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The Rollercoaster Ride: The Lived Experience of People Acquiring a Physical Impairment in Youth

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ABSTRACT

During our lifetimes, we embark on journeys, some planned and some unexpected. One unforeseen journey could be the acquiring of a physical impairment. What does it mean to follow such a journey in youth? This research addressed this question through a phenomenological study, guided by emancipatory principles. Using interpretative phenomenological analysis, information was gathered through interviews with six Maltese participants. The study discusses how this experience is visualized as a rollercoaster ride, yet stabilized by the sense of continuity and the support of significant others. There seems to be a fluctuating paradox of sameness and difference as individuals experience the phenomenon of physical impairment, reach new understandings, and develop a new mode of being-in-the-world.

Keywords: persons with disability, youth, acquired impairment, phenomenology

INTRODUCTION

During our lifetimes, we embark on different journeys, some of which we plan for and others we do not choose for ourselves. One such journey could be the acquiring of a physical impairment.[1] According to the World Health Organization,[2] approximately 15% of the global population have physical impairments, including congenital and acquired impairments – the latter involving either a sudden onset or a gradual progression. However, there are no statistical data regarding the prevalence of acquired impairment on an international level.[1] Information is also limited regarding the long-term issues affecting people with acquired impairments.[3] The dearth of information is equally evident in local statistics. For example, the latest local census in Malta, an archipelago in the Mediterranean sea between Sicily and the North African coast,[4] indicates that 877 persons aged 20 to 40 years have a physical impairment; however, this figure includes persons with congenital and acquired impairments.

My desire to explore issues related to acquired impairments stems from my work as a physiotherapist. Frequently I ask myself what is occurring within my client who has discovered that he or she has acquired a permanent physical impairment. Gendreau and de la Sablonnière[5] have noted that the person who acquires an impairment has the experiential knowledge to scrutinize the discrepancy between the experiences of having and not having an impairment, which can influence how one makes sense of the experience. The threat to life, the unexpected sudden onset of impairment, the slow recovery and the involved changes contribute to an experience that is different from that of chronic illness or congenital impairment.[6]

According to what the non-disabled world presents in media and cultural discourse,7 acquiring an impairment is mostly perceived as the unwanted tragedy that replaces the dreamed-of future.8 However, this view may only be what non-disabled persons assume. Numerous writers have noted that the experience of acquired impairment can yield affirmative positive outcomes.[9-12] Gill[13] described the border between the disabled and non-disabled communities as a troubling disjuncture. That border is an elusive one, and the shift from one side to the other can instantly happen to anyone.[14] Bishop[15] talked about the difficulty and emotional dynamics that professionals experience with clients who acquire an impairment. DeSanto-Madeya[16] has stated that healthcare professionals need to learn about the real worlds of persons living with acquired impairments to realize the great difference between the rehabilitation experience and their clients' actual lived experiences.

The acquiring of an impairment is vastly under-researched in terms of the lived experience, particularly relating to young people. While acknowledging the political reasons for concentrating on collective experiences of oppression during the last decades, the time has come to appreciate the diversity of individual experiences regarding acquired impairments.[17] Empirical studies tend to be reductionist to particular life aspects and seem to be founded on ableist views, which consider the non-disabled experience as the "normal" basis for experience.[18] Morris[19] stated that there is little opportunity for persons with disabilities to represent their experiences. The situation is probably worse in Malta, given the small size of the country and the proportionally small number of disabled youth living there. The few local academic studies that have explored the experience of becoming impaired have focused on particular impairments.

I chose youth as the focus of my research on acquired impairment. Being young myself, I believe it is an important stage in life, and am interested in how this generational stage interlinks with the acquiring of an impairment. Accordingly, founded on the premise that the persons experiencing the phenomenon are the experts about their lived experiences, my research aimed to explore what the phenomenon of becoming physically impaired in youth entails; what it means to experience this phenomenon in youth; what the possible changes linked to it are; and if there is any impact from the surrounding others.

