world. This sense-making can be participatory as it may involve other people actively participating in this redefinition. This can include medical professionals, friends, family, as well as online disabled influencers they have never met in person (Södergren and

Vallström, 2023). Some of them might become similar influencers themselves.

The transformation process after unchosen transformative experiences also involves the development of new capabilities and skills that modify everyday practices and determines how people with disabilities relate to their bodies, their social environment, and cultural norms. Hartblay (2020) explained this with the disability expertise concept, which is the “particular knowledge that disabled people develop and enact about unorthodox configurations of agency, cultural norms, and relationships between selves, bodies, and the designed world” (p. S26). Disability expertise is socially constructed and can be considered a sort of situated knowledge that makes them and their online community experts in designing everyday life and social presence. It challenges views that either portray them as heroic for their success or invoke pity for their misfortunes. Such unhelpful stances are referred as the “tragic hero” or “inspiration porn” (Blake, 2024).

The internet, specifically social media, provides a platform that circumnavigates many real-world challenges that those with disabilities face, including geographic and physical inaccessibility, and offers a degree of anonymity to avoid undesirable in-person prejudice. For non-incarcerated people with one of the many acquired disabilities, the problem is not too many but too few people “like me” who can provide support, information, and evidence that “I am not alone” (Lawless et al., 2022). Here, social media can be a game changer or even a lifesaver for those with acquired disabilities. Not only does it facilitate important online correspondence for those with rare disabilities, but it also provides advantages over face-to-face communications for the hearing impaired and those with problems socializing in groups (Parsloe, 2015; Peterson, 2017). Interacting online allows people with disabilities to construct their selves by communicating details of everyday life with humor and a sense of pride, sharing personal experiences, and developing new knowledge and tips helpful in overcoming difficulties (Tenderich et al., 2019). Emerging literature is starting to demonstrate how social media are making effective and positive impacts in everyday life beyond representation and cultural discourses. For instance, autistic consumers who engage with online peer communities can gain a cultural perspective on their identity, enhance their sense of agency, and approach their symptoms from a different viewpoint (Parsloe, 2015).

A further commonality faced is the stereotypes promulgated by television, film, and print media. For example, Saunders, et al., (2018, p. 936) find that media portrayals are of people who are “…vulnerable, pitiable, child-like, burdensome, lacking in social utility, violent, non-sexual, and even a ‘super cripple.’” They characterize this as invoking an inappropriate medical model rather than a more humanizing social model “…in which physical, social, and economic barriers imposed on people living with impairments are seen as the source of disability” (p. 926). In this medical model, there is an implied inclination to fix or cure those with a tragic and pitiable existence that must be heroically overcome. In other words, the mass media image disseminated is one that champions ableism and is the target of critical disability theory (Pothier and Devlin, 2006).

While social media can have a significant impact in terms of subverting disability stereotypes and ableist messages, it is not without its problems. For instance, aside from physical disabilities young people with intellectual disabilities disproportionately become the target of online cruelty, cyberbullying, and threats (Borgström, Daneback, and Molin, 2019; Trindade, 2024). Perhaps ironically, those with higher IQs are most likely to be the targets of such bullying (Didden, et al. 2009). For now, however, there is a lack of social media training and safety programs to address this problem (Bruner, Rietdijk, and Togher, forthcoming).

3. Methodology

We aim to answer the following research question: How do people with adult-onset acquired physical disabilities and visible differences navigate the coping and acceptance process toward establishing a disabled identity using social media? To address this research question, following the lead of disability studies (e.g., Cavusoglu and Belk, 2024; Falchetti et. al., 2015), we employed qualitative inquiry. Netnography deemed most appropriate due to its ability to integrate the analysis of social media representational affordances, offering deep data that is critical in conducting a rich qualitative study (Kozinets, Cavusoglu and Belk, 2024).

The research team for this study consisted of five non-disabled researchers. Three members of the research team have extensive experience studying disability. During the immersion phase, the researchers considered their positionality, recognizing that their experiences may be notably different from those of the participants. Two researchers gathered and analyzed the netnographic data, highly engaging in this (emic) process, while the remaining three authors have kept analytical distance (etic). We conducted this process independently and met on several occasions to discuss progress and to agree on or solve any incongruences. The process involved systematic observations and data collection from social media users discussing their acquired disabilities. The two researchers tracked social media conversations, posting patterns, and noted reflections on social media usage. Throughout this phase, they collaborated closely with the rest of the team, regularly discussing their findings, and sharing insights.

