

# The Disability Experience: Living with a Birth Defect Resulting from Thalidomide Exposure

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Émilie M. MEYERS\* <sup>1</sup>, Jeffrey W. JUTAI <sup>2</sup>

<sup>1</sup> Student, University of Ottawa, Canada

<sup>2</sup> Professor, University of Ottawa, Canada

\* *Auteur(e) correspondant* | *Corresponding author*: N/A

## Résumé :

(traduction)

La Thalidomide est un exemple classique du potentiel que la médecine a de nous nuire. En effet, la diffusion de masse de ce médicament à la fin des années 1950 a causé la naissance de huit à dix mille enfants présentant un handicap congénital. Cette tragédie affecte encore aujourd'hui la vie d'environ 125 personnes au Canada. Comment ces personnes vivent-elles, et quel a été l'impact global de leur handicap? L'article décrit l'expérience de vie d'une femme née avec une phocomélie des membres supérieurs causée par la Thalidomide. L'auteur a effectué une entrevue directe non structurée d'une heure avec cette femme, et elle lui a permis d'utiliser l'enregistrement pour pouvoir analyser les données plus en détails. Il y a découvert six thèmes principaux indiquant qu'un handicap physique causé par la Thalidomide peut n'avoir qu'un impact minimal sur la qualité de vie globale du sujet, à condition que celui-ci bénéficie d'un soutien adéquat et ait une image positive de lui. Le contenu de l'entrevue indique que vivre avec un handicap constitue une expérience unique pouvant avoir des conséquences positives. À la fin de cet article, l'auteur conclut qu'il est nécessaire de mener davantage de recherches approfondies afin de mieux faire valoir le point de vue des personnes handicapées.

## Mots-clés :

Thalidomide, handicap, expérience de handicap, handicap précoce

## Abstract:

The drug, Thalidomide, is a classic example of how medicine has the potential to cause us harm. The market flooding of this drug in the 1950's resulted in the birth of 8 to 10 thousand children with birth defects. Today in Canada this tragedy still affects the lives of approximately 125 individuals. How do these individuals live their lives and what has been the overall impact of their impairment? This article explores the lived experience of a woman born with upper limb phocomelia as a result of Thalidomide exposure. A one-hour unstructured face-to-face interview was conducted. Permission was received from the interviewee to make a voice recording of the interview allowing for a more concrete data review. The interview uncovered 6 primary themes indicating that a physical impairment resulting from thalidomide can have a minimal impact on an individual's overall quality of life, as long as sufficient support and a positive self identity is present. The interviewee's accounts suggest that living with disability is a unique experience that can lead to positive outcomes. The ultimate conclusion of this paper is that more extensive research is needed to further represent the voices of the disability community.

## Keywords:

Thalidomide, disability, disability experience, early onset disability

## Introduction

In the late 1950s, an unfortunate lesson was learned in the field of medicine. Insufficient testing allowed a drug with unknown devastating side effects to reach the market. The story behind Thalidomide is one of short duration but of significant impact on humanity. It will be a constant reminder that medicine has the potential to harm us (Duffin, 1999). Thalidomide was synthesized in 1954 and was regarded as a highly effective sedative used to treat morning sickness. By 1957, this drug was rapidly marketed in over 20 different countries (Lenz, 1992). It is only in November of 1961 that observations of several birth defects lead to the partial withdrawal of the drug across the world. Canada continued to sell Thalidomide until March of 1962 (Lenz, 1992). By this time, at least 8 000 to 10 000 infants were born in Canada and Europe with missing digits, arms, legs and deformities of internal organs. Today there remain only 5 000 survivors (Annas & Elias, 1999; Vanchieri, 1997). In Canada, this tragedy still affects the lives of approximately 125 individuals (Duffin, 1999).

It is hard to describe the precise effects of Thalidomide, because it is known to cause a wide variety of birth defects. However, the majority of Thalidomide cases result in bilateral limb defects such as upper limb amelia, missing fingers, lower limb defects and club foot (Smithells & Newman, 1992). Additional common afflictions are developmental abnormalities of the ears and eyes, abnormal innervation of facial muscles and cleft palate. Further observable conditions include internal abnormalities that affect the heart, kidneys, urinary tract, alimentary tract and the genital tract (Smithells & Newman, 1992).