PERSPECTIVE

Phenomenological research focuses on the lived experience, that is, "the embodied, socio-culturally and historically situated person who inhabits an intentionally interpreted and meaningfully lived world."[20(p181)] Going "back to the things themselves,"[21] such research values the concrete, subjective, lived experience and its attributed meanings, giving primacy to the expertise of the person experiencing the phenomenon. Phenomenological research acknowledges that the researcher cannot be detached, because “in order to see the world … we must break with our familiar acceptance of it.”[22(pxiv)] Heidegger introduced the term “being-in-the-world,” referring to the indissoluble embeddedness of the person in the meaningful world.[23] We are thrown into the world and it is impossible to detach ourselves from this unity to examine the “lifeworld” objectively.[24,25]

Heidegger and Gadamer agreed that there is no meaning without interpretation.[23] The meaningful world we live in forms the background for all our experiences and is interpreted during our meaning-making process. The circular interpretive links can be understood through the “hermeneutic circle,”[25,26] in which the phenomenologist’s point of departure is shaped by past experience, knowledge, and pre-understandings, and these are acknowledged and reflected upon as the phenomenologist enters the field of data collection. The focus shifts from the researcher to the participant, as the phenomenologist attends closely to the participant’s account. The encounter moves the phenomenologist to a new position within the circle as new information is being told and fresh understandings are reached.[27] Merleau-Ponty directed his attention to the body in understanding one’s lived experience, stating that “the body is the vehicle of being in the world.”[22(p82)] Existential phenomenologists believe that the lifeworld is composed of being a body in space, a self in time, and living with others.[28]

Some argue that phenomenology is not appropriate for disability studies because it has conventionally remained attached to the medicalized standpoint, making it potentially oppressive and reinforcing the tragedy model of disability through its emphasis on the impaired body, the personal experience, and attributed meanings.[29-31] However, the supreme value of insider knowledge and the centrality of the body are common aspects in the fields of phenomenology and disability studies. Heidegger does not restrict the term “being-in-the-world” to any ideal category of what makes a human being. Persons with disabilities are embedded in an a priori world as well.[32] In phenomenological accounts, persons with disabilities are given the chance to represent themselves, proving that they have valuable lives and a significant position within society.[33] A phenomenological attitude toward impairment presents the body as lived-through.[30,31] In line with the social model of disability, as oppression and prejudice are lived through the impaired body, the impaired body reflects such behavior as part of the lived reality.[31]

This study attempted to blend hermeneutic phenomenology with emancipatory research. Its framework corresponded with emancipatory research through valuing the significance of the lived experience, including the experience of any oppression; being accountable to persons with disabilities and empowering them; being potentially transformative, utilizing non-exploitative methods; and encouraging social change.[32,34]

METHOD

In keeping with the phenomenological foundations of the study, interpretative phenomenological analysis (IPA) was considered the most appropriate methodological framework. Interpretative phenomenology differs from descriptive phenomenology in that it goes beyond the descriptions of an experience to focus on the meanings embedded in such an experience.[35] Following Heidegger’s phenomenology, IPA emphasizes the worldliness of the lived experience within the social world,[36] putting an emphasis on first-hand experience and the consideration of the context.[20,37] In IPA studies, the person-in-context creates the first interpretation of the phenomenon, and the researcher interprets the participant's phenomenological account, hence having a "double hermeneutic."[38] IPA has an idiographic commitment as it focuses on detailed exploration of the lived experiences of a few individuals.[39-41] Its microscopic lens is focused on human diversity and variability,[20] making it ideal to explore disability matters. This explains why the study had a small number of participants.

Participants were chosen through purposeful intensity sampling, which was beneficial in selecting "information-rich cases that manifest the phenomenon of interest intensely."[42(p234)] The inclusion criteria were Maltese persons, aged 18 to 40 years, who had acquired a physical impairment of sudden onset in their youth. Participants must have had the impairment for at least four years and were living in the community. Persons with a brain injury or progressive conditions, or who had cognitive or communication difficulties, were not considered since the sample could possibly have become too diverse for an IPA study.[43] The physiotherapists working within the Physiotherapy Outpatients Department at the local rehabilitation hospital identified potential participants. Prior to commencement of the research study, approval was sought from the faculty's and university's research ethics committees, as well as the hospital's research committee and management.