Instagram was selected as the platform for study due to its widespread use, with 1,365,181 posts under the hashtag #disabled as of 2024. The platform was also instrumental in identifying online communities gathered around specific disabled influencers. Furthermore, Instagram is a platform used by key professional influencers (#disabledblogger with 41,755 posts and #disabledinfluencer with 11,429 posts) and everyday users who document their transformative journeys toward a new identity.

Researchers analyzed 17 profiles, which were purposefully selected, representing a diverse spectrum of influencers (mega, macro, and micro) as well as laypeople and followers who are diverse in terms of acquired disabilities and temporary ailments, from breast cancer survivors to boat or car accident victims. Other criteria for selecting the profiles include running publicly open accounts and containing enough information on the process investigated. The researchers agreed to stop investigating profiles when they reached data saturation, and no new significant themes were emerging. Details of the chosen accounts are presented in Table 1. Our diverse sample includes a pregnant woman, a woman advocating for adaptive clothing for Muslims with disabilities, two professional athletes who are part of Paralympic Teams, a content creator and writer, a dancer, a professional surfer and motivational speaker, a personal trainer, a model, and a former fashion student designing her own collection specifically for disabled people. Most profiles are owned by women, which is unsurprising as Instagram is a female-dominated platform on which 77% of influencers are women (Collabstr, 2023).

Researchers conducted a comprehensive visual and textual analysis of the selected profiles and the comments left by other users. This approach allowed us to identify common themes and patterns as well as irregularities, providing a deeper understanding of how those with acquired physical disabilities and visible differences publicly present and negotiate their identities in digital spaces and engage in the process of identity transformation with the aid of social media.

As the immersion deepened, the team recognized that observation alone would not suffice to capture the full complexity of participants' motivations and experiences. Consequently, the other three researchers on the team stepped in to the interaction stage of netnography and conducted semi-structured, in-depth interviews with 20 participants. The first round of interviewees was meticulously selected using purposeful sampling (Glaser and Strauss, 1967), a method involving researchers' contacts, disability-specific advocacy groups, and civic organizations.

#	Name of the account	# followers*
1	Bethany Hamilton	2.3M
2	Simone Pedersoli	100K
3	Lauren Rose	97K
4	Kate Stanforth	23.9K
5	Dani Zapata	22.9K
5	Sian Lord	19.7K
5	Repo Jasmine	18.1K
8	Ema_lambertini	16K
9	Talia Eilat	10K
10	Dana Donofree	10K
11	Keir Hogan	5K
12	Taylor Cutler	4K
13	Marissa Thomas	2K
14	Danielle McRease	1K
15	Jenn Starr	951
16	Blanca Lobo	630
17	Yasaman Poursalarii	431

Table 1. Analyzed Instagram accounts of the users with acquired physical disabilities

*Follower numbers as of June 12, 2024

.

A total of 12 interviews were conducted with people who have bodily disabilities such as quadriplegia (or forms of cerebral palsy), spinal cord injury, muscular dystrophy, and amputation. Seven interviews conducted with people who have acquired visible facial disabilities and differences, including four participants who were the victims of acid attacks, another who had exenteration of one eye due to sinus cancer, another suffering from Bell's Palsy, and one person with vitiligo, a chronic skin disease that causes patches of the skin to lose pigment. In this second group, some participants were identified and recruited using Instagram. They provided further netnographic data through their social media posts and were interviewed during the interaction phase. Acid attack survivors were recruited with the help of a non-profit organization in India that supports the survivors. These survivors were not social media active. Their interviews were vital as they allowed researchers to understand whether there is a difference in their journey toward accepting a new disabled identity without being social media active. Additionally, researchers had the opportunity to interview the public relations representative of a breast cancer fundraising fashion show held during Fashion Week 2023 in Milan. The theoretical sampling continued until no new data, topics, or concepts emerged and saturation was reached (Guest, Bunce, and Johnson, 2006), leading to rich narratives that answered the research question (Mason, 2002). Interviews were conducted in person or on Zoom. Each interview lasted from 40 to 70 minutes, allowing for more direct interaction with participants, enabling the researchers to probe deeper into how social media was used (or not used) in coping with acquired disabilities, navigating identity changes up to identity reconfiguration, and engaging with support networks.

