

Conversations from the Margins: Disability and the Path to Inclusion

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Abstract

This perspectives piece offers an exploration of the daily lives of people with disabilities living in Quebec, through a series of personal accounts. More than just an academic analysis, it serves as an invitation to reflect on the role of disability in our society, the fragility of existence, and the strength that emerges from it. By highlighting the voices of those often reduced to study subjects (Guenther, 2009), this perspectives piece reclaims their humanity and advocates for the (re)introduction of real voices and bodies in social research (Edwards, 2020), essential to our human essence, as narrative shapes and gives meaning to human actions (Sarbin, 1986). The testimonies of Camelia, Wilbur, and Henry (pseudonyms) illustrate the complexity of living through migration and social isolation, employment discrimination, and the struggle against overwhelming medical diagnoses. Their stories reveal both the harshness of their reality and the beauty of everyday life, where resilience and hope are woven into the fabric of their days. Through their journeys, the piece reminds us that inclusion goes beyond physical accessibility, engaging social bonds, and mutual recognition.

Keywords

Disability, Daily Life, Inclusion, Resilience, Testimonials

Introduction

This perspectives piece compiles brief narratives about the daily lives of people with disabilities in Quebec. Rather than a traditional academic article, it invites reflection on disability, the fragility of existence, and the resilience that fills life with hope and solidarity. It highlights voices often reduced to subjects of study, as Guenther (2009) argues, “part of my commitment to my research stemmed from a desire to 'give voice' to a group that is often made invisible” (p. 414), offering depth and characterization that academic formats sometimes overlook (Engel & Munger, 2007). Scientific studies involving human participants often assign numbers or alphanumeric codes to them, seemingly to lend a more scientific tone to the research protocols.

Addressing disability, this piece captures a fundamental human contradiction: the tension between frustration and openness to the future. It tells of a young man who became a key advocate for inclusion after losing his sight, a young immigrant woman in a wheelchair experiencing a city that is physically accessible but socially isolating, and an elderly man relying on caregivers but determined to age at home with dignity. A common thread runs through these stories: the everyday, both overwhelming and beautiful, where simple hopes take shape. As Studs Terkel (2004) notes, “to survive the day is triumph enough for the walking wounded among the great many of us” (p.22).

Since 2022, I have interviewed about twenty people with disabilities in Quebec (Mansilla et al., 2024). This piece presents three key narratives illustrating the role of storytelling in understanding disability (Clandinin, 2016). Each protagonist has faced life-altering events and a common struggle:

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overcoming loss, facing discrimination, and moving forward. Camelia's migration story reveals a life between Morocco and Quebec, where social ties feel more restricted despite material comforts. Wilbur shares his experiences with workplace discrimination and the challenges of having a guide dog. Henry, defying medical prognoses, continues his life despite alarming diagnoses. In a society that values efficiency and autonomy, individualism often overshadows interdependence. Yet, these testimonies remind us that inclusion and solidarity are essential. The participants refuse to be marginalized and claim their rightful place in the community, advocating for a more inclusive Quebec. As Henry, 66, who has total paralysis, states: "You choose a car, a stove, a fridge, and then you choose the moment you're going to die because you're tired. Well, no, that's not how it works. You have to have a certain hope."

Methodology

This study adopts a narrative ethnography approach (Feixa et al., 2020; J. Mansilla et al., 2022; Russo, 2020) within narrative inquiry (Clandinin, 2016), using three in-depth, semi-structured narrative interviews (Jovchelovitch & Bauer, 2000) with individuals with disabilities. Their lived experiences—mobility, public transport, social interactions, and personal challenges—are analyzed through an experience-centered narrative approach (Creswell, 2013; Squire, 2013) and thematically coded using NVivo. Rooted in the idea that storytelling shapes identities and social experiences (Grard, 2017), this method reconstructs experiences based on participants' values and strategies (Feixa et al., 2020). Each interview serves as a self-contained case study while allowing for comparative insights. They all begin with the open-ended question: What have

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been the greatest challenges in your life course, and how has your entourage influenced your journey? At the same time, the narrative format enabled participants to shape their stories, allowing the questions to adapt to their lived experiences.