In-depth, face-to-face interviews provided the raw material for this project. I opted for a topic-guided interview. The topic guide included topics that were repeatedly mentioned in the found literature as relevant to the phenomenon being studied. Observational notes were taken during the interviews. Each interview was followed by an accurate transcription of the audiotaped interview session. The transcript was supplemented with non-verbal communication, gestures, and behavioral responses, which were recorded in the observational notes. Participants verified their transcripts to make sure that the experiences had been captured accurately, providing them with control over their stories. Confidentiality and anonymity were guaranteed at all times, even beyond the study's completion. Real names were replaced by fictitious ones to protect the informants' identities. Given the small size of Malta, extra caution was taken to eliminate information that could have led to identifying the participants. I also kept a reflective diary throughout the research process to trace my personal journey within the process, particularly concerning my phenomenological and emancipatory positioning and the impact of my beliefs, values, and experiences.

Finlay[44(p186)] portrayed the analytic process as "a focused act of discovering out of silence, sediments of meaning, nuance, and texture." Following IPA guidelines,[37] the individual analysis was done manually after each interview, and then all interviews were compared in relation to each other. First, I engaged with the transcript of the interview through repeated close readings. The second stage involved note-taking, searching for recurring phrases, emerging questions, emotions, use of language, and potentially significant matters. In the third stage, the transcript was examined further to identify the patterns of meanings that were considered to capture the participant's experience. The emergent themes were then listed and grouped together according to their similarity. A table was drawn to illustrate these themes for each participant. The clustered emergent themes were then compared among the different interview transcripts to analyze similarities and differences. While similar themes were grouped together into a structure of superordinate themes, due importance was given to differences in meanings among the participants as these were believed to contribute to the holistic understanding of the phenomenon.[40,45] The fundamental meanings in the informants' experiences formed the narrative account through translated verbatim extracts.[46]

FINDINGS

These are the lived experiences of six Maltese individuals, aged 25 to 36 years (Table 1). Three of these individuals have a spinal cord injury; three have an amputation. Table 2 summarizes the themes and subthemes that were identified as common to all participants. It seems that rather than hitting the stop and restart buttons, the injury brought about a pause in the participants' lives – and they all decided to hit the play button and move on. As one participant remarked: "You don't have to restart life. You need to think a bit differently." An element of ongoing fluidity was evident in how the participants were making sense of their lifeworld. This sense of fluidity is understandable; we are always changing as we move along in life.

1. Experiencing The Rollercoaster Ride

Contrary to the predictable adjustment processes depicted in psychology literature,[47,48] from the moment of acquiring the physical impairment to today, life has unfolded as a rollercoaster ride for these youth, including both tough moments and enjoyable ventures, as also depicted in Cross, Kabel, and Lysack's study.[49] Keith described life as "one hell of a ride … but including everything. You know? When you ride a rollercoaster, you go: Whoooooo!"

Coming from a Western culture, which values youth, aesthetics, employment, and independence,[50] participants had never considered the possibility of acquiring a permanent physical impairment, and they found themselves thrown into an unknown worldview. The unexpectedness and the sudden news about the permanency of the impairment led to a turmoil of feelings and doubts, which varied among participants. Robert expressed this as: "How could I ever have imagined that I'd be at work, that I'd be injured as I am and that even my family would leave me?"

The concept of loss was referred to predominantly in terms of the loss of physical independence in their first years following injury, rather than the loss of identity. For instance, Keith expressed that being a very active person, he "literally lost everything [and had] … to ask others to do everything for [him]." The initial concerns started to fade as the participants achieved better function in daily life, as they explored and succeeded in new adventures, and as new opportunities came their way. All participants referred to what they described as their personal character and emphasized its significance in their lived experiences. In line with most literature,[51-54] most participants believe that the fact that the injury occurred in their youth led to quicker adjustment.

