

UNDERSTANDING RISK IN DAILY LIFE OF DIVERSE PERSONS WITH PHYSICAL AND SENSORY IMPAIRMENTS

¹Afnen Arfaoui, ²Geoffrey Edwards, ³Ernesto Morales, ⁴Patrick Fougeyrollas

^{1,2,3,4}Laval University, Quebec, Canada

¹ORCID: orcid.org/0000-0003-4219-2031

¹afnen.arfaoui.1@ulaval.ca, ²geoffrey.edwards@scg.ulaval.ca,

³ernesto.morales@fmed.ulaval.ca, ⁴patrick.fougeyrollas@cirris.ulaval.ca

Received: 2018-08-08 | Accepted: 2019-04-09 | Published: 2019-05-31

Abstract: Managing risk of injury in daily life is a task common to all humans. However, people with impairments face significantly greater challenges in both assessing and managing risk of injury. To find out more about how individuals with impairments understand risk, we developed a qualitative study design based on semi-structured interviews. Seven people with a broad range of impairments were recruited for the study. The interviews were analyzed and organized into a codification tree subdivided into four main sections: safety and risk management, risk situation portrayal, perceptions of safety measures and finally loss of control and strong sensations. The study revealed that the difficulties related to managing risk in day-to-day situations are much higher than for people without impairments and, indeed, are possibly under reported in the literature. The realization that risk is ever present in the daily lives of people with impairments has led us to reconsider how we move forward on the remainder of our study.

Keywords: people with impairments, risk perceptions, decision-making process, risk management and assessment.

Introduction

As part of a broader project seeking to determine a process for designing immersive and interactive installations that address issues of disability, we sought to understand how people with impairments perceive risk of injury. Part of our logic was both to accommodate the needs of people with impairments in terms of risk management when designing safe installations, but also with the additional perspective of designing installations that focus on the experiences of people with impairments. The problem of understanding risk and personal safety is itself a complex issue. Although other studies have suggested ways of ensuring safety from a functional perspective, few have focused on the perceptions of risk experienced by people with impairments themselves. Such studies may also potentially have benefits for designing services that better serve people with disability, as well supporting the process of rehabilitation and the training requirements following a sudden change in life situation.

Managing risk of injury in daily life is a task common to all humans. Children are taught to be aware of such risks and to develop management strategies. Because the task involves executive function (planning, judgement, decision-making), mastery of safety management strategies often occurs later than other functions - sometimes significant learning in this area is still going on in mid to late adolescence (Fänge et al., 2002). The process requires a form of environmental scanning, knowledge of the self and our own limitations, memories of past experiences (Cree & Kelloway, 1997; Greening, 1997), and often involves lifestyle choices (Edwards, 1961). Personal perception of risk plays a key role in the development of an effective strategy, which will likewise vary significantly from one individual to the next (Slovic, 2016). Thus, it is largely subjective (Landry, 2006). Furthermore, Flin et al noted that cultural, social, physical, political, and psychological factors each contribute to how an individual perceives risk and behaves in response to it. In other words, risk perception is multidimensional (Flin et al., 1996; Landry,

Arfaoui, A., Edwards, G., Morales, E., & Fougeyrollas, P. (2019). Understanding Risk in Daily Life of Diverse Persons with Physical and Sensory Impairments. *Journal of Accessibility and Design for All*, 9(1), 66-89. doi:<http://dx.doi.org/10.17411/jacces.v9i1.183>

2006). Researchers from different fields have focused on understanding human behavior in the face of hazards and how it can influence the day to day decision-making process (Edwards, 1961). Decisions are contingent on many factors (Edwards, 1954), indeed, they occur normally in sequences in response to changing circumstances and situations.

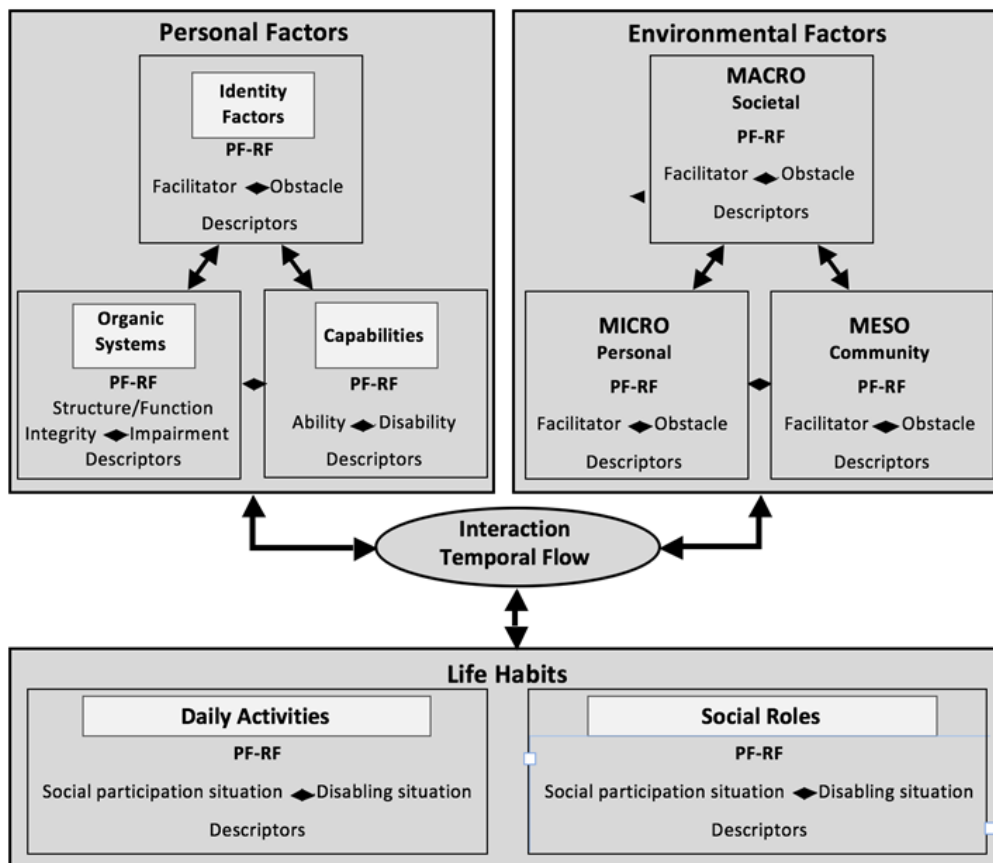
However, people with impairments face significantly greater challenges in both assessing and managing risk of injury. An everyday task such as crossing the street may seem easy for many people but it can become a complex and dangerous task for people living with impairments. Indeed, studies indicate that visually impaired (Cheong et al., 2008) or fully blind (Ashmead et al., 2005) pedestrians are more likely to make unsafe decisions compared to sighted pedestrians (Hassan, 2012). The ability to carry out this task is dependent on both impairments of the individual as well as the risk situation itself (Landry, 2006). People with disability are more often confronted with high risk situations and their reactions to risk are mediated by many factors. However, the literature on how people with disability handle risk management is inadequate - much of the work described above addresses the processes carried out by people without significant impairments. We hope this paper will encourage others to pursue this area of inquiry.