**1. "Ah, poor thing! She's a cripple, oh look! She's a limper." – Camelia
(51 years old)**

Camelia lives alone in a first-floor apartment of an old building in downtown Quebec, adapted for wheelchair users with remote-controlled doors. At fifty-one, she works for a local public institution, splitting her time between home and the office—the only workspace on her team designed for a wheelchair user. Several times a week, government-funded attendants help her clean her apartment. During my visits, a large bookshelf stands beside the dining room, filled with books on travel, neurocognitive therapies, and history. As she speaks, her hands trace the air, emphasizing her words. Her dark, radiant eyes—reminiscent of those who grow up near the Mediterranean—hold an intensity that makes every story she shares feel alive.

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I was born in Morocco, where I was the only girl in a wheelchair studying in the city. As my mother would say, in my condition, I was "the only crazy one who wanted to study." We were six children, three of whom had disabilities. Let's just say I was lucky to have an older sister and brother who were also disabled. I got the chance to see my future. My sister and brother had the same illness as me: muscular dystrophy. But my brother had type two, which means it started from birth. He never walked. My sister walked until she was ten, and that's when

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she dropped out of school. She finished all her elementary school and then stopped. I walked, yes, but I started using a wheelchair at 12 and stopped walking at 16. I could walk, I could stand, but it was too hard. I even stopped trying. It's a disease that attacks all the muscles, so the muscles of people weakened, not just the legs, but it started with the legs.

At eight, I would go to school, start running, and then fall. What I found really hard was that my parents, having two disabled children before me, never explained to me what the disease was, never. They were obviously lost with all of it, with the illness, but they didn't tell me that my sister had a problem, and that I was going to have it, and that I was even starting to have it! I didn't understand... I would fall, I was scared... and people, they would look at me. And I started noticing that people were starting to look at me. When I walked, I had to turn my foot to contract the muscle more and balance myself. So, I began to make compensatory movements, even with my hand.

How did you experience the gaze of others?

It wasn't just the illness, but society as well. There were those who called me a cripple, those who called me a limper, I would hear these words... People would say, "Ah, poor thing! She's a cripple, oh look! She's a limper." I was in a private school, lucky me! You know, because in public schools, the kids, the children, they would mock you. In the private school, there was a little more discipline, it was less obvious for them to insult me, there were rules, we had supervisors. Although it was difficult, it was less painful than being in a public school.

How did your school journey go?

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At the end of elementary school, I went to take my unified CM2 exam. It was an exam that, if you passed it, allowed you to move on to middle school, and then you would have high school. I walked. It was painful, but I did it. I was determined to walk until I couldn't walk anymore. And what happened was that I took the CM2 exam and ranked first in the whole city. I became very well-known [laughs].

For me, studies saved me. I remember my father came home with a newspaper in his hands, the city's newspaper, and my name was in it; I was the top student in the city. Even the governor of the city called my father to congratulate him, saying, "We'd like to meet this girl," and my father replied, "This girl has a walking problem, we don't even know if she'll continue her studies." And the governor said, "No, no question, she must continue, she is brilliant." It was a surprise for my parents. They were used to different things with my older sister and brother. For the older one, at a certain age, she had difficulty walking, so she stopped school. And my brother had never walked since birth. They expected the same from me, "Okay, she'll reach a certain age and then she'll stop, that's it." For my father, it was out of the question that I would stop, because the governor told him, "Well, if you need anything, I'm here"; but for my protective mother, it was, "Okay, but you're going to fall, it's not a good decision."

I did my first year of middle school. I walked. But it was really difficult, it was painful. I didn't have strength in my arm muscles to use crutches. So, what I did... I had two girls, it was special [laughs], I put one arm on one's shoulders, and the other arm on the other's shoulders. They helped me go to school. The school year started like in France, on September 15, but that year, I started in October, because they were waiting for all the classes that were on the second

floor to be moved to the ground floor. Yes, they moved all the classes downstairs. That was my first year.