Pushing their bodies beyond limits, the participants' "primary focus was to walk and retry to become a bit normal" (Alex). In agreement with other phenomenological studies,[50,55-57] independence for this group meant physical function, rather than autonomy. Most participants expressed their hope in terms of having an opportunity to improve their physical condition. However, such a possibility is not central to their worldview. Having already tried a stem cell procedure, Luke expressed that he still looks at his future as a wheelchair user because the chances of walking are very remote. These objectives of independence and normalcy might be criticized by disabled activists, but the concept of normalcy for the participants seems to mean that participants manage to do the things they wish to do. Keith mentioned that "the more the disabled person achieves independence, even the smallest thing, the more he's going to be exposed to more and more open doors."

All participants identified positive moments and outcomes within their lived experiences. From the memorable moments of achieving some sort of functional ability, to continuing to follow their dreams, to realizing the new opportunities ahead, to strengthening their existent relationships, each participant managed to get the best out of their lived experiences and move forward. The experience in itself has opened new opportunities for Keith, particularly in the educational and employment fields.

2. The "Turnover"

Robert said that "in a couple of seconds, your life turns upside-down." All participants related to areas in their lives that involved changes, but not necessarily negatively. The impact of such changes varied among them. They explained how they have been working around their impairment effects, such as pain and fatigue, with respect to their daily routines, educational and employment opportunities, careers, and leisure and sports activities. Rebecca explained that there are things she can do and others she cannot, such as being a hairdresser – because it requires long hours of standing. All male participants were unable to continue with their previous occupations or employment plans. Some participants had to move to a new house due to the inaccessibility of their previous home.

Then there were other fundamental changes, particularly about one's outlook on life. This is in keeping with findings from a study by Boswell, Dawson, and Heininger.[58] Alex shifted his life focus to enjoying life; Keith started focusing on potential life opportunities and "giving value to things that [he] didn't give to before." All participants mentioned that since the injury they have been more cautious about the future, in terms of both plans and expectations. Alex learned to "live day by day and see what happens" as he became aware that plans can change instantly. Yet, participants' accounts portray that life is there to be lived and they all have interesting future plans, such as marriage, new business ventures, and career developments. Samuel is planning to get married, Luke is looking for a new business, and Alex is saving money for holiday trips. Keith's biggest wish is to become a politician. It is crucial to differentiate between changes brought about by the disability experience and changes that are related to other life aspects. For instance, Samuel mentioned that he experienced the loss of contact with some friends, but that it was more related to the fact that everyone was focusing on romantic relationships rather than friendships.

3. Life Goes On

The sense of continuity expressed in the participants' accounts seems to have a stabilizing role. Participants illustrated how beyond their initial shock and inevitable changes, they continued to lead a fulfilling life. Rebecca expressed: "I, sort of automatically, continued my life." Some participants pursued their ongoing relationships. Some continued with their sports, leisure, and social activities. Rebecca recalls with nostalgia that, after her accident, "between 18 and 21, [she] used to go to Paceville Friday, Saturday, and Sunday because [she] loved dancing there." Luke said that he "never used to have any problems with these leisure things prior to [his] injury. Neither did [he] have any problems after, so [he] continued with the same routine right up to today." The level of continuity varied among participants. Those who had valuable resources and connections managed to carry on with their lives much better. Resources varied from an employment opportunity within the partner's company to having a supportive family and friends. Even amidst the uproar of acquiring the physical impairment and facing marital breakup, Robert is determined to continue with his life and grab whatever opportunity comes his way to be functionally better and the best father for his daughter.

4. I Am the Same, Yet Different

The greatest sense of continuity was noted regarding one's identity. All participants tried to hold on to their previous identities as much as possible. Rebecca described herself as: "I'm Rebecca, I love photography, I love dancing, I love to socialize, and I have a prosthesis." Previously a dancer, Keith became a dance teacher. Luke is still the car enthusiast and Alex identifies himself as a traveller and musician. These findings challenge the concepts of bereavement and biographical disruption,[59,60] and deny the discourse within rehabilitation literature[61,62] that claims that upon the acquiring of impairment, identity becomes founded in the disability experience. The notion of re-embodiment discussed by Papadimitriou[30] was not discussed extensively by the participants, but it seems that the wheelchair or the prosthesis has been integrated into the body image of each participant. Rebecca considers her prosthesis as an extension of herself and "feels very limited without it." She named each prosthetic leg she got along the years, as if she developed a relationship with each leg. However, she made it clear that her prosthesis is only part of her identity.