There is very little documentation concerning the survivors' childhood experiences of living with physical disabilities resulting from this tragedy. However, one 1964 study examined Thalidomide children's overall social, physical and cognitive adjustment. The findings indicate that these children possess a normal distribution of intelligence, the ability to develop and master motor activities, no major emotional disorders and no distortion in body image (Gingras et al., 1964). In an attempt to evaluate adult survivors' current social, physical and cognitive adjustment two new studies were published in 2007 and 2011. These studies each found that with age the majority of participants living with birth defects did experience a deterioration of their disability, which resulted in increased pain and fatigue. However, most respondents despite their poor health status reported good health or quality of life (Bent,

Chamberlain, Neumann, & Tennant, 2007; O'Carroll, O'Reilly, & Whitford, 2011). Thus it seems there is a positive outlook for Thalidomide survivors during all stages of life.

A face to face unstructured interview was conducted to uncover one woman's experience of living with birth defects caused by Thalidomide exposure. The author's goal in this report is to analyse this woman's life experiences from childhood to motherhood. For confidentiality purposes, the interviewee will be known simply as "Ruth". Overall this interview was conducted with the hopes of better understanding her experience of disability along with a more general understanding of the disability experience.

## Methods

In order to get a glimpse of who the interviewee is, a detailed demographic description follows. The interviewee is a married 48 year old female and is a mother of two. She is currently employed by in the child care services industry as an assistant director for a before and after school program. She was an only child, and attained a college level education. She is categorised as having an early-onset disability, which means she has had her disability since a very young age. This categorisation of disability accounts for 7-9% of all disabilities in America (Verbrugge & Yang, 2002). Her impairment can be identified as upper arm phocomelia (shorter arms than the average person) resulting from Thalidomide exposure.

The interview was conducted using an unstructured face to face method and lasted around one hour. It took place in the interviewee's home at the kitchen table. Permission was received from the interviewee to collect a voice recording of the interview. Over and above the audio recording the interviewer took detailed notes throughout the proceedings.

## Results

In order to describe the interview process and accurately present the collected information, the results section will briefly provide explanations for any adaptations made to the interview script and will subsequently provide a summary of the content of the interview. The content will be grouped and organized into 6 themes. During the inter-

view process minor modifications were made to the interview script. The majority of modifications to the interview script were made because the interviewee had answered a question earlier in the interview. The interviewer also omitted certain questions because they felt inappropriate and unnecessary after having heard previous answers. Following the interview it was discovered that the audio recording malfunctioned and only caught the first 5 minutes of the discussion. Luckily detailed notes were also taken as a precaution in case such an event took place.

Following is an account of the proceedings of the interview and a description of the themes that emerged. The first minute of the interview was spent identifying demographic information about the interviewee. Refer to the first 5 questions available in Appendix A. All the questions following number 5 allowed for the development of 6 major themes:

### **Theme 1: The evolution of a disability identity.**

The evolution of “Ruth’s” disability identity was evident throughout the interview. For example “Ruth” repeated twice during the interview, “If you would have asked me to do this 10 years earlier I would have said, no I don’t have a disability”. Now she admits that since her involvement with TVAC she has opened her eyes to the fact that she is a person affected by the Thalidomide drug and has concluded being different is not a bad thing. She identifies mostly to the able-bodied community but also to her disability community. Studies indicate that individuals with an early-onset disability often have stronger disability identities; this aligns with the interview findings (Verbrugge & Yang, 2002).

### **Theme 2: Coping strategies that minimize the impact of discrimination.**

This theme was surprising because often the largest obstacles for the disabled are not the physical limitations but the social attitudes and stigma surrounding their disabilities (Olkin, 1999). However, the interviewee claims, “I have had very few times where I have felt discriminated against. I tend to remember more the positive events”. When asked to provide an example of discrimination she mentioned a bully in grade school who used to call her “little miss no hands” but claims all children go through some form of

bullying. This is a form of positive coping and has minimized the impact of discrimination on “Ruth” overall interactions with society, in contrast to the expected norm. Today she experiences very little discrimination in her every day life.