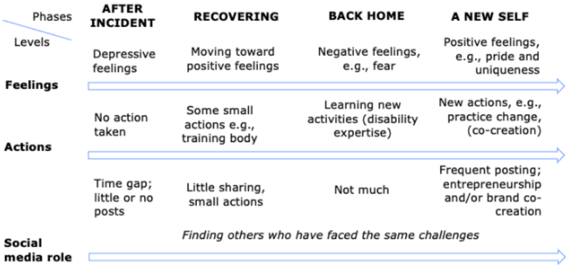
The data analysis followed an integrative process involving continuous research collaboration. After the initial netnographic data was collected and analyzed by the two netnographers, they shared their relevant findings with the rest of the team. This created an iterative cycle of discussions between the netnographers and the interviewers, allowing for cross-comparison and deeper exploration of the themes. Therefore, the data collection and analysis during the integration stage of this study were not linear processes. Instead, they were iterative, with each informing and shaping the other. This approach, guided by grounded theory (Glaser and Strauss, 1967), allowed researchers to discover new potential directions or theories.

4. Findings

Findings from the netnographic study reveal a coping process focused on a new identity that the participants experienced. The process is composed of several phases (i.e., after incident, while recovering, back home, and building a new self), and each included two levels (i.e., feelings and actions undertaken by the participants) proceeding at various paces on a timeline, as depicted in Figure 1. Social media have a specific role in helping participants focus on positive phases.

The first phase *after incident* is experienced by the participants in the immediate aftermath of a traumatic incident. This could include amputation of one arm after a shark attack, blindness, and deafness. Data reveals nervousness, helplessness, depression, and fear at this stage. The participants also expressed difficulty accepting society labeling them with the term "disabled." Our 29-years-old female participant who was attacked by acid, burning and scarring her back, right shoulder, and side of her face states:

> *"I don't consider myself as disabled… the governmental office told [me] to apply [for a] disabled/handicapped card. But I said those who cannot see, those who cannot walk should get a handicapped card. I can see. I have legs and hands. Maybe right after the attack happened, the handicapped card was okay but after several operations I am stable now. I don't need the card."*



Phases / Levels	AFTER INCIDENT	RECOVERING	BACK HOME	A NEW SELF
Feelings	Depressive feelings	Moving toward positive feelings	Negative feelings, e.g., fear	Positive feelings, e.g., pride and uniqueness
Actions	No action taken	Some small actions e.g., training body	Learning new activities (disability expertise)	New actions, e.g., practice change, (co-creation)
Social media role	Time gap; little or no posts	Little sharing, small actions	Not much	Frequent posting; entrepreneurship and/or brand co-creation

Finding others who have faced the same challenges

Figure 1. The coping process toward a new identity

In this phase, the participants show they are energized and ready to fight the disease. For instance, 42-years-old male participant who had an eye removed due to sinus cancer explained this phase:

> *"If I were to focus on one thing, it wasn't so much how I felt about my new face, it was surviving a cancer. So, what do you want to do? Do you want to look a bit different, or do you want to live? You know, that was kind of the way that I had to program myself to feel about it. Once I got past that point where I actually could hope that everything would be okay from a health perspective, I think I was already beyond the worry or the care."*

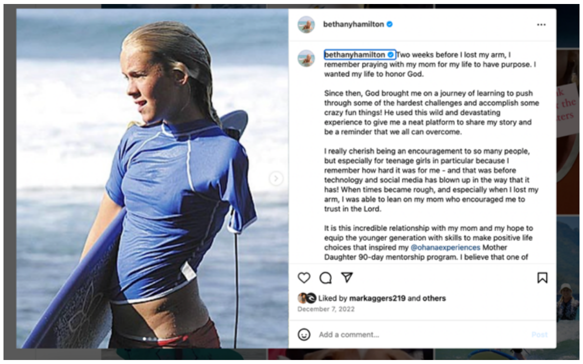
During this phase, the data from social media users is notably scarce, as they appear to need time to process their emotions before sharing their accounts. However, in some instances, they reflect several years later the darkness post incident, with a positive annotation, already pointing toward the acceptance and recovery phase.

The second phase, *recovering*, is when they begin to accept their new self upon reflection and through meeting their similarly disabled peers. This phase is characterized by an epiphany, where they start moving toward positive feelings and undertake small actions, such as rehabilitating their bodies. They start sharing increasingly via social media in this phase. For instance, our 25-years-old female participant who experienced Bell's Palsy explained her recovery process:

> *"I do think that the advocacy thing on social media was, at the beginning, a way to actually heal. Like a bit of 'if I put this out there into the world and say that I'm comfortable with it, then people won't feel like they can ask questions or make fun of you'. Because if you're comfortable with it, they know it's not going to hurt. Like it was a bit of a 'fake it till you make it'. But I would say [it took] about 12 months to honestly feel really comfortable."*