In this paper, we present a study which sought to better characterize the perception of safety risks across a broad range of impairments. We adopted a qualitative research methodology. Seven individuals were recruited to provide information about their daily struggles with risk and risk management strategies. The outcomes of this exploratory study will feed into the design of a series of immersive and interactive installations (Genest, 2014). Furthermore, we draw on the Disability Creation Process (DCP) model as a way of framing our study. The Disability Creation Process (DCP) (Fougeyrollas et al., 1998; 2019) offers a robust model for understanding disability and its relationship to personal aptitudes and environmental factors. It does so in a way that is formulated differently than the International Classification on Functionality, Health and Disability (ICF)

Arfaoui, A., Edwards, G., Morales, E., & Fougeyrollas, P. (2019). Understanding Risk in Daily Life of Diverse Persons with Physical and Sensory Impairments. *Journal of Accessibility and Design for All*, 9(1), 66-89. doi:<http://dx.doi.org/10.17411/jacces.v9i1.183>

(WHO, 2001; Levasseur et al., 2007; Whiteneck & Dijkers, 2009; Fougeyrollas, 2010). In particular, the DCP formulates the relationship between the person and the environment as a function of their Life Habits. Within the DCP model, the notion of Life Habits refers to the social activities that a person engages on a daily basis, along with the social roles that he or she adapts in a particular sociocultural context and according to his or her characteristics (age, gender, identity, etc.) (Fougeyrollas et al., 1998 ; 2019). The concept of Life Habits is one of the significant features of the DCP model, in fact it is the bridging concept that brings together its different elements (see Figure 1).

Figure 1. Human Development Model and Disability Creation Process (HDM-DCP 2) (Fougeyrollas, 2010)



Legend :
 PF-RF : Protective Factor - Risk Factor

© INDCP 2010
 www.ripph.qc.ca

Arfaoui, A., Edwards, G., Morales, E., & Fougeyrollas, P. (2019). Understanding Risk in Daily Life of Diverse Persons with Physical and Sensory Impairments. *Journal of Accessibility and Design for All*, 9(1), 66-89. doi:http://dx.doi.org/10.17411/jacces.v9i1.183

It appears directly evident, based on the interviews we undertook, that risk management is articulated in terms of a person's Life Habits, and therefore the DCP model appears to provide a particularly suitable framework for this work. Furthermore, the mismatch frequently observed between personal capabilities and environments highlights the situation whereby poorly designed environments may exacerbate risk of injury for people with impairments (Fougeyrollas, 2010). The aims of the present paper are therefore to examine the perception of risk and the decision-making process involved in accommodating such risk among people with impairments, using the DCP model to provide a structuring theoretical framework.

Methodology

We began by recruiting and interviewing a broad range of people with impairments, using a set of structured questions to elicit relevant information. We then analyzed the interviews in order to identify risk factors (Short 1984) affecting people with impairments and then situate these within the DCP model. Against this background, we explored in more detail how people with impairments experience risk (Taylor & McKeown, 2013). Rather than focus on a particular disability profile, we explored this question across a broad range of disabilities, using a qualitative study design based on semi-structured interviews (Denzin & Lincoln, 1994). The study size was limited because of the exploratory nature of the work. We originally aimed to select nine participants - three people each with motor, sensory and cognitive disabilities. However, due to difficulties with recruitment, seven people were ultimately interviewed.

Participants were recruited using a variety of means: the different clinical programs of the Institut de réadaptation en déficience physique de Québec (IRDPO) -- that is, the motor, visual and hearing impairment clinics - and via the Regroupement des organismes de promotion 03 (ROP 03) which is the official association for the promotion and defense of the rights and the

interests of people with impairments in the Quebec City region. Additional inclusion criteria were that the participants be able to engage in verbal exchanges. Of the seven persons who took part in the study, five had reduced mobility (walker, manual wheelchair or motorized wheelchair), one was visually impaired and one was hearing-impaired. All were aged between 30 and 59 years. Tables 1 and 2 present in summary form, the pathologies of the participants and their demographic characteristics.

