

A daughter's experience when her mother is struck by dementia

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Essay

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Summary

Background: Dementia affects not only the person who is sick, but also their close family. Knowledge about their experiences can be helpful for healthcare personnel who interact with patients and their families.

Objective: To examine families' experiences when a loved one is affected by illness and does not have long to live. The experiences are taken from Marie Peterson's documentary novel *Du tror du vet alt* (You think you know it all). The following question is the starting point: 'How does it feel to be a daughter when your mother is affected by dementia?'

Method: The essay is used as a critical exploratory method.

Results: The story provides insight into what it is like to be a family member when a loved one becomes sick, in need of help and nearing the end of their life. When a family member becomes ill, there is a desire to understand what is happening. A multitude of questions are thrown up as the disease progresses, and even more when death is approaching. It may seem paradoxical that Marie tries to ‘reach out to her mother’ without ever managing to do so. Marie’s need to understand is also at odds with the realisation that she needs to ‘let go’. What help can be given to a family member who is struggling to comprehend what is happening whilst simultaneously trying to let go?

Conclusion: The book shows the relational interplay between a sick mother and her daughter up to the point of the mother’s death. The daughter’s empathy with the mother’s suffering, and her struggle to regain her footing are enlightening, and help the reader understand what is at stake between the two of them. Thus, the book is a unique source for understanding both mother and daughter. It inspires conversations about relationships, life and death – and the need for support from the nursing profession.

The purpose of this essay is to examine family members’ experiences when a loved one is affected by dementia. The starting point is a daughter’s experience with her mother’s dementia journey. The theme is explored by analysing Marie Peterson’s documentary novel *Du tror du vet alt* (You think you know it all) (1). The essay is a reflection of a daughter’s experiences, and is based on the question: ‘How does it feel to be a daughter when your mother is affected by dementia?’

A desire to understand

Marie experiences a series of events with her mother that trigger a desire to understand. One such event is when her mother wants to go to the bank and Marie accompanies her. The mother’s problems with language mean that it is not always easy to understand what she is saying.

‘I need to have for my hands...’

‘Do you mean gloves? ... This one goes on your right hand, and this one on your left.’

This simplistic explanation irritates the mother: ‘You think you know it all’, she hisses (1, p. 7).

The book opens with this exchange. We see frustration and underlying irritation, and a clash of strong wills and fiery tempers. Marie's mother is a retired school librarian. She has always been and still is a strong and independent woman. She has had a tough life, but has always thought it important to manage on her own. She is now becoming increasingly forgetful.

As a child of divorced parents, Marie has not grown up with her mother. Her mother left home when Marie was two and her sister was just a baby: 'She's my mother, and I'm her daughter, but we've never been part of each other's everyday life' (1, p. 124). Now the daughter is putting considerable effort into understanding and helping her ailing mother, whose need for help is becoming greater as time passes. The mother herself insists on managing on her own, and objects to the intervention.

When life is turned on its head

Marie's life is turned upside down when her mother becomes sick. Her sister calls: 'Mum can't tell the time'. The information seems completely surreal. 'She can so', replies Marie (1, p. 19). It transpires that her mother's cognitive grip on life, including telling the time, is slipping away. Her memory is failing and her behaviour is changing. The changes make Marie feel uncertain and confused.

It hurts Marie to see her mother searching for words. She never gets to the point, which makes her feel embarrassed. Marie tries to identify a system in the linguistic deterioration. Understanding abstract concepts is becoming difficult for her mother. 'It's logical', Marie thinks, 'but why are the verbs disappearing before the nouns?' The language is noticeably stripped down.

In an effort to understand her mother, Marie goes through old letters she has received from her. She compares letters from before her mother became ill with letters she has received since. Marie looks at the handwriting, looking for the 'tone' in the letters. The early ones are impersonal. When she was 12, she received a matter-of-fact letter, as if her mother was writing to a friend her own age. In the last letters, her mother shows affection: 'Big hug, hope you come soon, kiss, kiss, kiss' (1, p. 17). Now that Marie is an adult, her mother calls her 'her little nestling' (1, p. 97). Mother and daughter have always been out of step.

Trying to understand her mother by understanding herself

In the beginning, the visits to the mother are dictated by specific needs. Marie listens to her in an attempt to understand a mysterious and brutal disease. She wants to try to preserve her mother's memories. Marie gradually notices that she herself changes tack. It becomes more and more about her own life rather than her mother's life. It is striking that the first part of the book documents Marie's struggle to understand her mother, while the last part is about Marie trying to understand herself. Meanwhile, her mother is falling apart... (1, p. 51).

«Her mother's illness triggers a need in Marie to understand what her mother is going through and how the disease is changing her behaviour and language.»