In this phase, social media's role in socializing and gaining self-confidence is critical. As another acid attack survivor, 28-years-old female, explains her journey, she mentions appreciation for Facebook by stating:

> *"I met my husband [on] Facebook 8 to 9 years [after] the accident. I could not go out. So, I spent a lot of time on Facebook. It all started with a 'hello'. I had hatred towards love at the time because someone who "loved me" threw acid on me. So, I thought that love cannot be good for anyone. But he wanted to stay by my side as a friend. He made me step out of [my] home, and he supported me to get admitted in an open school. He told me that my face is not the main part of life."*



bethanyhamilton Two weeks before I lost my arm, I remember praying with my mom for my life to have purpose. I wanted my life to honor God.

Since then, God brought me on a journey of learning to push through some of the hardest challenges and accomplish some crazy fun things! He used this wild and devastating experience to give me a neat platform to share my story and be a reminder that we all can overcome.

I really cherish being an encouragement to so many people, but especially for teenage girls in particular because I remember how hard it was for me - and that was before technology and social media has blown up in the way that it has! When times became rough, and especially when I lost my arm, I was able to lean on my mom who encouraged me to trust in the Lord.

It is this incredible relationship with my mom and my hope to equip the younger generation with skills to make positive life choices that inspired my @ohanaexperiences Mother Daughter 90-day mentorship program. I believe that one of

Liked by markaggers219 and others
December 7, 2022

Figure 2. Bethany Hamilton's (BH) post for the recovering phase

Similarly, as shown in BH's post (Figure 2), she writes almost 20 years after the incident of the shark attack that led her to lose one arm, reflecting on when she first got back into the water, training her body to use only one arm. She emphasizes the support of her mother, God, and community with positive feelings. This is an example of a grateful phase shared on social media, where they encourage others and share their appreciation for the people who were close to them after the incident or, in the case of illness, the initial stages of the disease.

The third phase, *back home*, is when they are confronted with returning to their previous environment with a new self. During this phase, there is a high risk of depression as participants may isolate and struggle with adapting to an unfamiliar sense of self in a familiar setting. Our data shows limited posting on Instagram from disabled people at this point, mainly consisting of reflecting to this phase to emphasize the importance of the support of family and friends to overcome these intense moments. One of our participants, 26-year-old female, who uses mobility aids due to Ehlers-Danlos syndrome, a chronic illness that affects flexible joints, reflects on the role of her partner during this phase:

> *"I still have insecurity now [about] 'how does he feel'? ... he didn't choose me as a disabled person, he chose me as an able-bodied person who became disabled. So naturally, I still have these questions… about those feelings. And I feel like I'm lucky to have the experiences I do, because I can kind of check myself and realize that that's just internalized ableism, and he's never shown me any reason to not be supported and loved."*

Similarly, our 29-years-old, female, acid attack survivor participant explains her early post-accident self:

> *"Earlier, I used to not go out. I used to think that I was the only one like this, scarred by an acid attack. But after coming to [an] NGO office, I have been able to see so many other girls like me. Then I began thinking that if they can survive then so can I. Then, I began to get confidence from them. Sometimes when I just get up from my sleep, I feel like I have transformed back to my old looks. But then I go and look into a mirror, and I remember again... I had beautiful long hair before, but when he threw the acid it all fell down, burning."*

The final phase, *a new self*, concerns the individual's discovery of a new self, realizing they are happy with their new identity. This is when their second life starts. Their physical differences are considered part of their identity. For instance, our 25-years-old female participant with Bell's Palsy explained:

> *"And now it's been almost five years. So, I would say I'm completely comfortable. I don't think twice about it. To be honest, every time someone asks me about my facial difference, now I kind of [think]… 'well, that's weird that you're asking about that,' like, I'm so comfortable in it.*"

This phase is characterized by positive feelings and ongoing achievements as well as the discovery of new passions. The new self is also marked by new consumption, in which the participants may ask companies to create adaptive products. Our data shows that companies cater to disabled individuals primarily in the sports industry. However, interview data reveals that these are mainly emerging companies, not large established corporations. This is a clear indication of the reluctance of established brands to branch out to underserved market segments. Interviews with managers responsible for a breast cancer fundraising fashion show at Milan Fashion Week 2023 reveal that emerging designers with limited market presence predominately took part in creating the survivor fashions, while more well-known designers were notably absent. This may also be because established brands were cautious about participating due to concerns that it would target too niche of an audience and potentially undermine their brand image by featuring non-traditional body types.