Table 1. The pathologies of the participants

Impairments	#
Visual impairment	1
Hearing impairment	1
Ehlers-Danlos	1
Osteogenesis imperfecta	1
Congenital limb deformation	1
Spinal cord injury	2
Total	7

Table 2. The demographic characteristics

Sex	Men	4 (57%)
Sex	Women	3 (43%)
Age	30-39 years	2 (29%)
Age	40-49 years	2 (29%)
Age	50-59 years	3 (43%)
Civil status	Single	6 (86%)
Civil status	Cohabitation	1 (14%)
Civil status	Married	0 (0%)
Civil status	Divorced	0 (0%)

Arfaoui, A., Edwards, G., Morales, E., & Fougeyrollas, P. (2019). Understanding Risk in Daily Life of Diverse Persons with Physical and Sensory Impairments. *Journal of Accessibility and Design for All*, 9(1), 66-89. doi:<http://dx.doi.org/10.17411/jacces.v9i1.183>

Civil status	Widowed	0 (0%)
Children	Yes	4 (57%)
Children	No	3 (43%)
Education	Primary school	0 (0%)
Education	High school	1 (14%)
Education	College	2 (29%)
Education	University	4 (57%)
Annual family income	0 - 19 999\$	3 (43%)
Annual family income	20 000 - 39 999\$	3 (43%)
Annual family income	40 000 - 59 000\$	0 (0%)
Annual family income	60 000\$ - +	1 (14%)

Interviews, as indicated earlier, followed a semi-structured format. This allowed us to present a series of targeted questions designed to explore issues of personal safety, risk-taking and risk perception. The interviews varied in duration between 90 and 120 minutes. Socio-demographic information (see Tables 1 and 2) was first collected via a separate form. The rest of the interview was subdivided into three sections: (a) Safety and risk management; (b) Loss of control; and (c) Experiences of vertigo. The questions regarding vertigo were related to a particular feature in the proposed design of the interactive installations. To assist participants to understand the context of the study, two videos were presented, one at the beginning of the first section and one at the beginning of the last section.

The principal questions addressed in the first section of the questionnaire, were: What does risk mean to you? Do you consider yourself to be someone who takes risks? How do you expose yourself to risk? How do you react in a situation where you are exposed to danger? What are some of the challenges in daily life as a person with impairments that can expose you to risk? Do you consider being attached (e.g. via the arms or legs), a measure of safety or a

removal of your freedom of movement? For the second section, dealing with loss of control, typical questions included: What does loss of control represent for you? How interested are you in thrill-seeking and strong sensations (such as a roller coaster, skydiving, bungee jumping, even descending a steep slope in a wheelchair)? And for the final section, concerned with vertigo: Do you encounter vertigo in your day to day life? Have you ever experienced situations that involved adrenaline reactions and feelings of vertigo? Note that the interviews were carried out in French.

All sessions were audio recorded and then transcribed verbatim. To facilitate analysis, the transcripts were systematically coded (Denzin & Lincoln, 1994) and then analyzed with the NVivo software (Gibbs, 2002; Chowdhury, 2015). The collected data were sorted qualitatively and categorized within a range of analytical strategies (Tracy, 2010; Maxwell, 2012). This categorization produced a rich description of the study themes and was used to generate a set of codes related to the different sections of the questionnaire, as mentioned earlier. To refine the coding process, several meetings of the study team were held to discuss the code, sub-codes and the coding tree.

The diversity and the richness of the answers during the interviews generated more data than originally expected, which fed the coding process. In fact, defining the main codes was the hardest step of the analysis process. We introduced assessment criteria based on efficiency and relevance to determine whether or not the codes contributed to the understanding of the issues addressed. In addition to the selection criteria that we predefined - such as the singularity of the experience (Edwards et al., 2014), its diversity and the body-environment relationship (Kennedy, 2012) we added more specific criteria such as past experiences and how this can affect the decision-making process, to avoid duplication and improve clarity.

For the final coding tree, we identified four main codes; each of these was later further divided into sub-codes. In the initial stage, more than ten sub-codes were identified for each main code, so we had to eliminate less

important data and focus on the most meaningful categories to ensure the study results were robust and contributed to the understanding of the decision-making process of people with impairments. Table 3 presents the resulting codification tree which summarizes the different themes of the study, each of which will be presented in more detail in the following section.

Table 3. The coding tree

Codes	Sub-codes
Safety and risk management	Assessment phase Adapting the lifestyle Avoiding the errors of the past
Risk situation portrayal	Inaccessible environment Exceeding physical limits Living with an impairment
Perception of safety measures	Increasing the risk of injury Essential elements to ensure safety
Loss of control and strong sensations	Adrenalin Stress and anxiety Vertigo

Results of the coding exercise

The final four main codes were: (a) Safety and risk management, illustrating how people with impairments manage risk - especially on a daily basis; (b) Risk situation portrayal, which describes specific situations confronted by people with impairments that could lead to serious injuries or unsafe decisions; (c) Perception of safety measures, which seeks to determine whether or not people with impairments accept to be overprotected and how they interpret safety measures; and (d) Loss of control and the

Arfaoui, A., Edwards, G., Morales, E., & Fougeyrollas, P. (2019). Understanding Risk in Daily Life of Diverse Persons with Physical and Sensory Impairments. *Journal of Accessibility and Design for All*, 9(1), 66-89. doi:<http://dx.doi.org/10.17411/jacces.v9i1.183>

development of strong sensations, including a range of reactions occurring when people with impairments lose control or face an unusual situation.