Her mother's illness triggers a need in Marie to understand what her mother is going through and how the disease is changing her behaviour and language. The visits to her mother also awaken a longing to understand who her mother was, and by extension, a desire to understand her own childhood. The conversations, the time spent looking through photo albums and reading old letters become discoveries and insights that give Marie a new understanding of her childhood years, and that fill in some of the blanks about the past and her mother's role in it.

Alzheimer's disease does not only put the spotlight on the mother and who she was; Marie is also confronted with herself and her previous and current relationship with her mother. In the end, Marie comes to terms with the situation – that she was not exactly successful in reconciling with her mother, 'but the most important thing was that we tried' (1, p. 157). Marie's story shows the universality of facing a frightening disease where death is an inevitable outcome. The need to understand what is happening and to take stock of one's own life when parents are close to death is something that all patients' families can experience.

Different levels of understanding

The deadly Alzheimer's disease throws Marie into turmoil. 'Leads to death, leads to death', Marie repeats, still not fully comprehending: 'How can you die of it? Do you forget to live?' (1, p. 21). Losing the ability to use language and to think is alarming, both for the person struck by the disease and for their family.

The clock-drawing test is simple, but demonstrates severe cognitive failure. The circle that the mother draws is not connected. After much doubt, she places the clock hands at 11 when she wants to show that it is 3 o'clock. The test situation is very embarrassing for the language enthusiast. For Marie, it is shocking. The test becomes a mark of the disease, as well as a symbolic declaration: Now the countdown begins. The mother's days are numbered. The thoughts become intrusive. Marie makes coffee and thinks: 'dementia'. When doing the washing up her nagging thought is: 'Alzheimer's is fatal ... the doctor said 15 years ...' (1, p. 21).

Psychiatrist Lars Sjöstrand (2) writes that people understand at different levels – concrete as well as existentially. Explanations of cellular changes that kill brain cells represent one level, but this does not touch on questions related to death and existence. Sjöstrand calls it ‘the phenomenology of death’. Marie is confronted with her mother’s looming death. Her mother’s existence is coming to an end.

Existence characterises the conscious person and involves ‘standing up or exceeding oneself’ (2, p. 22). That is exactly what Marie does. For her, the idea of her mother’s death entails an existential challenge. Marie has a genuine desire to reach out to her mother, but time is now short. Marie tries out the word ‘mum’. Her mother is not ‘mum’, and never has been. When Marie thinks about her mother, she thinks of ‘Siv’. Sometimes she just thinks about her laughter. She thinks of someone who did not care about protecting her when she needed it the most – and who rejected her daughter’s questions by starting to cry.

Seeking shared experiences

Marie often visits her mother now that she is sick. Hours are spent looking at old pictures. Shared experiences that neither of them remember clearly. Her mother dancing in front of a mirror, ready to go out. Her hands are always busy, strong and rough. Marie does not remember a single caressing touch. Looking at pictures serves at least two purposes; it is something that mother and daughter can do together, and it evokes memories.

Time is always an integral part of our experiences. As such, we do not just live in the here and now, but seek to link the past with the present with a view to the future (2). At the same time, looking at the pictures makes Marie realise just what a small part she played in her mother’s reality. Symptomatically, Marie finds a photo from their trip to Telemark, where she is barely visible – only half of her boot can be seen at the edge of the picture, and the rest of her is not in the shot (1, p. 108).

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Her mother’s disease makes it clearer to Marie that life has its limitations, and triggers a need to take stock. The deterioration in her mother’s body and her impending death make it clear that this is a last chance to reach out to her. Or rather – a last chance for Marie to have the experience of her mother wanting to reach out to her eldest daughter. ‘That was a ridiculous wish’, she admits (1, p. 147). Nevertheless, she gives it a go. Photos and old letters serve as aids to Marie’s stock-taking. The outcome is bad for Marie; her mother is the same as she has always been: self-absorbed and self-centred.

Death sums up life

In the end, Marie has to force her mother into a nursing home. Her mother is suffering from a lack of care following a long period of living alone in her flat. Heart-wrenching scenes ensue. Both mother and daughter are temperamental. They stand screaming at each other. The mother is steadfast and angry, and Marie is in despair. There is little to suggest here that the mother-daughter relationship is getting any closer. Or is that exactly what is happening? Marie's mother fumes and screams. Marie gives as good as she gets (1, p. 78).

Marie's struggle to understand takes place at several levels; on the concrete level – in terms of the progression of the disease, and her mother's behaviour and needs. Efforts to understand also take place at the abstract level – in relation to the life that was, which is soon over, and to death. Both for her mother and herself. Death is life's final destination, and becomes an end point that helps to delimit and define life (2). The conceptualisation of the mother's imminent passing sums up life in its entirety, not just the mother's life, but also Marie's. The need to understand is all-encompassing for Marie.