Most participants emphasized that their youth was not robbed from them. They associate themselves with being young and give importance to aesthetics, fashion, leisure, and future planning like any other youth, as noted by Wedgwood.[63] Luke "always feel[s] like a youth and will keep on feeling like that … [He's] trying not to get old." What is remarkable about Luke is that the disabled identity is not perceived as a threat to his youth identity. Both identities coexist together without any hint of friction. Participants referred to the different roles they adopted in different contexts. For example, Alex is a young man, a worker, a musician, a traveller, a son and a parent, as well as an amputee. This notion of the coexistence of identities and roles compares well with the literature[63,64] in that a person has multiple coexisting identities, each of which comes to the forefront according to contexts and time. Robert did not consider himself as a youth, but focused more on his identity as a parent.

Although most participants associate themselves with being young, they also acknowledged that they are not like any other youth. Alex expressed that sometimes he finds himself detached from others, feeling like an "outcast" and wondering how normal he is. Rebecca is aware that she's not like her friend who's 25, and that she hobbles and cannot wear shorts or skirts without being self-conscious. Yet most participants try to ignore such elements of difference. Accordingly, 4 out of the 6 participants do not consider themselves disabled. This is consistent with the assertion that persons with disabilities do not necessarily take on the disabled identity,[65,66] especially since they are still young.[67] Alex explained that he has few functional limitations, such as his inability to run or take a long hike without pain, but many non-disabled persons are unable to do these activities as well. Participants expressed how the Maltese culture's perceptions about persons with disabilities hold them back from identifying themselves as disabled. Participants tend to feel disabled only when other individuals and services are involved. Samuel, Luke, and Robert expressed that they want to lessen the amount of burden they are on others. Only Luke and Robert associated themselves with the disabled identity. In Luke's eyes, disability has to do with lack of ability. He stated that his self-esteem is affected when he compares himself to individuals who can walk.

5. Living in a Social World: The Supporting Role

We share our lifeworld with others and thus our relationships with others are intertwined in our personal lived experiences. All participants recognized those persons who have been offering their support from the start. All participants identified the family as being crucial to their lived experiences. The strong familial bonds also seem to be reflected in the high level of support and parental influence received by the participants. These findings follow the conclusions drawn by Schembri Lia[68] that Maltese families are resilient and are a source of guidance and support. With an affirmative approach, Rebecca's parents perceived her as their daughter above all else and never treated her differently because of having an amputation. She recalled how once she told her dad she couldn't wash the dishes because she didn't have her prosthesis on at the time and how he just grabbed a high stool for her to sit on to wash them.

Alex and Robert testify that despite their physical impairments, they still fulfill the role of a parent. During his interview, Robert highlighted several aspects of any father's role: being there to play with the child, passing on noble life values, supporting the child in all matters, and respecting the child's position about marital issues.

Most participants emphasized the positive impact of their friends on their self-concepts and youth life after the injury. Friends were crucial in continuing to enjoy leisure activities and retain the joy of youth central to the person's life. Keith's friends "still saw [him] as Keith. So they would, for example, get [him] fashion necklaces … stereo, CDs, [and] the headphones to listen to Guns 'N' Roses" when he was in hospital, while Alex's friends used to forget that he could not run when they used to play Ring and Run, as they "treat[ed] [him] as one of them." There was unanimous agreement among participants that disabled peers are also important in their lives, as made equally evident in previous research.[50,57,69,70] Having a shared worldview, there seems to be a greater sense of equality, empathy, and understanding among disabled peers, which distinguishes them from other types of social support networks.