Code #1: Safety and risk management

The issue of personal safety is a matter of urgent necessity in the daily encounter with challenging situations for people with impairments. In fact, all of the female participants said that it is difficult to manage, in addition to the risk of injury itself, also the stress caused by it. This problem of dual management appears to be the primary reason why all the participants developed a structured decision-making process to ensure their own safety. Furthermore, the process thus determined varies from one person to another. For some people, this process had become concrete through simple daily actions. All participants agreed that the first step must be an assessment phase. This consists of measuring the risk and determining appropriate responses in the most efficient manner. During the assessment phase, a variety of factors needs to be taken into account, including physical boundaries, the nature of the environment, the available time, the person's pathology and their past experience. These factors vary from one person to another and lead to different decisions and prioritizations of issues.

- [...] you just go with your instincts on finding the way. Crossing the street may look like an easy thing to do, but not for me. I have to think about everything, my steps, the people and the cars around me. I have to trust my intuition. (Man: Visually impaired; free translation)
- [...] To grab something from the fridge, I have to think through all my actions otherwise I can find myself (my wheelchair) caught between the kitchen table and the dishwasher. (Woman: Congenital limb deformation; free translation)

People with impairments adapt their lifestyle and their body to their level of functioning to avoid being in risk situations. In fact, according to the five individuals with motor impairments, it is important to have their wheelchair

customized to better suit their mobility needs and their lifestyle, whether they live in the city or in the country, and regardless of the type of wheelchair used. Indeed, the choice of the wheelchair (e.g. powered or not) is also usually a result of this decision-making process. These decision-making processes accompany what we call the risk assessment phase. People with reduced mobility think through, logically, possible risks and ways of tackling them as well as potential consequences, then make their decisions based on this assessment in order to choose the right wheelchair and even particular lifestyle choices:

- [...] This year is going to be my 20th in a wheelchair. I used to live in the suburbs of Quebec where I chose to use a manual instead of a motorized wheelchair. I only needed to move around my area, to run errands. Once I moved to Quebec City, I had to change my wheelchair and get a motorized one to get around safely. (Man: Spinal cord injury; free translation)

People with impairments manage to ensure control over high-risk situations generally as a result of being conscious of their functional limitations as well as relying on their ingenuity and survival instincts. Indeed, the female participants of the study reported that a lack of self-confidence could lead to a lack of independence in certain situations and hence increase dependency on others. They, therefore, learned to “listen to their bodies” and to adjust to their functional limitations.

- [...] I used to go to the park for a walk every Sunday for an hour. It may seem that an hour is not that much time, but believe me time passes slowly and it feels like forever. Don't get me wrong I enjoy spending that time, but sometime I regret even going out. Managing my walker and walking in the same time drains my energy. I found myself exhausted, incapable of thinking about my own safety [...]. I know now that I can't go alone, and that my body has its limits that I have to respect. (Woman: Ehlers-Danlos syndrome; free translation)

Arfaoui, A., Edwards, G., Morales, E., & Fougeyrollas, P. (2019). Understanding Risk in Daily Life of Diverse Persons with Physical and Sensory Impairments. *Journal of Accessibility and Design for All*, 9(1), 66-89. doi:<http://dx.doi.org/10.17411/jacces.v9i1.183>

Also, people typically learned from past experience to avoid repeatedly being in a similar risk situation. Ensuring that problematic situations did not re-occur was a high priority. Both men and women declared that they succeeded in preventing dangerous situations by avoiding repeating the same mistakes they made in the past. This memory scanning process appears to be part of the assessment phase:

- [...] When I was young, I used to go often to the swimming pool with my brother to play with him. I used to get into the pool via stairs until I learned that my little brother jumps into the pool, so I had to do it too. What I forgot is that jumping without seeing where to land can be dangerous, which it was. I did it, I jumped without knowing where I was going to fall and I got injured in my legs. Since that day, I learned that what I had done wasn't safe and I never did it again. (Man: Visually impaired; free translation)

Code #2: Risk situation portrayal

The interviewees identified their impairments as one of the main causes for being in risk situations. Based on their experiences, they associated risk in everyday life with their impairments combined with their interaction with the environment. Indeed, the majority of participants mentioned how every time they went beyond their physical limits, they found themselves in a vulnerable situation. These were usually situations in which they had to overcome obstacles in relation to their impairments.

- [...] Every time I go to the park with my two disabled kids is a challenge. Both of my kids use manual wheelchairs, so I have to assist them throughout the day which is no simple task, since I use a walker myself. It is difficult for me to manage my own safety as well as that of my kids. Pushing my children's wheelchairs and moving at the same time exceeds my limits and exhausts me physically. (Woman: Congenital limb deformation; free translation)

- [...] When I was younger, I used to go to the swimming pool from time to time for relaxation, a few lengths or maybe an aqua gym class, the pool was the perfect place to spend my free time. Today, I'm aware that spending that much time in the swimming pool can be dangerous. [...]. Going beyond my physical limits is a risk that can cost me my life. (Woman: Ehlers-Danlos syndrome; free translation)

Based on these observations, we may posit that the second phase of risk management is the development of a structured decision-making strategy. Some people do this consciously, and others rely on spur of the moment contexts to develop appropriate decision-making practices.

