

Compassionate Communities for All from Children to the Elderly throughout Japan

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Background

Japan experiences a declining population and is facing an age of high mortality. In order to realize a society in which people can live their final days as they wish, wherever they live, it is important for healthcare professionals to be sincerely engaged with them until the end of their lives. The fundamental part of end-of-life care is a relationship with people who have “suffering that is difficult to resolve” and who have not been able to value themselves, so that they can feel that “it is OK to live as I am” and “I am grateful to have lived”. On the other hand, this is not something that only professionals should be able to do; citizens, from children to adults, are also encouraged to learn together. What we have learned as end-of-life care can be useful for all people living in the present, and the first step is to make it personal.

Objectives

To review 10 years of practice. We developed an educational program that enables people who do not necessarily specialize in medicine to practice the essentials of spiritual care, which is crucial in working with people in the final stages of life. Since it is important to reflect on one's own experiences, we have also created a system for continuous learning. The program has spread nationwide in a grassroots manner, and everyone from children to the elderly are learning about it. The topics are not necessarily death or dying.

Design & Methods

The essence of spiritual care cultivated in hospice and palliative care was defined as five tasks, and the concept of a Universal Hospice Mindset was created. Based on this, the first educational program was developed, and the course was held nationwide (Phase 1). We also developed a program for those certified to share in their own workplaces and communities and supported the establishment of communities of continuous learning in each region (Phase 2). We developed programs that children could also learn from, as well as tools to enable certified individuals to conduct their own workshops (Phase 3).

