

THE COURAGE TO FORGET:  
AN INTERPRETIVE STUDY OF EXISTENTIAL CONCERNS REVEALED IN GROUP PROCESSES BY  
INDIVIDUALS LIVING WITH DEMENTIA

By Suzan Bollich, PhD

*Abstract*

The existential experiences and concerns of individuals living with dementia are largely unknown. I am proposing a hermeneutical or interpretive study to lay bare and make meaning of the voiced existential experiences and concerns of individuals living with dementia.

*Introduction*

Pacific Institute and the AgeSong Senior Communities are organizations that help create therapeutic environments for the elderly. One program area of Agesong Senior Communities is dementia care designed by Pacific Institute. This program takes an interdisciplinary individualized therapeutic approach to dementia care. It aims to provide therapeutic spiritual, social, psychological, emotional, and physical care for individuals living with symptoms of dementia. However, more in-depth attention to, and understanding of the existential experiences and concerns of people living with dementia, is needed in dementia care. One way to bring attention to, and gain more in-depth understanding, is to study individuals who can still verbalize their experiences of living with dementia.

*Purpose of the Study*

The purpose of this study is to lay bare the voiced existential experiences and concerns of individuals living with dementia. I believe that the voiced experiences, concerns and feelings of individuals living with dementia remain consistent when these individuals become non-verbal due to one symptom of dementia, aphasia.

*Research Question*

What are the existential experiences and concerns of individuals living with dementia?

THE COURAGE TO FORGET:  
AN INTERPRETIVE STUDY OF EXISTENTIAL CONCERNS REVEALED IN GROUP PROCESSES BY  
INDIVIDUALS LIVING WITH DEMENTIA

By Suzan Bollich, PhD

*Rationale of Study*

Expressive therapy groups for individuals living with dementia are particularly effective. Expressive therapy groups take the form of signing, listening to music or poetry, movement, and art-making, for example. They provide a space for creativity on individual and community levels, as well as increase the physical, mental, emotional, and spiritual well-being of individuals. In this modality, existential experiences and concerns *could* be expressed and interpreted. But I have found that when individuals living with dementia are provided a place to share and process their experiences, they *directly* express existential experiences and concerns.

There is a profound quality of knowing, of sensing, that bubbles up when an idea emerges from intuition rather than from actual experience. It feels like both unsettled knowing and grounded truth. This is the feeling I encountered when I conceived the idea of facilitating group process meetings with individuals who are living with dementia, yet could verbalize their lived experiences and concerns. This idea has come to fruition, and I have met with this group four times thus far.

For the first meeting, I wanted to convey the intention of a “therapeutic” group process, so I began this way: “This is the first time we are meeting together and the intention of having this group is to create a therapeutic environment where you can discuss anything that you would like to.” Immediately, a group member asked: “What do you mean by ‘therapeutic environment?’” I thought quickly and said: “What I mean is that we will create a safe, non judging space for you to speak about whatever you want to speak about. For example, you might like to speak about what it is like for you to live here; or, you might speak about any concerns that you are having.” Then, the unsettled knowing feeling took hold of me again, but not for very long. Not for long because I knew I had stumbled on something significant when group members immediately began to speak about feelings of

THE COURAGE TO FORGET:  
AN INTERPRETIVE STUDY OF EXISTENTIAL CONCERNS REVEALED IN GROUP PROCESSES BY  
INDIVIDUALS LIVING WITH DEMENTIA

By Suzan Bollich, PhD

isolation, aloneness and despair. Some spoke of living without choice and freedom (e.g., the imposed inability to come and go as desired). Two members shed tears about their family's decision to place them in a care facility, that they had no choice in the matter. Some of the members spoke about the disconnection with family, as well as being a burden to their families. Upon hearing such experiences and concerns, I felt as though my heart was stopping; the realness of what I was hearing was both halting and exhilarating. Witnessing such raw truth can have that effect.

Much of my training has centered on existential-humanistic psychology. But I was not expecting to hear group members' existential experiences and concerns when I conceived the idea of facilitating these groups. However, when I did hear the group members concerns, I immediately interpreted them to be existential concerns. How could I not? For example, some members of the group spoke about living in the here and now. However, this here and now way of existence is very distinct from the in-vogue spiritual dictum to live in the here and now. Living in the here and now for people who have very little or no short-term memory means a lack of a sense of excitement about having a plan for the future, planning a dinner for a loved one, for example; it is devoid of anticipation or the expectation of a luminous moon rise, for example.

In this way, living in the here and now with dementia takes a kind of existential courage. I have interpreted this as the courage to forget. Hence, the intention of this study is to employ a hermeneutical or interpretive research method to lay bare and make meaning of the existential experiences and concerns of individuals living with dementia.