Regardless of whether people with impairments manage their lives by adopting a decision-making strategy or constantly assessing every movement and situation, they still find themselves frequently in high-risk situations - situations that are beyond their control or limits, often causing severe injuries and emotional disturbance. All the interviewees considered that living with an impairment cannot be completely controlled and because of this, it is impossible to predict what the future holds and what can happen when encountering obstacles or even waking up every morning to go to work. Simple activities such as eating or getting dressed are normally taken for granted, but for a person living with an impairment, having to adjust her movements constantly involves some risk of getting injured or harmed.

- I don't think that living is a risk [...], however, I am aware that even if the environment is adapted to my needs and let's just say that there is no way that I can get hurt, I will still get myself into a highly risky situation. (Man: Osteogenesis imperfecta; free translation).

A third stage of risk management is, therefore, the process of adapting responses to challenges thrown up by the environment, and a fourth appears to be the management of strong feelings aroused by the challenges faced. Environmental challenges constitute an essential part of our overall understanding of risk and its perception (Sparf, 2016). In fact, inaccessible

Arfaoui, A., Edwards, G., Morales, E., & Fougeyrollas, P. (2019). Understanding Risk in Daily Life of Diverse Persons with Physical and Sensory Impairments. *Journal of Accessibility and Design for All*, 9(1), 66-89. doi:<http://dx.doi.org/10.17411/jacces.v9i1.183>

environments exacerbate the impact of disability and make it difficult for individuals with impairments to make decisions to ensure their safety. Despite the fact that each of the participants was characterized differently, either woman or man, young or old, motor, visual or hearing impaired, they all highlighted the importance of the environment and how it plays a major role in determining whether they feel safe and secure. It was noted that environmental factors are closely linked to the encounter with accidents and the problems of social inclusion.

- [...] The environment has to be an adapted safe living space. For more than 10 years, we kept noticing the state of road and sidewalks in Quebec, there is no doubt that getting around town with a wheelchair has become more difficult and dangerous. [...] Leaving my apartment to do my grocery shopping at the local supermarket can cause me injuries. (Woman: Ehlers-Danlos syndrome; free translation)

For people with limited mobility, choosing to live in a city and learning to adjust their life habits to feel safer poses a challenge. Every day, these people must adopt a decision-making strategy, trust their instincts and decide which route to take to get to the grocery store without getting hurt. Every decision needs to be carefully considered in order to avoid the risk of injury and harm.

- [...] Do you know how much time it takes me to get from my place to the corner coffee shop? It is around 20 minutes; I have to take the same path every time I want to have a coffee. It may seem easy to make the right decision and choose the fastest path to the coffee, but not in my case. I have to go with the most secure path, the one on which I have never been hurt. My lucky path. The only path I feel able to take without fearing being run down by a car, or slipping and falling. (Woman: Congenital limb deformation; free translation)

Some participants commented that although the lack of planning increases the risk of getting injured, it is still hard to anticipate every possible

Arfaoui, A., Edwards, G., Morales, E., & Fougeyrollas, P. (2019). Understanding Risk in Daily Life of Diverse Persons with Physical and Sensory Impairments. *Journal of Accessibility and Design for All*, 9(1), 66-89. doi:<http://dx.doi.org/10.17411/jacces.v9i1.183>

situation. Indeed, living with impairments forces you to be attentive to everything and to take time processing all situations. The slightest detail counts and can make a huge difference in the decision-making process for ensuring their own safety.

Code #3: Perception of safety measures

People with impairments are often protected by family members or physiotherapists who are involved in their everyday life. Finding the right balance between appropriate protection and overprotection can, however, be difficult. Safety measures have always been present in their lives, whether through the use of assistive devices or via access to adapted means of transportation. Security measures are taken as precautions to avoid the risk of injuries. Social and health care services try to increase the quality of care and patient safety, whether by running public awareness campaigns or articulating risk within professional organizations (Taylor & McKeown, 2013). Although such measures are usually appropriate, they carry their own risks and not just benefits. For example, many of these measures are sometimes also responsible for causing injuries. Some wheelchair users prefer not being attached to their device rather than being "Unsafely attached", because they may have already been injured in the past in such situations.

- I hate being attached to my wheelchair. On my way home, I once took the wrong path and I found myself caught in a large hole in the road. I tumbled off my wheelchair but since I was attached, I got stuck. This accident caused me multiple fractures (arms, ribs). (Man: Osteogenesis imperfecta; free translation).

Other participants feel that safety measures are essential to assist them in their activities and to increase their sense of personal security. Without such measures, these individuals feel threatened and they tend to isolate themselves, hence limiting their possibilities for social inclusion.

Arfaoui, A., Edwards, G., Morales, E., & Fougeyrollas, P. (2019). Understanding Risk in Daily Life of Diverse Persons with Physical and Sensory Impairments. *Journal of Accessibility and Design for All*, 9(1), 66-89. doi:<http://dx.doi.org/10.17411/jacces.v9i1.183>

- [...] For the last couple of years, I stopped taking the public transport for one reason: I don't feel safe travelling without being attached. My wheelchair kept moving every time the bus driver turned. Now with paratransit (special transportation services for people with impairments) I feel more comfortable travelling around the city. (Man: Spinal cord injury; free translation).

Code #4: Loss of control and the experience of strong sensations

The absence of a sense of wellbeing and safety both reduces mobility and increases the occurrence of accidents and injuries, so we explored issues of loss of control and the strong sensations this might elicit. Indeed, five individuals pointed out that on a daily basis, they face a range of stressful and potentially dangerous situations: Crossing the street, cooking, getting out of the wheelchair, travelling to new cities, meeting new people, tackling a steep slope in a wheelchair, etc. In addition, we asked about extreme sports such as skydiving and bungee jumping in an attempt to illustrate the kinds of experiences that might involve the loss of control. We were looking for situations in which people with disability might go voluntarily beyond their limits and lose control over their bodily functions.