Often, disabled people feel underserved and underrepresented by companies that largely ignore their unique needs. This spurs them to become inventive and create what they need for their new selves and the new or modified practices. For instance, BH started creating new surfboards with a handle to allow her to surf with one arm. New products, which were featured on social media also include modified clothes, makeup, and adapted supplies for everyday activities such as bike riding and driving. Our 43-year-old male quadriplegic participant explains:

> "*We have created a custom jet ski. We designed a proper seat for people like me with a high-body injury… This kind of jet ski was not available in the market, so we did it, and organized an event for it.*"

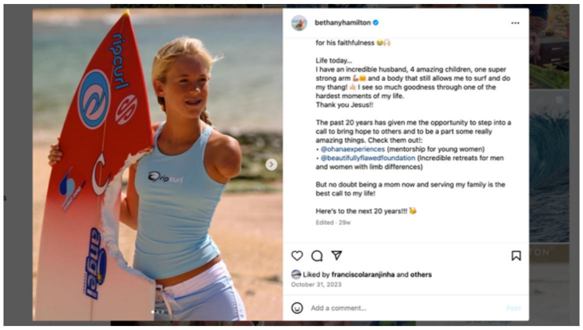
Another 42-year-old male quadriplegic participant reflected on a similar experience with motorbikes:

> *"Through my startup I have tried to launch my own solution for leather jackets because the jacket is the most difficult item to wear but at the same time the most important one with bad weather."*

As demonstrated here, the participants sometimes created new products and ventures for themselves to supply their needs and those in similar situations, thus showing proactivity and entrepreneurship.

Some instances of *co-creation* between disabled individuals and companies also emerged in which the two parties actively collaborated to create new products and services to cater directly to a disabled person's underserved desires. This is the case of BH's collaboration with Sharkbanz, an innovative virtual reality technology to visualize water dangers and deter sharks.

Data reveals that the creativity and innovation by newly disabled people can occur within existing communities (e.g., providing coaching activities) or lead them to enter new communities (e.g., coaching to anyone who wants to find inspiration and strengthen their mental health). Moreover, the individuals innovate both within the same industry (e.g., in sportswear, creating products and prosthesis for body injuries) and in new industries (e.g., offering retreats for those with body injuries and disabilities, and for anyone who wants to find inspiration and strengthen their mental health). The varying extent of innovation is shown in Figure 3 and outlined in Table 2.



bethanyhamilton

for his faithfulness 😭🙌

Life today...
I have an incredible husband, 4 amazing children, one super strong arm 💪🤗 and a body that still allows me to surf and do my thang! 👍 I see so much goodness through one of the hardest moments of my life.
Thank you Jesus!!

The past 20 years has given me the opportunity to step into a call to bring hope to others and to be a part some really amazing things. Check them out!:
• @ohanaexperiences (mentorship for young women)
• @beautifullyflawedfoundation (Incredible retreats for men and women with limb differences)

But no doubt being a mom now and serving my family is the best call to my life!

Here's to the next 20 years!!! 🥳

Edited · 29w

Liked by franciscolaranjinha and others
October 31, 2023

Add a comment...

Figure 3. BH's post on the new self, inventing new practices within the same and new communities

Community Industry	Existing community	New community
Existing industry	Creating products and services in same industry for those with body injuries and disabilities. E.g., coaching activities for disabled people	Creating products and services in the same industry for anyone who wants to find inspiration and strengthen their mental health. E.g., coaching activities for anyone
New industry	Creating products and services in new industry for people with bodily injuries and disabilities E.g., becoming artists #disabledartist **246,467** posts E.g., Becoming dancers in a wheelchair E.g., Start traveling and seeing the world - #disabledtravel **36,497** posts.	Creating products and services in a new industry for anyone who wants to find inspiration and strengthen their mental health. E.g., providing retreats; arranging travel; meditation; dietary programs for anyone

Table 2. New practice innovation

Our data also show that in this phase individuals may serve to inspire non-disabled people, through their expression of happiness and gratitude. For instance, our 46-year-old female participant with vitiligo explained her experience with interacting others:

> *"When vitiligo became more obvious, people started to stop me. For instance, once in the shopping mall a woman approached me, and she was quite shy, and she asked me what I do for my disease [as] she had the same disease, but it was just starting. She said she would try some stuff and let me know if it helps her. So, she saved my phone number and from then on when she tries some supplement or something else, she texts me. And for example, when I was having a blood test, the nurse who was doing blood work also had vitiligo and she also asked me the same thing. It's not like I searched for them, it is random."*