Most participants noted that the acquiring of the physical impairment did influence their relationships with their partners or potential partners, but not necessarily in a negative way. Agreeing with Scherer,[71] Keith claimed that self-perceptions might play a greater role than others' perceptions in relationships. Accordingly, Rebecca stated: "I always approach it that if someone didn't accept my leg, they didn't really deserve me. Because it was part of me whether they like it or not …" Both Samuel and Luke were in a relationship at the time of injury, both of which continued afterwards. Participants described their partners as being very supportive and encouraging. Contrastingly, Robert's injury was followed by a marital breakup, which made the lived experience more complex. North[72] has noted that the acquiring of an impairment may challenge family dynamics and relationships.

Most participants expressed words of gratitude toward the healthcare professionals, for going the extra mile to support them. Rebecca confessed that her consultant was like a grandfather to her and "he used to come on a daily basis and give [her] a quote and he used to make [her] laugh and he was really sensitive." This reveals how humanizing values, such as sensitivity, patience, positive attitudes, and understanding, can take priority over medical expertise. In line with the concept of "lifeworld-led care,"[73] Keith conveyed that "the first thing that they [*referring to therapists*] consider is that you want to live. You have to continue with your life."

Participants discussed the Maltese health services at length. The closing down of the spinal cord injury (SCI) specialized unit, the limitations within the prosthetic unit, the physical environment of certain healthcare settings, the lack of specialized training and resources, the challenge of putting knowledge into practice, and the fact that the services were offered to individuals of all ages under the same roof were all mentioned as downsides. Those participants who had the opportunity to receive health services abroad referred to the huge difference between Malta and locations abroad in terms of specialized settings and the rehabilitation experience, as well as the available resources and training opportunities.

Agreeing with Evans,[74] most participants stressed the fact that they are the persons who know best about their own experiences. Samuel extended this element of expertise to his family members. Keith appreciated that some professionals acknowledged his own expertise and perceived him to be better than them at addressing people about the disability experience. Yet, it seems that some professionals are still holding strong onto the power of expertise.[75,76] Both Samuel and Rebecca highlighted that having an impairment does not make you an expert knower about the experience of all persons with impairments. Each lived experience has its own expert knower, since no two experiences are the same, even when the impairment is similar, as highlighted by Samuel when he said that "everyone in his life is facing different situations, experiences, and obstacles." Rebecca also referred to the role of media in the public portrayal of the disability experience. Persons with disabilities who speak in public must emphasize that their experiences are merely theirs, and they should not make sweeping statements about other persons with disabilities.

Additionally, all participants referred to their encounters with the non-disabled population. This issue revolved around the fact that individuals vary in their responses toward persons with disabilities, but the clear majority are usually negative since they are based on notions of disablism and ableism, as concluded by Loja, Costa, Hughes, and Menezes.[77] Rebecca referred to the lack of exposure that makes individuals feel uncomfortable and unknowledgeable about how to react when they meet someone with an impairment. The lack of understanding about the experience of having an impairment lets curiosity take the lead in people's questions.[77] Keith also commented that people are overprotective in their approach when "they mummy [disabled persons]." Amputees talked about hiding the prosthesis to avoid the labelling and pigeonholing process. Yet, those participants whose injury occurred more than 14 years ago acknowledged that there was an improvement along the years in people's responses toward persons with disabilities in Malta. Keith associated this improvement with more active participation of persons with disabilities in the public arena, increased exposure, and improved knowledge.

CONCLUSION

Drawing on the experience of six Maltese persons who acquired a physical impairment in their youth, this study showed how there seems to be a fluctuating paradox of sameness and difference as the individuals experience their lived worlds, reach new understandings, and move along the hermeneutic circle to develop a new mode of being-in-the-world. The rollercoaster ride brings with it changes related to day-to-day routines, the home environment, employment opportunities, life perspectives, and future orientation. Such experience is also marked by positive outcomes, and the sense of continuity transpires as the stabilizer that enables the person to experience being-in-the-world in an ordinary way. Accordingly, public spaces should offer opportunities to persons with disabilities to present the disability experience as a different mode of being-in-the-world. The voice of the person must remain authentic when publishing stories of persons with disabilities; and disability-awareness campaigns ought to be geared to highlighting the lived reality of impairment, acknowledging both the ups and downs of such a lifeworld, as concluded by Hammell.[78]

Services need to ensure that their structures and allocation of resources respond to the needs of persons with disabilities, even if they are small in number. The concept of lifeworld-led care is new to the Maltese healthcare context, but it could be an enabling tool in improving local services and empowering our clients. Professionals need to start thinking of structuring services through a bottom-up approach to give primacy to the expert knower – the person with an impairment. Furthermore, the relevance of peer counselling among persons with disabilities needs to be discussed and developed into a formalized service.