Despite the fact that most risk situations are a part of their daily existence and their ongoing routines, they still find it difficult to successfully carry out these tasks while managing feelings of fear, anxiety, and stress. For example, two of the female participants indicated that they suffer from vertigo or dizziness.

- [...] I normally don't feel dizzy but to be honest with you, lately I noticed that every time I leave my place to go out, I start sweating with my heart racing and I even experience sometimes panic attacks which can end with losing consciousness. But this won't stop me from living my life normally. (Woman: Ehlers-Danlos syndrome; free translation)

Arfaoui, A., Edwards, G., Morales, E., & Fougeyrollas, P. (2019). Understanding Risk in Daily Life of Diverse Persons with Physical and Sensory Impairments. *Journal of Accessibility and Design for All*, 9(1), 66-89. doi:<http://dx.doi.org/10.17411/jacces.v9i1.183>

Discussion and conclusion

These interviews suggest that people with widely different impairments experience similar levels of risk in their everyday lives, and that these risk levels are significantly higher than those experienced by people who don't have to deal with an important functional limitation. We believe the issues of risk assessment, risk management and both the perception and experience of risk need to be studied more systematically than they have been dealt with in the past. Indeed, the fact that several of those interviewed report difficulties managing the intense emotional reactions that result from encountering high-risk situations suggests that the impact of dealing with higher levels of risk has been underestimated. This may have import for the ways people who have acquired impairments are trained to adapt their lives to accommodate the challenges this imposes, and for those experiencing a decline in mobility, for example, with age.

At the same time, despite the high levels of risk, both as perceived and as actually experienced, the people interviewed had all, regardless of their particular functional limitation, found creative ways to manage the risk of physical injury in order to carry out their lives. Much of this was, however, based on previous experiences where functional limitations had been tested - many reported having had "close calls" or even situations in which serious injury resulted from misjudging the risk involved in a particular context. For example, one woman spoke about her "lucky path", the one and only route along which she had never been at risk. Hence this person chose a strategy of avoiding making changes, for fear of increasing the probability of being hurt.

However, managing risk under these circumstances is revealed to tax a person's resources over the long term. Several among our study group felt confined by the constraints around risk avoidance and risk management that they had had to deal with over many years. For example, for a person born with osteogenesis imperfecta, falling out of the wheelchair could cause

Arfaoui, A., Edwards, G., Morales, E., & Fougeyrollas, P. (2019). Understanding Risk in Daily Life of Diverse Persons with Physical and Sensory Impairments. *Journal of Accessibility and Design for All*, 9(1), 66-89. doi:<http://dx.doi.org/10.17411/jacces.v9i1.183>

painful fractures and hence the person must be alert for risk situations constantly - any relaxation of this awareness may result in further injury. The woman with the "lucky path" noted that an excessive focus on lessons from the past prevented her from living her life fully in the present. Hence dealing with these high levels of risk over long periods of time often leads to conflicting constraints. This complexity in risk management is also not widely acknowledged as being a part of the experience of disability - obviously, however, risk management will be more complex for some forms of impairments than for others.

The results of our study also show that all the participants, regardless of the nature of their impairments, managed risk in approximately four stages: (1) an assessment phase; (2) the adoption of a structured decision-making strategy; (3) adapting decisions actually taken due to unexpected events; and (4) managing the sometimes intense feelings elicited by these challenges. As indicated above, the latter raises important issues for clinical programs and occupational therapy, which should ensure individuals are prepared emotionally to manage such feelings or have recourse to counselling or support.

As mentioned earlier, people living with impairments learn to respect their physical limits in a defined process, to avoid high-risk situations. Life habits are adjusted according to specific characteristics such as past experiences and body limitations. Disability is fundamentally singular (Fougeyrollas, 2010). People experience disability differently, and develop ways of living and life habits that best represent their own character and survival skills. Disability, like race, ethnicity, gender and sexual orientation contribute to defining the person and their identity (Thomson, 1997). Such personal factors necessarily influence the decision-making process, especially when interacting with environmental factors that act as obstacles and which therefore generate disabling situations (Fougeyrollas et al., 1998).

In addition to dealing with the risk of injuries and the complications of finding the right decision-making process, people with impairments are confronted with other challenges such as managing their own feelings every time they face a risk situation. The feelings of insecurity and anxiety that arise when risky situations are perceived may lead to a feeling of vulnerability, e.g. whenever a person loses control over their situation. In an attempt to explore these feelings, we asked participants about extreme sports and situations involving loss of control that may require an efficient assessment of feelings. Participants had different ideas about what constitutes a situation involving loss of control: some noted they experience loss of control when they feel stressed, anxious or even lost faced with an unknown situation. Others considered extreme sports such as bungee jumping or skydiving to be inaccessible for almost all people with impairments, not least because they already deal with “extreme” situations in their daily lives.

All participants highlighted the vital role played by their occupational therapists. Their occupational therapists helped them develop their daily routines and their creative and technical skills, guiding them toward a healthy lifestyle. Learning to acknowledge their past while looking towards their future, allowed participants to embrace their current fears and to face up to the fact that their lives will always be risky but that with an appropriate decision-making process they can manage risk effectively. The conscious assessment and planning process carried out by people with impairments contrasts markedly with the automated, unthinking scanning process undertaken by most people without impairments.