Were there any accessibility improvements in your hometown?

Nothing. There was nothing adapted... imagine everything that's here (she thinks about Quebec), and take it all away [laughs]. The social services, all the organizations that were a little ahead, were for blind people, and for the deaf and mute. Honestly, nothing, we didn't even see it in the street. We would see beggars, for example, lying on the ground. I felt like people considered me a disabled person, a fool, or something like that. I had this anger. And I was going to show them that I was better than their children. That's all. It wasn't because I was super motivated by studying. Not at all [laughs]. It was just that. It was the anger, to show them that I had something better than their children. All the people who insulted me in the street, and all the people who said, "Ah, poor thing, poor cripple! She can't walk, poor thing."

2. "When I had my first child, I realized that I wouldn't be able to see them, as if I had lost my sight the day before." – Wilbur (44 years old)

We sit in a white-walled office in downtown Quebec. Two chairs, a computer, and a kitchenette—for heating meals and making coffee—fill the space. He speaks slowly, carefully weighing each word, attentive to my sentences and intonation. A woman, likely his colleague, brings him a coffee. As a leader within an association advocating for the rights of people with visual impairments, he

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carries himself with quiet wisdom. His words embrace life, echoing like a sage's voice in the mountains—thoughtful, resonant, full of heart.

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I lost my vision suddenly, I had an accident. It's been 27 years. I was 16. I was still in high school. I got hit by a train. So, that's how it happened, I lost my vision all at once. I had other injuries to take care of as well, but the rest healed up pretty well... I knew nothing about disability. I had seen, maybe in fourth grade, a blind person who came to my class to raise awareness. I had seen disabled people in situations like that. When I was young, I lived in Longueuil, near Montreal, so there was more diversity, of all kinds. These were things I had encountered, but from a distance. I didn't have anyone in my family with a disability or anything like that. So, it was really new, I jumped in headfirst, and it all happened at once.

I'd say it wasn't easy to adapt, but at the time, it was relatively easy. I think there was still a state of shock; I didn't fully realize what was happening to me, and I was well surrounded by my family and friends. I wasn't neglected or abandoned, I had support in my functional rehabilitation process, if I can put it that way. On the other hand, I'd say the psychological adaptation, even the grieving process, is something I went through later, it took me years to realize what I had lost. Over the years, you start facing your first discriminations, when you're looking for a job, when you're refused a taxi because you have a guide dog. When I had my first child, I realized I wouldn't be able to see them, and at that moment, I'd already been without my sight for about twelve years. It broke my heart, as if I had lost my sight the day before. That's when I became aware of

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it. It had always been there, but I didn't know it until I was confronted with it. The fact of not being able to see my children, I knew it would be like that, but when I didn't have them, I didn't miss it. I didn't have that awareness. Then, all the social roles assigned to men, fathers, workers, all of that. When you become a father, and at some point, you realize there are things you can't do, you can't give your kids a lift the same way others do... or when it comes to organizing a weekend activity, for example, you have to plan it with accessible transport, but it's complicated, it's slow. I'm used to it, but my kids aren't really. When it comes to roles, I became more aware of it when I separated because then, you're on your own, doing all sorts of things without support. Or you don't take your kids fishing because it's too complicated, but they go on a fishing trip with your ex's new partner. That hurts, honestly.

But, again, it took me some time to realize that because, at first, the kids are young, and things go okay, but when they're older, that's when you see that when you talk about activities: "It would be fun to do this!" and they say: "No, no, we're not really interested." And then you realize they're doing something they like, but with someone else, not you. What I understand in that is that the level of constraints associated with carrying out certain activities for me, they find it annoying. I'm very aware of that, but at the same time, it's just my life. But yeah, it's this realization that, for them, in those conditions, it doesn't interest them because all the aspects of accessible transport, planning, this and that, they don't need that in their lives. Now they're 12 and 15, they're teenagers who don't want to know too much about their parents [laughs]. Maybe when they're older, they'll be able to realize it a bit themselves.