This project has contributed new findings to an under-researched area and demonstrated the potential of phenomenology within disability studies. I consider the blend of hermeneutic phenomenology with emancipatory principles as a success, as participants were at the forefront of the entire research process. This combined approach was the first of its sort in Malta. Further phenomenologically-oriented emancipatory research within disability studies is required, particularly regarding acquired impairment and youth, and possibly having a longitudinal design. Such research can put more pressure on society and social institutions to question themselves and work harder to promote respect for persons with disabilities.

The small sample size can be perceived as a threat to representability and generalizability, but it was not the study's purpose to proceed along those lines. The study was designed to focus on individual experiences, remaining attached to the day-to-day lived experiences of the participants and presenting possibilities of lived reality. The fact that participants had different types of physical impairments can be seen as a limitation in this study. However, physical variables may not be the main influencing factors when a person becomes impaired, as evident in this study and others.[69] The study findings present a more holistic view of reality than studies that focus on specific physical and rehabilitative aspects, and give a new perspective to the experience of acquiring an impairment, incorporating elements of positivity and continuity. Should the study design have incorporated a longitudinal design, it could have possibly contributed further to the gap in current literature. Being a researcher and a physiotherapist with a special interest in disability studies may sound conflicting, but my dual role as a researcher and a physiotherapist enabled me to better analyze the disability experience from different standpoints. Reflexivity has been instrumental in holding on to the emancipatory aims of this research, acknowledging my positioning, and moving forward to new perspectives.

Ultimately, through this research journey, I reconfirmed my conviction that the person experiencing the phenomenon is the expert knower; this has strengthened my desire to better understand the person in his or her mode of being-in-the-world.

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About the Author

Maria Cynthia deBono is a Maltese physiotherapist, with a special interest in rehabilitation, disability studies, client empowerment and education. She has worked in several rehabilitation settings for clients of all ages, and had the opportunity to visit rehabilitation hospitals in Finland and Slovenia. In 2015, she earned her Master's Degree in Disability Studies at the University of Malta. Considering herself as a highly-motivated individual with an eagerness to acquire new knowledge and share it with others, she is a strong believer that the client is the expert knower and promotes the view that healthcare professionals can be enablers in the lives of persons with disability.

Table 1: Demographic Representation of Participants

	Gender	Age	Age @ Onset	Years Since Injury	Impairment	Education	Work	Status	Living
Robert	M	36	32	4	Amputation	Secondary	Unemployed	Separated	Alone; has carer
Samuel	M	25	20	5	Paraplegia	Secondary	Part-time accountant	In a relationship	With parents
Rebecca	F	25	15	10	Amputation	Tertiary	Full-time student	In a relationship	Alone
Luke	M	34	20	14	Tetraplegia	Vocational	Self-employed	In a relationship	With partner
Alex	M	35	14	20	Amputation	Secondary	Full-time office work & part-time	Single; father	Alone
Keith	M	36	16	20	Tetraplegia	Tertiary	Full-time office work	In a relationship	With partner

Table 2: Major Themes and Subthemes

Experiencing the rollercoaster ride

- The unexpected journey
- Responding to the situation
- Living a “normal” life
- A streak of positivity

The turnover

- Working around the impairment
- Moving home
- It’s a right, not a favor
- Perceiving life differently
- Living day by day

Life goes on

- I am the same, yet different
- The extended body
- The youth in me
- An element of difference

Living in a social world: the supporting role

- Still our child
- Involving kids
- “Come on, friend”
- “Who deserves me?”
- “He was disabled too!”
- The professional relationship
- The expert knower
- Within the community