This participant reveals her openness to others in this phase. This phase is when participants share the most on social media and typically involves positive feelings and actions, including sharing daily successes and family-related achievements (e.g., getting married, having kids, going on trips with friends, getting a job). It is also reflected in the vocabulary and hashtags used (#disabledandcute 259,129 and #disabledandproud 135,770), names of the profiles, bios, and self-presentations. Most of the analyzed profiles talked about their disability either verbally or by using emoticons such as 👩‍🦽, 🦿, 👩🏿‍🦯. They also use positive phraseology such as "confidence," "empowerment," and "advocacy", and hashtags like #bodypositive and #bodyimage.

They act as inspirational role models, proudly representing their existing and new communities. Indeed, they became influential and tapped into disabled communities (e.g., families with disabled kids; disabled communities) or became influential for the general, able-bodied public.

5. Discussion

The findings provide a nuanced understanding of the coping process toward a new identity that users with disabilities experience. This process unfolds in four distinct phases - after incident, recovering, back home, and a new self - each encompassing specific feelings and actions. Our analysis highlights the central role of social media in this journey, particularly emphasizing the positive phases of recovery and "new" identity formation, inspiring others both within and outside their communities. On the other hand, social media activity during more negative phases, such as immediately *after incident* and *back home* is limited, often focusing retrospectively on the hard times they lived through, and the critical support provided by family and friends during those stages. This suggests that while social media plays a role in sharing experiences, the intense nature of these phases may lead victims to rely more heavily on their immediate in-person support networks.

Social media provide users a place to voice their experiences and interact with their (and others') communities, thus becoming a vital platform for sharing progress and receiving encouragement during the journey. It is a platform to crystallize their feelings and actions across each phase of the journey toward a new identity. Our findings reveal that once the newly disabled people have overcome the shock, they find new ways to move on with life and accomplish the same tasks they were doing prior to the incident, but in different ways. Thus, they accept and embrace their new positive disabled identities. After accepting their situation, most of them prefer not to be labeled or identified as "disabled," especially if they continue living their lives (e.g., sports, work, dating, or commuting) in ways like their pre-accident selves. They produce new discourses and vocabularies about disability that can challenge traditional stereotypical views. This is especially the case once disability becomes an internalized part of their identity, and this formative experience becomes an unexpected resource for their self-development. Impairments lose their negative meanings and evolve into constructive identity traits. Being part of an experience and discursive construction, they become a powerful tool to oppose the dominant logic of ableism. This is often accompanied by victims starting entrepreneurial activities, producing their own products, or urging companies to offer products and services that cater to their needs and those of others experiencing similar challenges. The narrative of self-understanding and reconfiguration toward a rejuvenated sense of being, coupled with the creative endeavors, are elevated as resources that can inspire any person facing difficulties, mourning and grief that go beyond disability.

Another critical aspect of our analysis is the revelation of empowerment and advocacy that social media facilitates. People with disabilities utilize social media platforms to raise awareness, advocate for policy changes, and educate the public about the challenging realities of living with disabilities and physical differences. This advocacy is not only personal but also communal, as they connect with others facing similar challenges, forming support networks, and starting a collective action for the betterment of the broader society.

In conclusion, the journey toward rebirth and a new identity formation for people with disabilities is deeply intertwined with social media's affordances to provide a platform for representation, expression, support, and innovation. Furthermore, it plays a crucial role in advocacy and raising awareness, contributing to a more expansive change in the societal perception toward disabilities. Through social media platforms, people with disabilities not only redefine their own identities but also influence the discourse surrounding disability, revising the traditional view of a tragic fate that disqualifies, restricts, or totally excludes, and instead promote a vision that highlights inclusion and active participation in the public sphere both offline and online.

6. Managerial and policy implications

Data revealed a promising market segment concerning underserved disabled people. Companies should consider designing and supplying products to facilitate new practice needs. This could greatly benefit the companies' image concerning diversity, equity, inclusion, and accessibility. The degree of product innovativeness needed to cater to this market segment may be only incremental, as often companies could position new products targeting both abled and disabled consumers (e.g., in the case of kids' toys, and some garments, including jewelry, watches, and makeup). Our findings emphasize the benefits for companies to co-create with the members of this market segment, especially if they are niche entrepreneurs who know the challenges and needs of this underserved minority. Finally, our analysis offers a blueprint for managers on how to innovate in new and existing products. This can be applied to product and service innovations and extended from incremental to disruptive innovations across multifaceted industries. Indeed, companies that can recognize and engage with this evolving landscape could foster meaningful connections and drive innovation that aligns with the needs and aspirations of this resilient community.