Letting go

There is a pained undertone to Marie's quest in the book. She desperately wants to reach out to her mother, and has a deep need for her mother to be willing to reciprocate: 'That's why I visited her so often. I hoped she would want to get to know me. I hoped she would be, not a mum, because it was too late for that, but someone who was a bit more normal' (1, p. 147).

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Marie then has a revelation. She suddenly sees the barriers that she herself has erected in her relationship with her mother. She surrenders them now. It happens in a single defining moment: '... and it took no longer than changing hands on a shopping bag ... That barrier had remained in place for many years, with myself as the strictest border guard' (1, p. 146). Marie suddenly realises that she has been on the defence. She now sees her mother in a different light: 'She's so small, so thin, just an old lady really, totally harmless' (1, p. 152). Marie can now even accept compliments: "'I like you a lot,'" her mother says. My mother has never said that before' (1, p. 159).

Marie's mother is slowly disappearing. Her movements are becoming stiffer. Her gaze is becoming empty. She cannot follow what is going on. 'How do you let go', Marie wonders (1, p. 153). She understands that she needs to loosen her grip and let go, 'but I don't know if I can' (1, p. 153). The grief comes first. Suddenly and directly, and in images: '... as if I'm filling up with water. When it reaches the heart, it suddenly transforms into a stone that forces its way into the bloodstream ... and circulates ... and every time it passes the heart the pain returns' (1, p. 155). An all-consuming grief, felt in every breath: '... at its worst when I breathe in. No, when I breathe out' (1, p. 155).

The grief seems to help Marie let go. It signifies that the time has come. Marie 'lets go' by imagining her mother sitting in a boat, half turned away and looking out at the water. The bow of the boat is in the sand. Marie squats down and holds the railings on the boat with both hands. She does not want to let go, but she has to. 'Mother looks so lonely! And it's as though my hands know what to do. They let go of the boat. And as she glides out, I realise that I made it. ... Strictly speaking, our attempt to reconcile was completely unsuccessful, but the most important thing is that we tried' (1, p. 157).

Coming to terms with her childhood

A childhood can be a long 'sentence' to serve. Now well into adulthood, Marie still feels a sense of longing for her mum. The mother of her childhood was rarely there for her. Marie feels aggrieved by her mother's choices and actions. Actions always involve a risk of causing hurt, claims Hannah Arendt (3). The very nature of actions means that they can have detrimental effects for others, often without the person carrying out the action being aware of it (3, p. 236).

One way to understand Marie is through how she comes to terms with the neglect of her childhood years in adulthood. The photos that she and her mother look at show that she was not part of her mother's life. The letters signify her mother's impersonal and scant involvement when Marie was a child. According to an 'Arendtian' interpretation, the daughter may have been hurt without the mother knowing or realising that she had caused offence. Readers of the book are left to speculate how it is possible for a mother to let her child down so badly, without 'realising what she is doing'.

By their very nature, actions are irrevocable (3, p. 236). Even if her mother had regrets, her past actions could not be undone. Marie has to live with the consequences of her mother's actions. Must people live the rest of their life with the burden of others' past mistakes? 'No', Arendt says, 'The possible redemption from the predicament of irreversibility – of being unable to undo what one has done though one did not, and could not, have known what he was doing – is the faculty of forgiving.' (3, p. 237). What's done cannot be undone.

Forgiveness can release a person from the consequences of hurtful actions, and give them a fresh start. It is not the action that is forgiven, but the person. The aggrieved party says 'you hurt me' (3, p. 237). The question of forgiveness primarily applies to actions that are not intended to be hurtful, in Arendt's opinion. Actions with malicious intent are another matter. 'The reason for the insistence on a duty to forgive (...) does not apply to the extremity of crime and willed evil...' (3, p. 239).

The importance of forgiveness

Forgiveness entails a form of relationship, claims Arendt, indicating that it is an interhuman experience (3, p. 241). Some of the most powerful descriptions in the book are when Marie writes about the new relationship that arises from the defining moment she experiences. Broken relationships are resumed. The ability to forgive has a bearing on mental health (4, 5).

'To reconcile' means to bring together. This is precisely what Marie writes about. Mother and daughter are brought together again, but not in such a way that there is harmony in the relationship. Marie discovers the barriers she herself has put up, and lets them go. Her mother did not play much part in her daughter's life, but in spite of this, Marie breaks down the self-constructed barriers to reconcile with her mother. While Marie tries to understand and hold onto what is happening, her mother's life is nearing its end, and Marie has to let go. For Marie, it is about letting go of her own defence mechanisms, and also letting go of the mother she became close to as her life was drawing to a close.