### **Theme 3: Family Support and Coping.**

The interviewee indicated that coping was mostly possible through close relationships with friends and family. “Ruth” expressed immense appreciation towards her parents for their constant support. She said “My mom always told me I could do what everyone else can... She worked so hard at making me view myself as normal... I remember when she fought with the school board to put me in a normal class”. Her mother obviously played a pivotal role in her positive social adjustment. Family support was key to her self image.

### **Theme 4: Experience with personal health and the health care systems.**

An overall positive experience with doctors and hospital is described by “Ruth”. However, she did go through many corrective and esthetical surgeries during her childhood to improve the functionality of her upper limbs. Even if she does not remember her experiences, she claims “My first surgery was when I was 6 months old... before I started school I went through 12 to 13 surgeries”. “Ruth” claims that her most difficult experience at the hospital was undergoing a corrective surgery, which took place under 5 years ago. It was 6 weeks before she recovered and she felt very helpless being out of work. “Ruth” also claims that today she is experiencing pain in her neck and shoulders.

### **Theme 5: Romantic relationship.**

“Ruth” talks about a very healthy romantic relationship that evolved between her and her husband. They first met in high school. However, she says “When he left for college I thought that was it, but he continued to call on special days like Valentines Day”. She ended up at the same college as him and they ultimately married. Currently “Ruth” is happily married with 2 children, demonstrating how her disability proved to cause no difficulty in finding a life partner.

## Theme 6: Being a mother.

Very few issues emerged about “Ruth’s” physical disability interfering with the daily tasks of being a mother. However “Ruth” got emotional when discussing her high expectations from her children. She could not hold back tears as she explained “Because I was not perfect, my first child had to be perfect... I was too difficult on him”. She continues on to state “My children are my life”. She raises them to not feel pity for people with disabilities, but to see them as people with challenges like everyone else.

## Discussion

The interview content brought forward some interesting findings that the author further investigates using theories relating to disability, acquired from the scientific literature. A first concept that merits further investigation is “Ruth’s” evolving identity relating to disability. Throughout her life she identifies to all three of Olkin’s disability identity groups, which will be described further. Initially she denies her disability and thus identifies more with the able bodied community. At this stage she is relating to Olkin’s functional limitations group. A transition of disability identity takes place later in her life as a result of her involvement with the TVAC association. She begins to get politically involved with her disability community and starts viewing disability as a social construct. At this point she is identifying with Olkin’s civil rights group. Today “Ruth” is no longer involved with TVAC. She has incorporated her disability into her self concept and tries to live a normal life. Today she identifies with Olkin’s disability identity group (Olkin, 1999). The literature indicates that identifying with a disability culture is important, as it allows for a transformation of consciousness about ones self which is a great form of rehabilitation (Galvin, 2003). This is evident in the interviewee’s case as she admits: “I feel confident with who I am today”, thus depicting how progressively she has built a strong identity and a sense of self worth.

More so, the interviewee’s experience of discrimination deserves a detailed analysis. Discrimination and stigma associated to disability is recognised as a common problem for social integration. According to Goffman’s framework about stigma, “Ruth” who possesses a non concealable impairment, would be expected to experience negative attitudes of discrimination from her overall surroundings (Goffman, 1986). However she claims to have had very few

such encounters. Her overall experience may be related to her positive coping through her social skills and her competencies. It is known that as a person integrates the disability into a robust sense of self, others are more likely to display similar positive attitudes (Olkin, 1999). Such an explanation fits “Ruth’s” personality profile perfectly. She is a very competent woman, who makes frequent use of her social skills and her disability identity is strong.