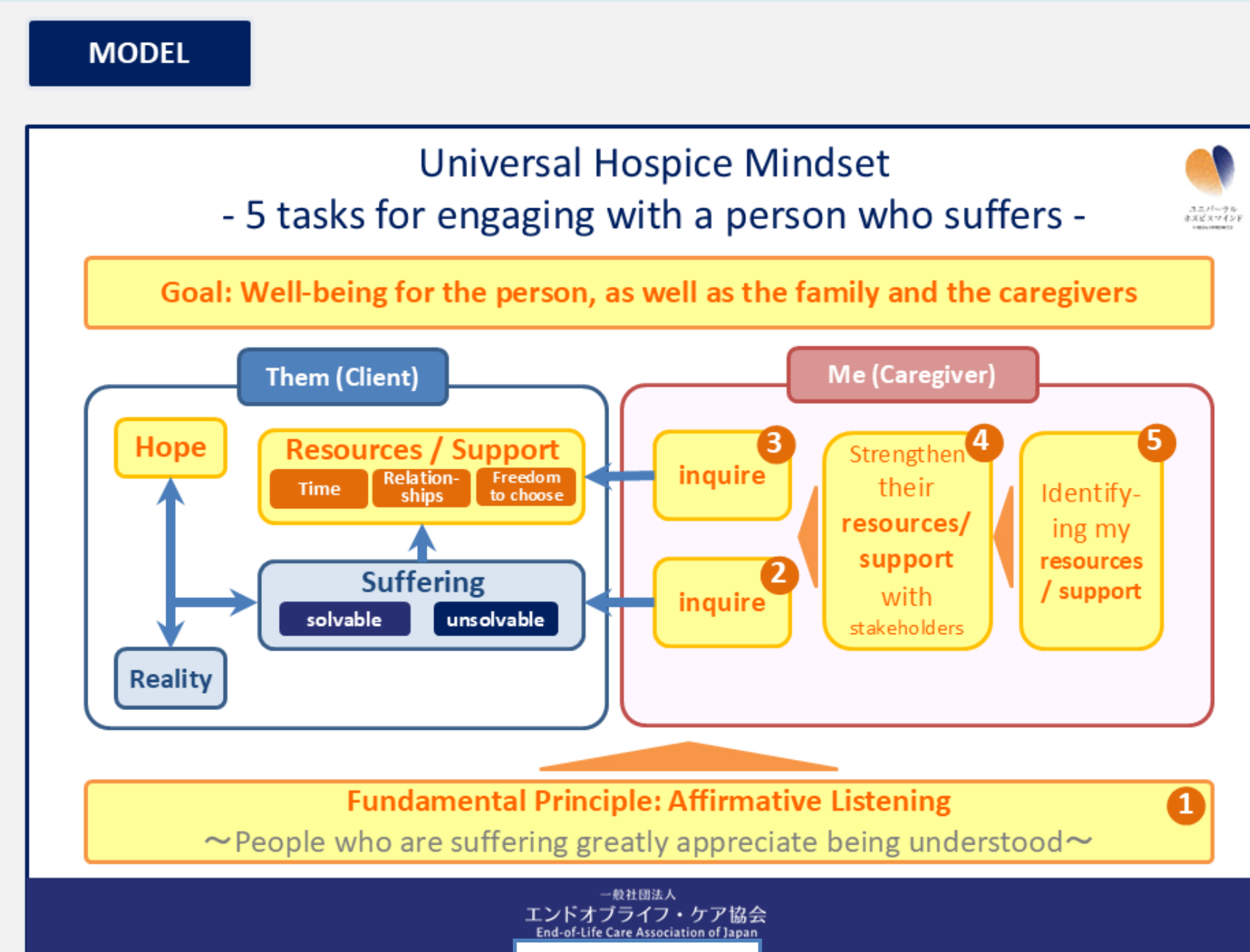
Results

The End-of-Life Care Supporter Basics Course was offered to 8,666 people from 2015 through September 2024. Although quite a few professionals have difficulty in dealing with spiritual pain, there are increasing reports of improvements in the quality and quantity of end-of-life care through practical learning. In addition, 56 communities across the country have spontaneously emerged. Voluntary workshops are being held nationwide in local communities, medical and social work professional education, etc. In 2018, Lessons of Life also launched a certification program.

