

Patients with Infective Endocarditis and their relative caregivers' experiences during illness: A Qualitative Study

Delal Sarmanlu¹⁺², Knud Ryom¹, Signe Stelling Risom²⁺³⁺⁴, Marianne Nybro Grum⁵, Bianca Bech⁶, Hanne Højlund² and Trine Bernholdt Rasmussen²⁺³

¹Department of Public Health, University of Aarhus, Aarhus, Denmark; ²Department of Cardiology, Herlev and Gentofte Hospital, Copenhagen, Denmark; ³Department of Clinical Medicine, Faculty of Health and Medical Sciences, University of Copenhagen, Copenhagen, Denmark; ⁴Institute of Nursing and Nutrition, University College Copenhagen, Copenhagen, Denmark; ⁵Department of Cardiology, Rigshospitalet, Copenhagen, Denmark; ⁶Department of Cardiology, Zealand University Hospital, Copenhagen, Denmark

Purpose

To explore and elucidate patients with infective endocarditis (IE) and their caregivers' experiences with each other's participation during the patient's course of illness including hospitalization and recovery at home.



Methods

Empirical data were collected using qualitative, semi-structured dyadic interviews. Theories within social support, psychological well-being, and social psychology were used to interpret findings. Five dyads were interviewed consisting of four male and one female patient (age range 25-83 years) and their cohabitating spouse or partner (age range 34-70 years).



Results

Data revealed the participants' way of providing **social support** during the patients' course of illness, particularly by emotional and physiological assistance, practical assistance and attitude transmission. This was seen by the care and comforting the couple shared, practical help, joyful visits during hospitalization, a positive outlook on things and the ability to put things into perspective.

Participants reported on aspects of their **psychological well-being**. Most patients experienced negative feelings and depressive symptoms, and the caregivers experienced sleep deprivation, worries and exhaustion. Nevertheless, the participants emphasized positive aspects which contributed to their psychological well-being, such as having a purpose in life, i.e., their children and having a partner with a positive attitude, and caregivers described the importance of 'sticking together'.

Social psychology brought insight into different coping strategies. Some of the participants described how they used 'problem-focused coping' when facing existential issues as they sought important information head-on and communicated their feelings and thoughts. Others used 'emotion-focused coping' allowing each other to distance themselves from stressful situations or distracted themselves with walks or playing with the kids. Finally, 'protective buffering' was used by some, as the patients subconsciously hid their feelings because they did not want to cause concern, and the caregivers hid their feelings and tears, as well as neglecting their own needs to protect the patient.

Data revealed two additional themes derived as being 'A demand for psychological counseling' and 'Experiences with health care professionals'. Patients and caregivers reported that psychological counseling would be an important step in their well-being after discharge. Moreover, the participants described their positive experiences as well as an example of a challenging experience with the health care professionals at the hospitals, which had had an impact on their experience.

"For me it was a reassurance that there was someone from my family who could calm me down when I was scared and sad ... He has helped me so much, I wouldn't have come this far without him (...) Sometimes I have had a bit of a crisis ... then it's very nice that there is someone who can see things in a larger perspective and say, "look at where you were three weeks ago" because it is hard to remember yourself sometimes."

"In the intensive care unit, as soon as I opened my eyes, she had to be right next to me, then I would calm down (...) If I don't see her inside a room then it's like, you know, like a fish all alone in the sea (...) We have always supported each other. Sometimes I fall and then she is the one who holds me ... when she falls, I hold her (...) The most important thing is that partners support each other."

"It has been hard ... it was many months at the hospital where she couldn't do anything. You had to help her with toilet visits, help her in the shower, you had to lift things for her ... it was tough man, I wouldn't wish this on my worst enemy (...) It is tough to be so close and be a relative, especially when you are alone with it ... it gives you hair on the chest ... and some scars ... But we are here now and that is the most important thing. Look, she's sitting there and smiling ... that's what's important ... it really is the most important thing"



Conclusion

Patients with IE and their caregivers' participation during illness played an important role in their lives. Increased attention in clinical practice and in future research on how to create an environment that ensures a person-centered approach and supports the patient-caregivers dynamic during hospitalization and subsequent rehabilitation could be beneficial.

Corresponding author:
Trine Bernholdt Rasmussen. Department of Cardiology,
Herlev and Gentofte Hospital.
E-mail: trine.bernholdt.rasmussen@region.dk

Declaration of interest:
None