This study has been extremely pertinent for our broader effort to develop a series of immersive and interactive installations for people with impairments. The identification of the four phases of the risk management process provides the basis for how we plan to organize the installations. The purpose of the qualitative study was both to narrow our understanding of the kinds of experiences that people with impairments may be looking for in an

Arfaoui, A., Edwards, G., Morales, E., & Fougeyrollas, P. (2019). Understanding Risk in Daily Life of Diverse Persons with Physical and Sensory Impairments. *Journal of Accessibility and Design for All*, 9(1), 66-89. doi:<http://dx.doi.org/10.17411/jacces.v9i1.183>

immersive environment, and also to ensure that we understand how to manage safety issues within the installation design process. However, given the limited size of the study, we are aware that the results may be representative but not conclusive. Also, the fact that our youngest participant was 32 years old meant that the experience of younger people was not studied. Typically, the group with ages 20 to 30 takes more risk than older people due to their lack of experience and the nature of their personality. At this range of ages, we expand our life choices. Indeed, a willingness to take risks and develop a sense of adventure, are essential to the creation of a healthy adult lifestyle. On the other hand, young people with impairments often experience higher levels of social isolation than do their able-bodied peers (Strax, 1991). Hence there is a need to study risk-taking and its perception in the context of personal isolation as well. Our study improved our understanding of how the risk of injury in daily life is managed by people with disabilities, but the small size of the population studied limits our ability to generalize from our conclusions. Measures are being taken to ensure that more participants between 20 and 30 years old will be included in the other stages of the project.

A focus group including a range of people with incapacities, including several of the original participants, was organized to report on our preliminary findings and to validate an initial installation proposal. As a result of the reassessment that followed the study reported here, we are now developing an immersive experience that offers unusual experiences of comfort rather than high degrees of risk as we had initially planned. Our installations hence integrate the four phases of risk management in order to provide a rich, safe and liberating experience for people with a wide range of impairments.

Ethical approval

The ethical approval for the study was sought and obtained in June, 2016, from the Research Ethics Board of the IRDPQ. All study subjects were given

Arfaoui, A., Edwards, G., Morales, E., & Fougeyrollas, P. (2019). Understanding Risk in Daily Life of Diverse Persons with Physical and Sensory Impairments. *Journal of Accessibility and Design for All*, 9(1), 66-89. doi:<http://dx.doi.org/10.17411/jacces.v9i1.183>

an anonymous code and these were used during discussions about the participants. The collected data were locked away to protect participant identities. A detailed interview guide was prepared and distributed by email before the interview. Before starting the interview, participants were invited to sign a consent form and a declaration they had been informed about the study. They were informed that they could drop out of the study at any time without penalty. Whether or not they continued with the interview, they received a small monetary compensation (50\$ if they came to the Institute, 30\$ if they were visited at home).

Acknowledgements

Our thanks to the participants of the study and to the Regroupement des Organismes des Personnes handicapées de la région 03 (ROP03) who provided support for this project from its inception.

References

- [1] Ashmead, D. H., Guth, D., Wall, R. S., Long, R. G., & Ponchillia, P. E. (2005). Street crossing by sighted and blind pedestrians at a modern roundabout. *Journal of Transportation Engineering*, 131(11), 812-821. doi: 10.1061/(asce)0733-947x(2005)131:11(812)
- [2] Cheong, A. M., Geruschat, D. R., & Congdon, N. (2008). Traffic gap judgment in people with significant peripheral field loss. *Optometry and vision science*, 85(1), 26-36. doi: 10.1097/OPX.0b013e31815ed6fd
- [3] Chowdhury, M. F. (2015). Coding, sorting and sifting of qualitative data analysis: Debates and discussion. *Quality & Quantity*, 49(3), 1135-1143.
- [4] Cree, T., & Kelloway, E. K. (1997). Responses to occupational hazards: Exit and participation. *Journal of Occupational Health Psychology*, 2(4), 304.
- [5] Denzin, N. K., & Lincoln, Y. S. (1994). *Handbook of qualitative research*. Thousand Oaks, CA: Sage Publications.

Arfaoui, A., Edwards, G., Morales, E., & Fougeyrollas, P. (2019). Understanding Risk in Daily Life of Diverse Persons with Physical and Sensory Impairments. *Journal of Accessibility and Design for All*, 9(1), 66-89. doi:<http://dx.doi.org/10.17411/jacces.v9i1.183>