Relevance for nurses

How is Marie's story relevant to nursing? Can nurses do anything in the reconciliation process between a mother and daughter? It is highly likely that a nurse will encounter mothers and daughters in, for example, nursing homes, as relatives and patients. Being given a life-threatening diagnosis is painful on various levels for patients and relatives. Painful situations can open up opportunities for good conversations about relationships and forgiveness. The time can therefore be important both for the ailing patients and their relatives (6). Being aware of this can make a difference to how nurses deal with a patient's relatives.

«The accusatory title of the book – You think you know it all – can also affect nurses who already think they know what a patient's relatives are going through.»

A lack of knowledge about other people's existential experiences makes it easy to resort to clichés in conversations (7). The accusatory title of the book – You think you know it all – can also affect nurses who already think they know what a patient's relatives are going through. Conversely, knowledge about other people's turmoil and life challenges can be a good starting point for good conversations, if a patient's relatives so wish. When nurses actively listen and respond to input, relatives can gain strength from the interaction.

An open and caring attitude is the best starting point for understanding the other person's perspective. Patients' relatives may not want to talk to nurses about existential issues. Nevertheless, they need to be treated with respect and an understanding that life can be painful. It is essential that nurses are aware of the pain of others. In Marie's situation, the mother and daughter are feeling their own personal pain in different ways.

Reflections on method

The essay is used as a critical exploratory method (9, 10). Ontologically, this method involves using human experiences as a basis for developing knowledge. In epistemology, critical questions are posed about the experience (the text) in order to garner reflections and discover the inherent meaning of the experiences (9). The method becomes critical and exploratory when the questions result in personal preconceptions being challenged, enabling new insights to emerge (10). It is Marie's experiences with being the daughter of a seriously ill mother that are examined.

Michel de Montaigne is known for developing the essay as a literary genre. According to him, 'essay' meant to try or test (11). Literary texts can be fertile sources for testing out our personal understandings, both from a moral and professional perspective, thereby developing insights into human diversity. In this article, arguments are explored by essayistic reflections on Marie's experiences.

Fundamental element of the method: asking questions

Gadamer (12) argues that asking questions plays an important role in learning from experience. The essence of the question is to generate possibilities and test them out (12). My purpose of asking critical questions about the book's text is to shed light on the daughter's experiences when her mother 'falls apart'. In the essay, I have tried to understand the experiences in ways that may be relevant to nursing. Marie's story is unique in the sense that it is based on her personal experiences. Yet her experience can be representative of what many people go through in similar situations. Collecting knowledge and understanding from an experience represents an analogic form of reasoning that can be transferrable, and thereby constitute a significant contribution to learning (13).

Analysis

The systematic examination of the book's text has taken place in three stages (9). In the first stage, I read the entire book in order to get an overview. I then asked questions about the text, paragraph by paragraph, page by page, chapter by chapter. During this phase, units of meaning were identified that are relevant to the experience of being a daughter when the mother's cognitive ability becomes impaired. I distributed the units of meaning into categories and themes, which showed three main themes in the efforts to understand Marie's experiences:

1. A need to understand arises.
2. The understanding takes place at various levels.
3. Managing to let go when the inevitable death takes place.

In the third stage, I examine the phenomena through theoretical reflection (9). Here the themes are illuminated using theory. Arendt's (3) descriptions of 'action' and 'forgiveness' are particularly useful for gaining an insight into Marie's struggles during the process of letting go and saying goodbye to her mother.

Validity

The reflections are intended to capture the inferences from Marie's experiences, and how these can prompt research questions (10) that are relevant to the development of knowledge in nursing. The determining factors in terms of validity of the new insights are whether readers recognise the phenomena described and whether they are considered to be relevant to nursing practice.

Role of the researcher

Writing about other people's experiences can be challenging because these experiences will always be understood in the context of the author's own preconceptions. Hermeneutics and interpretation relate to the binding of people to a tradition that will always influence new realisations (12). The challenge in all interpretation work is therefore to be conscious of one's own standpoint. The reader will determine whether the reflections here create recognition that can serve as a guide for nurses and healthcare personnel in their work.

Closing reflections and conclusion

When a family member becomes ill, a need arises to understand what is happening. A multitude of questions are thrown up as the disease progresses, and even more when death is approaching. It may seem paradoxical that Marie tries to 'reach out to her mother' without ever managing to do so. However, she finds peace and a sense of reconciliation in the knowledge that they tried.

Understanding takes place at various levels. While actively trying to understand what is happening, death is approaching. Paradoxically, Marie needs to let go whilst also trying to understand. What help can be given to a loved one who struggles to understand and hold on, whilst simultaneously needing to let go?

The book shows the relational interplay between a sick mother and her daughter up to the point of the mother's death. The daughter's empathy with the mother's suffering, and her struggle to regain her footing are enlightening, and help the reader understand what is at stake between the two of them. Thus, the book is a unique source for understanding both mother and daughter. It inspires conversations about relationships, life and death – and the need for support from the nursing profession.

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