Moreover, the policy implications of this research include the advocacy for inclusive media representation, the implementation of robust anti-harassment policies by social media platforms to support individuals with disabilities, the promotion of algorithmic fairness to prevent biased content suppression that could disproportionately affect disabled users, and the provision of incentives for inclusive consumer products and services.

7. Limitations and future research

While this study offers valuable insights into the coping process and profound identity transformation of people with physical disabilities and differences on social media, acknowledging the limitations that accompany these findings is crucial. In our netnographic study, we analyzed only public accounts, which predominately represent "the new self" stage, specifically of people with acquired physical disabilities. As we analyzed the posted content of the users, the activity of the "readers" or the "silent users" was not part of this inquiry but can become an important investigation in the future. Furthermore, people with acquired intellectual disabilities may warrant future research to provide a broader understanding of the reconfiguration of the "new self" across different types of disabilities. While Instagram was the sole platform used in this study, it is worth noting that the affordances of other platforms (e.g., YouTube, TikTok, or Reddit) could offer unique alternative perspectives.

Netnography provided valuable insights into this research topic; however, ethnography could contribute further value by investigating the physical lifeworlds of the people being studied. Our study included predominantly female users, thus we strongly suggest expanding gender diversity in future studies.

Furthermore, our research captures a cross-sectional snapshot of user activities and posts at a specific point in time. While this approach has its merits, a longitudinal study would be more effective in capturing how the coping process and identity transformation evolves over time.

8. References

Argan, M. T., Argan, M., & Özer, A. (2016). A Netnographic Study on Virtual Community of Patients with Spinal Cord Injury (SCI) in Turkey. *İnternet Uygulamaları ve Yönetimi Dergisi*, *7*(1), 31-43.

Baumeister, R.F. (1999). Self-concept, self-esteem, and identity. In V. J. Derlega, B. A. Winstead, and W. H. Jones (Eds.), *Personality: Contemporary Theory and Research*. Nelson-Hall Publishers, 339-375.

Belk, R.W. (1988). Possessions and the extended self. Journal of Consumer Research, 15, 139-168.

Blake, M. (2024). *Beautiful People: My Thirteen Truths About Disability*. New York: Hachette Books.

Bogart, K. R., Lund, E., & Rottenstein, A. (2018). Disability pride protects self-esteem through the rejection-identification model. *Rehabilitation Psychology, 63*(1), 155-159.

Bogart, K.R. & Dunn, D.S. (2019). Ableism Special Issue Introduction. Journal of Social Issues, 75(3), 650-664.

Borgström, Å., Daneback, K. & Molin, M. (2019). Young People with Intellectual Disabilities and Social Media: A Literature Review and Thematic Analysis. Scandinavian Journal of Disability Research, 21 (1), 129-140.

Bruner, M., Rietdijk, R. & Togher, L. (forthcoming). Training Resources Targeting Social Media Skills to Infor, Rehabilitation for People who have Acquired Brain Injury: A Scoping Review. Journal of Medical Internet Research.

Carel, H. & Kidd, I.J. (2020). Expanding transformative experience. European Journal of Philosophy, *28*(1), 199–213.

Cavusoglu, L. & Belk, R.W. (2024). How to make a collaborative videography using Phygital affordances to study sensitive topics. Qualitative Market Research, 27(3), 413-432.

Cavusoglu, L., & Atik, D. (2023). Extending the diversity conversation: Fashion consumption experiences of underrepresented and underserved women. Journal of Consumer Affairs, 57(1), 387-417.

Chan, A. & Lempp, H. (2018). Garment+: Challenging the boundaries of fashion for those with long-term physical disabilities. The Journal of Dress History. 2(1), 26-43.

Collabstr (2023). 2023 Influencer Marketing Report: Influencer Marketing Statistics, Trends, and Predictions. https://collabstr.com/2023-influencer-marketing-report

Cusforth, Z. (1951). Academic value of research participation by undergraduates. American Psychologist, 41, 317.

Didden, R., Scholte, R., Korzilius, H., De Moor, J., Vermeulen, A., O'Rielly, M., Lang, R., & Lancioni, G. (2009). Cyberbullying among Students with Intellectual and Developmental Disabilty in Special Education Settings. Developmental Neurorehabilitation, 12 (3), 146-151.