How do you perceive the way others look at you in a society that's increasingly individualistic, where everyone is focused on their own affairs?

When it comes to disabled people, I've heard people say: "Oh my God, I wouldn't want to be in that situation." You know, there are social groups, like the LGBTQ+ rights, women's rights, all that, and everyone agrees with those. A person who claims certain rights for these groups, I think people feel some empathy. But when it's a pressure group trying to advance the rights of disabled people, I think people don't feel empathy but rather pity.

Let's talk about mental fear. There's physical fear, nobody wants to fall and hurt themselves, but there's also mental fear, the kind that keeps us from stepping out of our comfort zones.

That's true. And the less you do something, the less you're able to do it. I won't speak for all disabled people, but let's say that visually impaired people, in general, tend to be more socially isolated. The more isolated you are, the harder it is to step out of your cocoon when you want to do an activity with others. People lose their social reflexes, how to behave, even how to hold a conversation. I think the more isolated you become, at some point, you get more rigid about yourself and your problems, so it becomes more difficult to exchange with others because it becomes exhausting for them to talk to someone who just brings everything back to themselves and doesn't have much openness to other people's realities. It's no longer an exchange.

3. "They're going to make me die if they lock me in their institutions, I choose life." – Henry (66 years old)

I step through the garage door. A young, slender brunette smiles and asks me to wait in the living room. I sit in silence. The suburban house in Quebec feels still—until the hum of an electric wheelchair breaks the quiet. He approaches, nodding in greeting. His entire body remains paralyzed, except for his head. With a tilt of his chin, he grips the joystick with his mouth and steers his wheelchair to face me. His round eyes, full of curiosity, resemble those of a teenager. A whole wall swings open like a door. The young woman steps through and asks if he needs anything before leaving. "My girlfriend lives on the other side of the house, but we're still a couple," he says with a cheerful voice.

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What do you think about institutions for people with disabilities?

People with disabilities are locked up in long-term care centres (CHSLD). I will never live in a CHSLD, unless I have a stroke or something like that. I mean, if I'm no longer able to control myself at all or if my brain isn't functioning anymore, then they can put me anywhere. But if I were in an institution, I would already be dead. For sure. With the disability I have, if there's even a slight reduction in services, I would die because if I end up in an institution tomorrow morning, I'll end up with a catheter or a diaper. No matter how they try to make it more pleasant for people, it's still a diaper. And staying in my own waste for four or six hours is out of the question. I have all my sensitivity; that's my advantage. I have all my mind; that's the advantage of being a bit stubborn and knowing what I want. This way, I'm the one who leads my life, I choose the aides who come to help us,

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all that. These are our choices. We prepare the schedules, we handle the pay, all that. I cost much less to the state this way. It's my freedom. Freedom has a cost.

In my life, the cost I bear is taking care of my own matters, not letting myself be organized by social economy companies, CLSC, or anything like that. I may have them in my life because I'm forced to, but they don't govern my life. They're here because I have no choice. You have to feed these little creatures if you want [laughs]. I let them do their work, and I give my choices. We invest a lot of money in certain things, but at the same time, we deprive ourselves of freedom. Because in an institution, I would cost a lot more than 100,000 dollars a year. And right now, I receive about 65,000 dollars of services a year, and I live in my own home, which costs less. Freedom is also about taking your place as an individual in society, in the state. You pay taxes; I mainly pay taxes, fewer taxes because I don't work anymore, but when I worked, I paid taxes too. But I mean, because I cost less, I think I'm an economy for society, because society doesn't have the right to let me die, but they will make me die if they lock me in their structures. Well, I choose life.

We talk about assisted dying in many societies, what is your position?