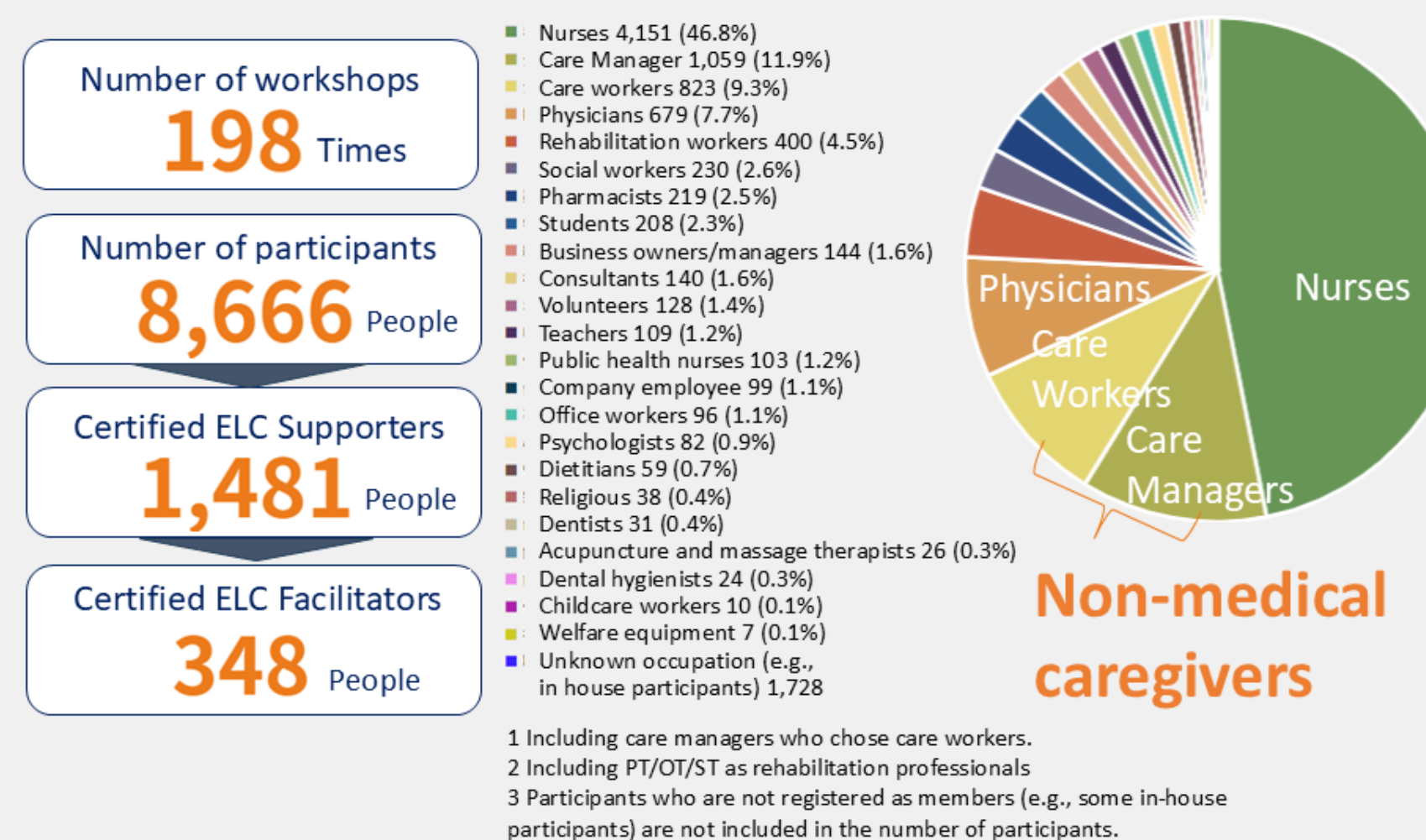
Analysis

Phase 1

Development of Supporters (Individuals)



RESULTS End-of-Life Care Supporter Basics Participants and Next Steps



RESULTS Participants' Reactions

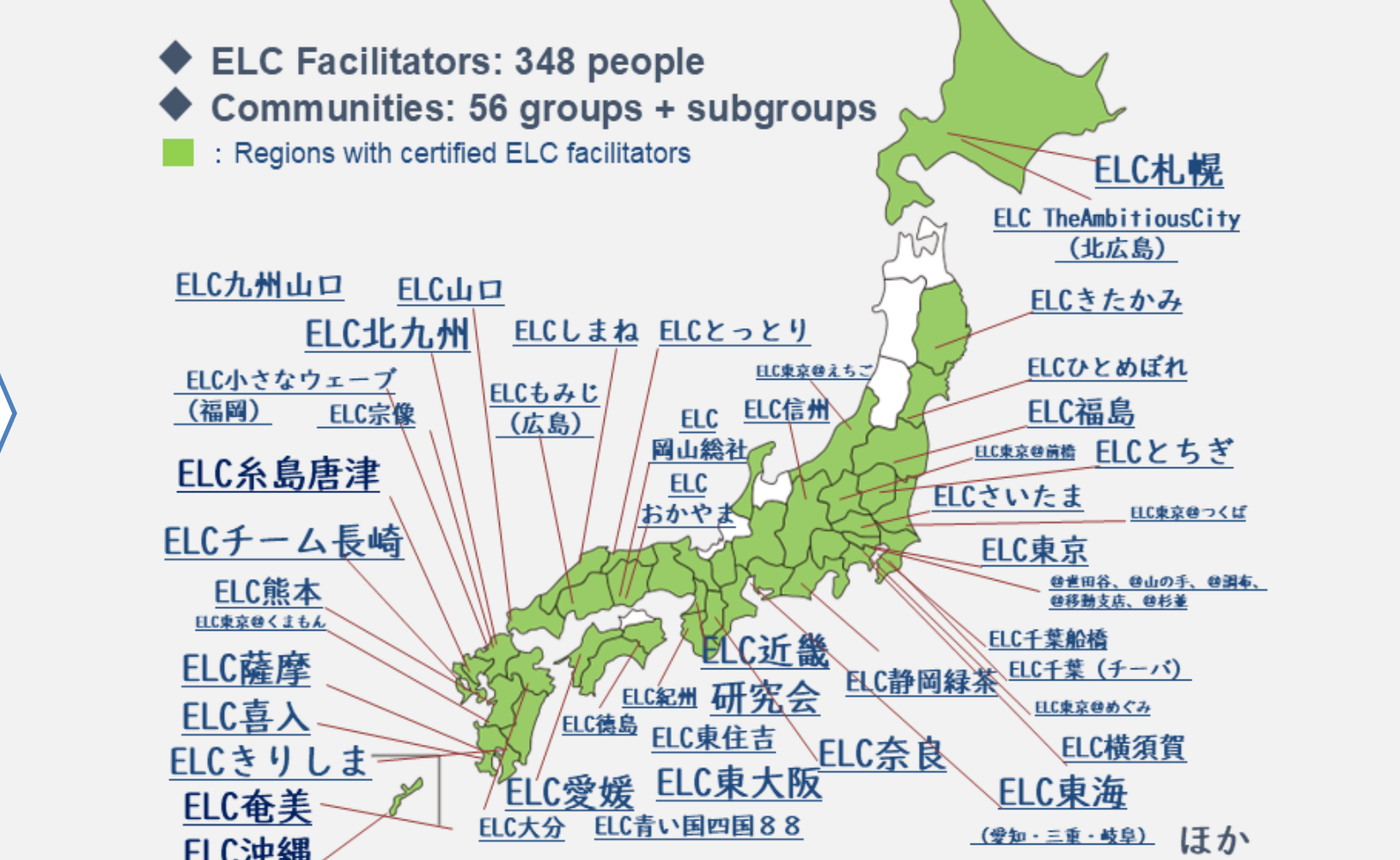
- Hesitation**
- When the patient tells me he/she want to die, I don't know what to say in return...
 - I wonder if there is something more I can do...
 - A sense of loss after seeing them off...
- Confidence**
- Supportive communication with repetition, silence, and questioning
 - Work together with people from diverse backgrounds to verbalize support
 - Knowing and strengthening the support of those who support
- “What I thought ‘could never be possible’ turned into ‘might be possible’.”
 - “I became able to focus on the ‘future’ of the patient, which I had been avoiding, and to see it as ‘support’.”
 - “Through the role play, I realized that there are differences in the way the listener and the speaker perceive the patient's thoughts and feelings, and that there is joy in being able to share them with the patient.”
 - “As a caregiver, I had been thinking of understanding, supporting, and solving the problems of others, but I realized that I had been giving myself a sense of impatience and difficulty, and this changed my way of thinking.”
 - “I saw something in End-of-Life Care that is common to all people, not only those in the final stages of life, but also those who have difficulty living, children, and all people.”

