



# "Dignity and the Meaning of Life: The Life Experience of Spinal Muscular Atrophy Patients"

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Hsin-Mei Ho<sup>1</sup>, Fan-Hao Chou<sup>2</sup>

1. Department of Nursing, Kaohsiung Municipal Ta-Tung Hospital, Kaohsiung, Taiwan  
 2. School of Nursing, Kaohsiung Medical University, Kaohsiung, Taiwan

## Background

Of all the Autosomal Recessive Inheritance that occurs to a child, the Spinal Muscular Atrophy (SMA) ranks as the second. SMA is a chronic and rare disease that cannot be cured. If the child is seriously ill, he might die before two years old due to the infection of his respiratory tract. Because his slowly progressive myasthenia invades to the intercostal muscle and the muscle next to the spine, the child that survives might have Scoliosis and the function of how his lungs dilate in breathing might be influenced. Recently, medicine still hasn't found any effective therapy, so we focus more on taking care of their respiratory system.

## Purpose

Through the clinical nursing experience, the researcher found that a SMA patient often encounters many difficulties, and he needs to overcome all kinds of limits during the process. Some of the patients' life experiences really need to be understood, so we can provide them a better care, and make good use of the medical sources. For instance, we need to understand the patients' true feelings, the pace of their lives, how they seek for healing, etc. However, we seldom discuss the process of how they fall ill and their feelings. Thus, the objective of this research is to discuss SMA patients' psychological processes and the meaning of their lives.

## Methodology

In this study, we can show the essence of their real life experience by using phenomenological methodology. We conduct in-depth interview to collect our data. We use pen recorder as an auxiliary tool, and transcribe the patients' life experiences. We want to fully understand their psychological processes, turning points, and their reactions. Then, we want to discuss the patients' dignity and the meaning of their lives.

## Results

**Table 1. The Background of The Participants**

Assumed Name	Age	The Age of Onset	Years They Fell Ill	Type	Educational Background	Main Caregiver	Marital Status	Job	Religion
Ann	25	4	21	III	High school	Cousin	Unmarried	Information	Christianity
Mei	26	1	25	II	High school	Parents	Unmarried	Information	Buddhism
Jing	41	10	31	III	High school	Sister	Married (A kid)	Art editor	Buddhism
Cheng	25	13	12	III	Bachelor	Parents	Unmarried	Civil servant	Buddhism
Ya	54	13	41	III	Junior high school	Son	Married (Two kids)	None	Christianity
Xiang	44	14	30	III	Master	Parents	Unmarried	Teacher	Buddhism
Lan	28	3	25	III	Doctor	Parents	Unmarried	Research assistant	Buddhism
Qing	25	1	24	III	Master	Parents	Unmarried	Research assistant	Buddhism
Chun	42	1	41	II	Bachelor	Foreign caregiver	Unmarried	Teacher	Buddhism

**Table 2. The Topic and Secondary Topic of a SMA patient's life experience**

Topic	Secondary Topic	Description
Loss of control	1. Degeneration of their muscles	1. Fell down easily
	2. Unable to be independent	2. Difficulties in daily life 3. Need family's help 4. Become family's burden
Breakthrough the limitation	1. Using assistive device	1. Make good use of wheelchair
	2. Accessible environment	2. Adapt to the change of the environment 3. Reaction to physical limitation 4. Concentrate on daily life
Pursue the dignity	1. Face the challenge independently	1. Face all kind of challenge independently
	2. Development of social life	2. Become a independent person 3. Build a positive thinking mindset 4. Enrich their working life
Regain the hope	1. Cherish their life	1. Cherish the limited life
	2. Self-control	2. Have faith in ourselves

## 1. Loss of control

The process often starts from seeking medical advices when the participants fall ill. Then, it come to the moment when the doctor certifies that this disease is incurable. As time goes by, the participants start to fall down easily, because their muscles gradually lose its functions, and they would encounter some difficulties in their lives.

## 2. Break through the limitation

When a SMA patient knows that this disease is incurable, he suffers both physical and mental torture at first. He will find tools that are important to his daily life, and he starts to rely on wheelchair. Wheelchair becomes the best transportation in his life. His mind will become more positive, and he will make good use of the wheelchair in order to make his own life more convenient.

## 3. Pursue the dignity

The participants can't well-developed their life's goal like a normal people because they suffer from this long-term disease. This disease might threaten their personal economy, the society and the independence of their mind. The start to devote themselves to work, and become financially independent. Their lives become colorful while pursuing the dignity of achieving their own life goal.

## 4. Regain the hope

The reason we live is because we want to find back our physical autonomy. SMA patients have no idea what will happen in their future, but they still live optimistically. Even though they know their lives aren't going to be perfect, they still try hard to live. Only if we have faith in ourselves, will we optimize the Great value in our lives no matter in what kind of ways of living.

## Conclusion

We hope that people can be familiar with SMA patients through the experience they shared, and how they reacted to their disease. We offer a window to show the nursing assistants and the public what the SMA patients need. Professionals should give the patients sense of trust and care based on the patients' dignity, and avoid letting the patients feel being discriminated. The professionals need to take initiative to offer the wheelchair and other sources in order to let the patients accept the wheelchair. Also, the professionals should help the family members to understand the function of the wheelchair, and improve the convenience of the patients' lives.

Clinical staff are suggested to make a life experience working guide that apply to these rare disorder patients. Other clinical workers may refer to this guide and learn from it in the future. When helping the patients adapt to their disease, we will actively provide the patients some assistive resources. Through the help of the patients who also suffered from the same disease, we can understand what the patients and their family members need. We can understand their feelings and experiences. Finally, we will help the patients develop their own capability, and reach their final goal-surpass themselves.