I also don't choose assisted dying. It's outside of my concept of life. My freedom to live is much more important than my freedom to die. I don't want to decide to die because I'm fed up, I'm tired, or I'm worn out. I don't want to do that. Maybe I'll change my mind. Only fools don't change their minds, but that means I probably won't [laughs]. I've always thought: "If I get tired of life, I'll go somewhere where there's a cliff, where I'll drink alcohol, and I'll finish it. That's my choice, but asking for help to die, I'm not okay with that, personally. I'm open to what others want. I'm open to it. I have no problem with it. It's everyone's right

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to choose their end or their way of life, but for me, I don't see it that way, and I'm not ready to open a door to that yet. Maybe I'll open it, but probably by then it will be too late, and it will be done. It shouldn't become a trend to say, 'If something happens to me, I'll immediately ask for assisted dying.' I know I'll be considered retrograde in this, because society is evolving, and some people don't see the quality of life in every second of life. They see it in their autonomy; they don't see it in what an elderly, sick, struggling person might want to continue. They don't see it like that, because life is too easy for most people, and they won't find the value that's there.

For me, life is the most precious thing. There are people who commit suicide because their girlfriend left. Some people kill, that's another side. That might be more freedom, but I think it's more about: "She's not with me, she won't be with anyone." That's deciding for others, isn't it? We're in a society that doesn't truly value life. People are searching for meaning, and they're looking for it everywhere, in Buddhism, spirituality, crystal balls—they look everywhere, but the truth is within us, and we need to discover it, I think, at least. I sound like an old priest [laughs]. There's a search for meaning that might be going wrong or not happening at all. Meaning is too often placed on work, leisure, money—all sorts of reasons, everything that comes with money. It's become that if you don't succeed at work, you're nothing. That's not true. Everyone wants a certain ideal, but it often comes down to how many trips you take a year, the house, the car, the girlfriend, a dog, two cats. You know, you choose a car, you choose a stove, a fridge, and you choose when you're going to die because you're tired. Well, no, that's not how it works. You need to have some hope.

Fear of others, this feeling that shapes our relationships today...

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It's okay, the fear of others. For example, the people who work here, the aides who help me, I don't want to treat them like employees, even if the people responsible for my case at the government tell me, "You shouldn't do that, Henry." I talk to people, and I make sure I get along with them so that they feel good with us too. They, at the government, say to keep distance from the aides because they think you might always be exploited as a person, because you're the vulnerable one. I know I'm vulnerable, but that's not how I live. I don't live waiting for someone to come here and steal from me or abuse me, or whatever tragic aspect of human nature that may happen. Most people aren't like that. So, if it happens one day, it will, but up until now, it hasn't. With your fears, I mean, it's a way to die slowly, too. What I'm saying is for me. It's my way of living, my philosophy of life, if you will, but it's just mine; it doesn't belong to others [laughs].

How did your perspective on disability shape your approach to work, family, and community involvement?

I saw that there was work to be done, and when we're young, we're impulsive, and we go for it. So, I wanted to live like everyone else. That's always been my philosophy. I didn't want to live as a disabled person wanting special services and all that. I wanted to live like everyone else. That's always been the case. I have a daughter, four grandchildren, so for me, it's always been a normal life. For me, disability wasn't really something that stopped me from doing things like everyone else. No, I wanted to live like everyone else, that's always been my motto. Among the leaders of community organizations for disability, there was that same feeling, we shared an ideology more than the disability itself. It was about enabling everyone to develop, not just creating leisure activities.

When you see certain stereotypes on TV about what a happy, healthy, successful person should be, and you feel like it doesn't match you, what do you think?

That's it, if you look for the problem within yourself, you're in trouble because you'll slowly fall into something. But me, I look at others, and I say, "What do you want? If they think that way, so be it. I can't think that way." Like I said earlier, I had a child, and she gave me four grandchildren. I don't need much else. I have my girlfriend who lives just next door because we each have our own apartment, but we're still a couple. That's it, what more could I ask for? To eat two more shrimp every once in a while? Not even [laughs].

How do you see the link between old age and disability?