Phase 2

Continuous Learning Communities (Spontaneously Emerged)

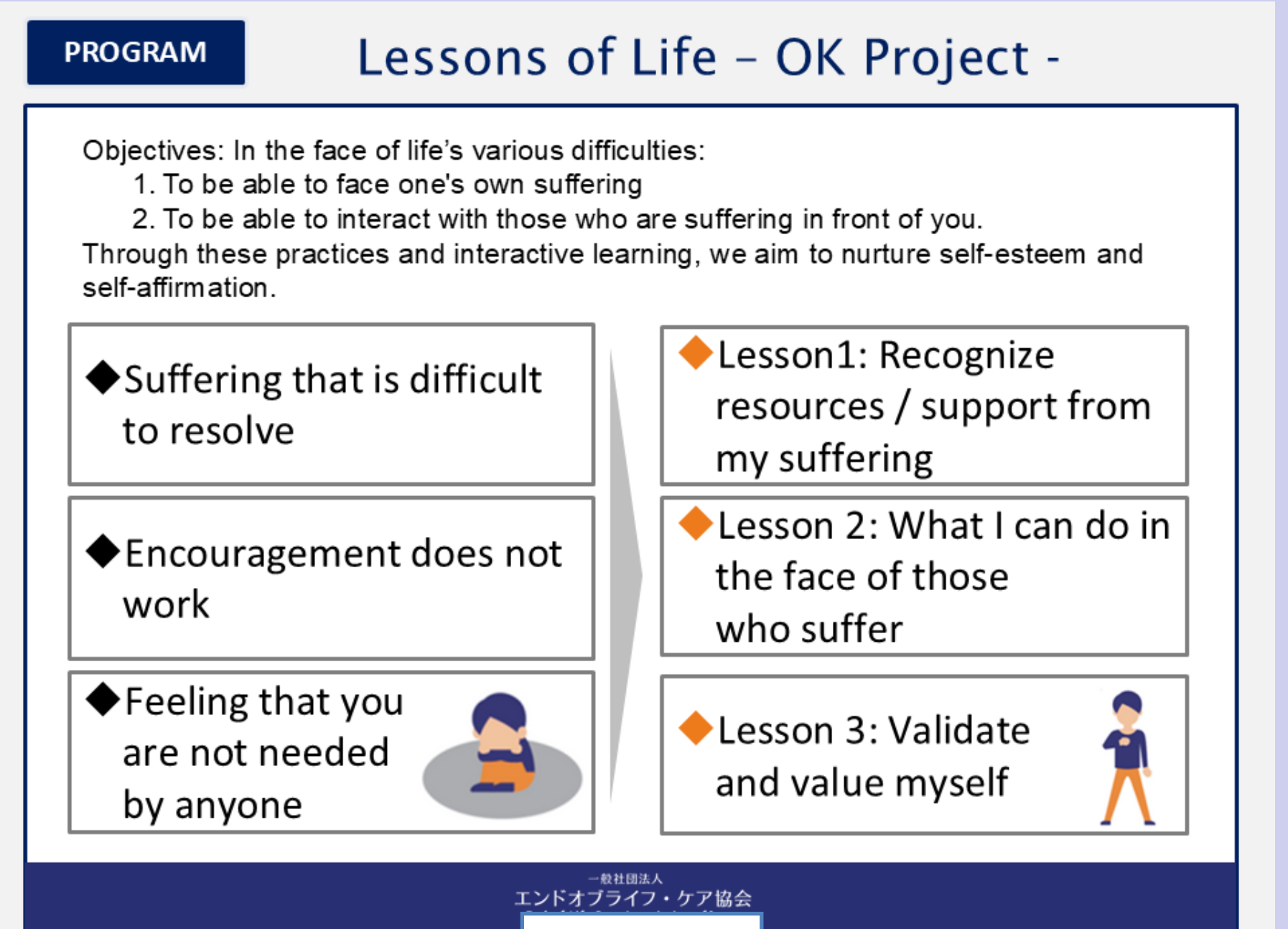


Formation of Learning Communities



Phase 3

Compassionate Individuals and Communities in Everyday Life



RESULTS Growing Diversification of Supporters Certified Trainers for “Lessons of Life”



RESULTS Participants' Reactions

- Awareness**
- For myself**
- “I have been bullied since I was a child. But I didn't understand it at the time, but now I think that I have been able to do my best until now because my most important friend has always been by my side. Today's story has made me think about that all over again.” (1st Grade Jr. high school student)
- For others**
- “Now that I know that suffering is the gap between hope and reality, and how important pets, family, and friends are, and how lucky I am to have people who support me, I will never say I don't want a sister again, why she was born, or that she should die or disappear. But I will try to be kind to my sister because when I get frustrated, I tell her I hate her even though I love her. But I'm glad I have a family.” (6th grader)
- Actions**
- “I, also, wanted to disappear from this world as soon as possible, but after attending this class, I decided to live a little longer. I was taught many things, so when I have a hard time, I will remember this lesson.” (5th grader)
- “I have various illnesses and people don't understand my illnesses, and they say negative things about me. So, if there are people who are in trouble, I would like to listen to them and support them. I believe that people sometimes suffer from their problems without expressing them in words, and they keep them bottled up. I also learned that it is only when you feel suffering that you can become aware of it. I also thought that I would be willing to support others.” (2nd Grade Jr. high school student)

Case

Changes at home (parent-child dialogues on a daily basis)

Before encountering the program	Ever since the mother and daughter started learning the program ...
<ul style="list-style-type: none">The mother and her daughter, who is in second grade, used to clash easily with each other.Normally, as a nurse, she is always smiling and sincerely engaged with her patients, but as a mother, she was depressed about the fact that she was constantly yelling at her daughter.“I feel like parenting is just a struggle. I'm not a good mother. I don't want to admit myself. I can't expose myself, and parenting feels lonely.”After the children went to bed, she apologized to her daughter's sleeping face every day and blamed herself (mother).	<ul style="list-style-type: none">Daughter and mother now have a common languageThe daughter unraveled her mother's suffering. She said, “Suffering is the gap between hope and reality, so your hope is like this, but the reality is like this, so you are suffering.”The daughter's eyes lit up as she told her stories. She said, “My friend was suffering, so I listened to her, and she talked a lot. She thanked me for listening. I could feel my relationship with my friend getting stronger.”The daughter's understanding of her friends has also changed. She used to complain all the time, but now she says, “I wonder if it's because he's in so much pain that he hurts people even though he knows in his head that he shouldn't.”The mother began to think of waiting for words to come out of her daughter. She used to immediately try to encourage and explain, but she swallowed her feelings of anguish with a little gulp, and started “silence, repetition, and questioning.”The mother faced the pain she had. She realized that there was a gap between her “hope” to be a mother who always smiles and gently wraps her children in her arms and her “reality” of being a nagging, angry mother, and that she was suffering because of this large gap.

The daughter is now in the sixth grade and became a certified trainer herself last year.

Conclusion

Now that communities of continuous learning have been established in various parts of Japan to study the essence of spiritual care, activities continue to expand in cooperation with the various activities already in place in the community. Reports of change are being gathered as those who have learned put it into practice with their families, workplaces, and others within a five-meter radius of their immediate surroundings. Even if the theme is not necessarily “death,” we believe that they have realized what matters to them because they have faced the suffering that is close to them. There is also a movement where people who have been helped by someone else feel that it is their turn to reach out to someone else. We would like to support more and more communities where such compassion and kindness circulate.

Our Theory of Change