- [6] Edwards, G., Noreau, L., Boucher, N., Fougeyrollas, P., Grenier, Y., McFadyen, B. J., ... & Vincent, C. (2014). Disability, rehabilitation research and post-Cartesian embodied ontologies-has the research paradigm changed? In *Environmental Contexts and Disability* (pp. 73-102). Emerald Group Publishing Limited.
- [7] Edwards, W. (1954). The theory of decision making. *Psychological bulletin*, 51(4), 380.
- [8] Edwards, W. (1961). Behavioral decision theory. *Annual review of psychology*, 12(1), 473-498.
- [9] Fänge, A., Iwarsson, S., & Persson, Å. (2002). Accessibility to the public environment as perceived by teenagers with functional limitations in a south Swedish town centre. *Disability and Rehabilitation*, 24(6), 318-326.
- [10] Flin, R., Mearns, K., Gordon, R., & Fleming, M. (1996). Risk perception by offshore workers on UK oil and gas platforms. *Safety Science*, 22(1-3), 131-145.
- [11] Fougeyrollas, P. (2010). *La funambule, le fil et la toile: transformations réciproques du sens du handicap*. Québec: Les Presses de l'Université Laval.
- [12] Fougeyrollas, P., Boucher, N., Edwards, G., Grenier, Y., & Noreau, L. (2019). The Disability Creation Process Model: A Comprehensive Explanation of Disabling Situations as a Guide to Developing Policy and Service Programs. *Scandinavian Journal of Disability Research*, 21(1), 25-37.
- [13] Fougeyrollas, P., Noreau, L., Bergeron, H., Cloutier, R., Dion, S. A., & St-Michel, G. (1998). Social consequences of long term impairments and disabilities: conceptual approach and assessment of handicap. *International journal of rehabilitation research. Internationale Zeitschrift fur Rehabilitationsforschung. Revue internationale de recherches de readaptation*, 21(2), 127-141.
- [14] Genest, V. (2014). *L'Infini : Réflexions Sur L'installation Immersive Interactive*. Mémoire de maîtrise inédit. Québec: Université Laval.
- [15] Gibbs, G. (2002). *Qualitative data analysis: Explorations with NVivo (Understanding social research)* (p. 100). Buckingham: Open University Press.

Arfaoui, A., Edwards, G., Morales, E., & Fougeyrollas, P. (2019). Understanding Risk in Daily Life of Diverse Persons with Physical and Sensory Impairments. *Journal of Accessibility and Design for All*, 9(1), 66-89. doi:<http://dx.doi.org/10.17411/jacces.v9i1.183>

- [16] Greening, L. (1997). Risk perception following exposure to a job-related electrocution accident: The mediating role of perceived control. *Acta Psychologica*, 95(3), 267-277.
- [17] [Hassan, S. E. (2012). Are normally sighted, visually impaired, and blind pedestrians accurate and reliable at making street crossing decisions? *Investigative ophthalmology & visual science*, 53(6), 2593-2600.
- [18] Kennedy, G. (2012). *An Ontology of Trash: The Disposable and Its Problematic Nature*. New York: State University of New York Press.
- [19] Levasseur, M., Desrosiers, J., & Tribble, D. S. C. (2007). Comparing the disability creation process and international classification of functioning, disability and health models. *Canadian Journal of Occupational Therapy*, 74(3), 233-242.
- [20] Landry, L. G. (2006). Preventing occupational injuries: Women's perception of risk from musculoskeletal exposures. *AAOHN journal*, 54(2), 75-83.
- [21] Maxwell, J. A. (2012). *Qualitative research design: An interactive approach* (Vol. 41). Thousand Oaks, CA: Sage Publications.
- [22] Short, J. F. (1984). The social fabric at risk: toward the social transformation of risk analysis. *American sociological review*, 49(6), 711-725.
- [23] Slovic, P. (1987). Perception of risk. *Science*, 236(4799), 280-285.
- [24] Slovic, P., Fischhoff, B., & Lichtenstein, S. (1977). Behavioral decision theory. *Annual review of psychology*, 28(1), 1-39.
- [25] Sparf, J. (2016). Disability and Vulnerability: Interpretations of risk in everyday life. *Journal of Contingencies and Crisis Management*, 24(4), 244-252.
- [26] Strax, T. E. (1991). Psychological issues faced by adolescents and young adults with disabilities. *Pediatric Annals*, 20(9), 507-511.
- [27] Taylor, B. J., & McKeown, C. (2013). Assessing and managing risk with people with physical disabilities: the development of a safety checklist. *Health, Risk & Society*, 15(2), 162-175.

Arfaoui, A., Edwards, G., Morales, E., & Fougeyrollas, P. (2019). Understanding Risk in Daily Life of Diverse Persons with Physical and Sensory Impairments. *Journal of Accessibility and Design for All*, 9(1), 66-89. doi:<http://dx.doi.org/10.17411/jacces.v9i1.183>

- [28] Garland-Thomson, R. (1997). *Extraordinary bodies: Figuring physical disability in American literature and culture*. New York: Columbia University Press.
- [29] Tracy, S. J. (2010). Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative inquiry*, 16(10), 837-851.
- [30] World Health Organization. (2001). *International classification of functioning, disability and health: ICF*. Geneva: World Health Organization.
- [31] Whiteneck, G., & Dijkers, M. P. (2009). Difficult to measure constructs: conceptual and methodological issues concerning participation and environmental factors. *Archives of physical medicine and rehabilitation*, 90(11), S22-S35.

Arfaoui, A., Edwards, G., Morales, E., & Fougeyrollas, P. (2019). Understanding Risk in Daily Life of Diverse Persons with Physical and Sensory Impairments. *Journal of Accessibility and Design for All*, 9(1), 66-89. doi:<http://dx.doi.org/10.17411/jacces.v9i1.183>

©© Journal of Accessibility and Design for All, 2019 (www.jacces.org)



This work is licensed under an Attribution-Non Commercial 4.0 International Creative Commons License. Readers are allowed to read, download, copy, redistribute, print, search, or link to the full texts of the articles, or use them for any other lawful purpose, giving appropriated credit. It must not be used for commercial purposes. To see the complete license contents, please visit <http://creativecommons.org/licenses/by-nc/4.0/>.

JACCES is committed to providing accessible publication to all, regardless of technology or ability. Present document grants strong accessibility since it applies to WCAG 2.0 and PDF/UA recommendations. Evaluation tool used has been Adobe Acrobat® Accessibility Checker. If you encounter problems accessing content of this document, you can contact us at jacces@catac.upc.edu.