I'm both now, I'm both elderly and disabled. But I'm going to stay young until I die. But, I'm almost 66 now [laughs]. Before I was 20, my disability was equivalent to muscular dystrophy, which didn't allow me to evolve much physically. I was regressing practically from birth. I walked when I was 18 months old. Then, I walked a little sideways, and I walked until I was 11. Then, I ended up in a regular wheelchair. For me, it was a bit like liberation because instead of falling all the time, everywhere, in a wheelchair, I managed. I did a lot of things. There were just the architectural barriers of the time that prevented me from doing things, but as I was pre-adolescent, it wasn't something that bothered me, that made me less happy. I lived my young life, and I had fun, I had everything I needed. But around the age of 15 or 16, doctors told me I'd die before I turned 21. My parents didn't tell me, but they definitely knew. But then, because they did tests at that time, when I was about 16, they said, "Oh, you'll live until you're 53 or 55." They gave me a reprieve. But by the time I was 50, about 45, I was

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thinking, "I'm not going to die at 53 or 55." I kept the deadline in mind, and then I thought, "Ah, I have a little time left before I drop suddenly, like Christopher Columbus [laughs], at the edge of the planet." So I kept doing my things. It was more like, you won't take away my will to live. You won't take anything from me. I'm the one who's going to build my path. And I'll build one year, two years, I don't know. Ah, I never know. I could die in my bed tonight. So, I'd rather die in my bed tonight than in a CHSLD in two months [laughs]. But it's not up to me to decide. It's the sword of Damocles we all have over our heads. And we balance it with hope. The rest takes care of itself.

Discussion

The three narratives reveal common themes in the experiences of people with mobility disabilities, particularly in relation to autonomy, institutionalization, and the value of life. One of the strongest recurring themes is the struggle for independence. Each participant expresses, in different ways, a deep desire to make their own choices, whether in terms of transportation, living arrangements, or end-of-life decisions. This autonomy is not necessarily linked to the absence of impairments but rather to the ability to develop daily strategies that foster a sense of control and self-determination. This finding aligns with previous research emphasizing that quality of life in aging is not contingent on the absence of disability, but rather on the ability to maintain autonomy in decision-making and daily routines (Montross et al., 2006).

Another key theme is the impact of institutions on dignity and quality of life. All three participants reject the idea of living in institutions, emphasizing the loss of agency that accompanies such placements. For example, Henry articulates a

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powerful critique of long-term care facilities, associating them with a form of passive death. This sentiment is echoed in the other narratives, where participants express a preference for systems that allow them to manage their own care and mobility within an environment that supports autonomy, values its members, and provides accessible housing. The findings suggest that policies and support systems should prioritize enabling people with mobility disabilities to live in inclusive environments that promote self-determination and social participation rather than enforcing institutional dependency (The Conference Board of Canada, 2018).

The theme of societal attitudes toward disability and aging also emerges. The participants challenge common stereotypes about aging with a disability, rejecting the notion that old age necessarily equates to decline and dependency. However, their narratives reveal how accessibility barriers continue to restrict their full participation in society. This is consistent with previous research showing that restrictions to social participation are primarily due to accessibility barriers rather than individual impairments (Best et al., 2022; Mahmood et al., 2020). The participants' experiences confirm that enhancing accessibility fosters a sense of inclusion and supports the full participation of people with disabilities in their communities (The Conference Board of Canada, 2018).

Finally, there is an underlying discussion about the role of hope and self-determination in shaping one's life trajectory. Whether it is Henry's refusal to be defined by institutional frameworks or the other participants' insistence on crafting their own mobility solutions, these stories illustrate a resistance to passive acceptance of structural constraints. This supports the broader argument that autonomy in aging with disabilities is not about the absence of impairments but

about the ability to make meaningful choices within an enabling environment (Montross et al., 2006).

Conclusion

The narratives of these three individuals highlight the complexities of living with a mobility disability in a society that still struggles to provide inclusive environments. Their stories illustrate a clear preference for independent living arrangements and the need for policies that prioritize personal agency over institutionalization. They also challenge conventional ideas about disability and aging, offering perspectives that emphasize self-determination, dignity, and the fundamental human desire to live on one's own terms. Rather than viewing disability solely as an individual experience, we must recognize it as a collective issue that requires rethinking not only the physical aspects of accessibility but also the creation of a path toward inclusion without barriers—one where narratives from the margins have a space for social participation, free from ageism and ableism.

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