Another concept that was brought forward in the interview is a family’s impact on the socialisation outcome of disability. Early-onset disability leaves family members with an important role in creating or inhibiting a positive identity for the child. The two most pivotal factors in the family’s response to a disabled child are, first to accept that child as a full member of the family and second to accept the disability itself (Olkin, 1999). Two studies confirm that an individual’s acceptance of their physical disability can be influenced by the degree of parental acceptance of the handicap and the mother’s psychological adjustment to the situation (Barakat & Linney, 1992; Gingras et al., 1964). “Ruth’s” outgoing personality and overall successful adaptation to her disability can thus be partially attributed to her family’s constant support, successful adaptation and her mother’s persistence in integrating her into normal society.

Additionally, even if the discussion of “Ruth’s” experience with the health care system is brief, it is valuable. The author recognised that “Ruth’s” strong, motherly and nurturing family roles made the recovery from her most recent surgery difficult to deal with. The conversation about this topic revealed her reluctance to accept her sick role. The sick role is the vulnerable status society allows people to assume when they are sick. The reluctance related to assuming this role is common in the case of most mothers (Geertsen & Gray, 1970). Even if the interviewee has very little recollection of her childhood surgeries, it is usually a very traumatic experience to go through. Often the foreign environment of the hospital and separation anxiety can cause a strong sense of loss of control for children, which can be very troubling. Moreover, her accounts of neck and back pain harmonize with new findings in the literature. A recent study on people living with the effects of Thalidomide indicates that of patients with limb loss, 40-45% experience subsequent pain affecting the upper spine or shoulders (Datta, Selvarajah, & Davey, 2004).

A final concept to address from the interview is the attitudes surrounding disability and relationships. A common myth exists that the able-bodied cannot be attracted to

disabled individuals. A study evaluating Thalidomide survivors indicates that 7 out of 10 survivors lived with a partner and over half had children (Bent, Chamberlain, Neumann, & Tennant, 2007). It is thus not rare for an individual living with a Thalidomide related defect to find a partner. Research also proves that when a person with a disability gets married, this union is more satisfying than marriages that are joined later by disability (Olkin, 1999). “Ruth’s” strong marriage to her husband is therefore supported by a vast amount of scientific literature.

In conclusion “Ruth’s” accounts show that living with disability is a unique experience that can lead to positive outcomes. The negative connotation that surrounds the concept of disability should be abandoned. Society should stop discriminating against this minority group and allow them equal status and opportunities. If all parents could raise their children to view individuals with disabilities in a positive light, like “Ruth”, society would become more tolerant. More extensive research is needed to further represent the voices of the disability community. This will promote the healthy desensitization of society’s negative perceptions of disability, and allow for a better overall understanding and acceptance of the disability experience.

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## Appendix A

### Interview Script

#### Introduction

The general aim of this interview is to uncover your overall life's experience as a person with a disability. Some personal questions may be asked, if you feel uncomfortable answering any of these questions don't hesitate to let me know. The interview will be split into two sections: the first includes demographic questions and the second includes questions relating to different life events:

#### Demographic questions

1. How old are you?
2. What is your current occupation?
3. How large was your family growing up?
4. What is your level of Education?
5. For the purposes of this project I must ask, what is the nature of your disability?

#### Life events and experiences

##### *Discrimination*

6. At what age did you first recognize that you were different from others and how did you come to realise this?
7. What period of your life was the hardest to deal with?
  - A) Probe: Would you say you faced certain forms of discrimination? If so can you give me an example

##### *Coping and Support*

8. How did you cope with peoples reactions to you?
9. Tell me about your relationship with your parents.
  - A) Probe: How did or didn't they support you?

##### *Disability identity*

10. How do you identify yourself with regards to your disability today?

11. Have you ever done any active lobbying in your community for yourself and others with the same impairment?
12. Do you believe having a disability from birth allowed for a better adaptation to living with a physical disadvantage?

##### *Experience with health care community*

13. How has your overall health been?
  - A) Probe: Have you been to the hospital often, if so for what type of treatment of care?
14. How have your interactions with the medical community been overall?

##### *Romantic relationship*

15. Tell me about how you and your husband met?
16. Did you ever question your ability to find a life partner?

##### *Motherhood*

17. What were the biggest challenges of being a mother?
18. Did you find your impairment got in the way of a lot of daily tasks?
19. How rewarding is it being a mother?