Dirth, T.P. & Branscombe, N.R. (2018). The social identity approach to disability: Bridging disability studies and psychological science. Psychological bulletin, 144(12), 1300-1324.

Entwistle, J. & Wilson, E. (2001) *Body dressing*. Berg, Oxford, England.

Falchetti, C., Ponchio, M.C. & Botelho, N.L.P. (2015). Understanding the vulnerability of blind consumers: adaptation in the marketplace, personal traits and coping strategies. Journal of Marketing Management, 32 (3-4), 313-334.

Farquhar, M. (1995). Definitions of quality of life: A taxonomy. Journal of Advanced Nursing, 22, 502-508.

Glaser, B.G. & Strauss, A.L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Mill Valley, CA: Sociology Press.

Guest, G., Bunce, A. & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. Field Methods, 18(1), 59-82.

Hartblay, C. (2020). Disability expertise: claiming disability anthropology. Current Anthropology, 61(S21), S26-S36.

Higgins, L. (2020). Psycho-emotional disability in the marketplace. *European Journal of Marketing*, *54*(11), 2675-2695.

Higgins, L., Husemann, K. C., & Zeyen, A. (2024). The disabling marketplace: towards a conceptualisation. *Journal of Marketing Management*, *40*(5-6), 371-377.

Kozinets, R. V., Cavusoglu & Belk, R. W. (2024). Transformative Netnography: Combining Representation, Social Media, and Participatory Action Research. In: Proceedings of the 57th Hawaii International Conference on System Sciences. pp. 2298–2307.

Lawless, M. T., Hunter, S. C., Pinero de Plaza, M. A., Archibald, M. M., & Kitson, A. L. (2022). "You are by no means alone": a netnographic study of self-care support in an online Community for Older Adults. *Qualitative Health Research*, 32(13), 1935-1951.

Markovic, J. (2022). Unchosen transformative experiences and the experience of agency. Phenomenology and the Cognitive Sciences, 21(3), 729-45.

Mason, J. (2002). *Qualitative researching.* (2nd ed.). Thousand Oaks, CA: SAGE Publications.

Moser, I. (2005). On becoming disabled and articulating alternatives: The multiple modes of ordering disability and their interferences. Cultural Studies, 19(6), 667-700.

Noble, C.H. & Walker, B.A. (1997). Exploring the relationships among liminal transitions, symbolic consumption, and the extended self. Psychology and Marketing, 14(1), 29-47.

Parsloe, S. M. (2015). Discourses of disability, narratives of community: Reclaiming an autistic identity online. *Journal of Applied Communication Research*, *43*(3), 336-356.

Peterson, H. (2017). The Use of Social Media by Adults with Acquired Conditions who use ACC: Current Gaps and Considerations in Research. Augmentative and Alternative Communication, 33 (1), 23-31.

Pothier, D. & Devlin, R. eds. (2006). *Critical Disability Theory: Essays in Philosophy, Politics, Policy, and Law*, Vancouver, BC: UBC Press.

Ratcliffe, M. (2019). The phenomenological clarification of grief and its relevance for psychiatry. In G. Stanghellini, M. Broome, A. Raballo, A. V. Fernandez, P. Fusar-Poli, & R. Rosfort (Eds.), *The Oxford Handbook of Phenomenological Psychopathology*. Oxford University Press.

Rosenberg, M. (1979). *Conceiving the self.* New York: Basic Books.

Saunders, B., Lansdell, G., Ericksson, A. & Bunn, R. (2018). Friend or Foe: The Media's Power to Inform and Shape Societal Attitudes Towards People with Acquired Brain Injury. Disability and Society, 33 (6). 932-953.

Södergren, J., & Vallström, N. (2023). Disability in influencer marketing: a complex model of disability representation. *Journal of Marketing Management*, *39* (11-12), 1012-1042.

Tenderich, A., Tenderich, B., Barton, T., & Richards, S. E. (2019). What are PWDs (people with diabetes) doing online? A netnographic analysis. *Journal of diabetes science and technology*, 13 (2), 187-197

Trindade, L. (2024). Disability is No Laughing Matter. A Critical Discourse Analysis of Disability Mockery on Social Media in Brazil. Canadian Journal of Latin American and Caribbean Studies, 49 (1), 22-36.

Upton, R.L. & Han, S.S. (2003). Maternity and its discontents: ''Getting the body back'' after pregnancy. Journal of Contemporary Ethnography, *32*, 670–692.

Walker, H. R., & Litchman, M. L. (2021). Diabetes identity: A mechanism of social change. *Qualitative Health Research*, *31*(5), 913-925.