

Emotional Experiences of Caregivers of patients discharged on VAD support (EECVAD)

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- I do **not** have an affiliation (financial or otherwise) with a commercial organization that may have a direct or indirect connection to the content of my presentation.

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Background

- Patients have been discharged home for over a decade on Ventricular Assist Device (VAD) support
- Initially as bridge to transplant, but more recently as destination therapy
- Need to understand the impact that VAD technology has on caregivers

Purpose

- To describe the lived experience of caregivers of VAD recipients discharged home on VAD support

Methods

- Phenomenological theoretical perspective
 - encourages researchers to call into question what is taken for granted (in this case, the experience of caring for a sick loved one)
 - hold in abeyance presuppositions about phenomena
 - aim is to attempt to capture the essence of experiences

(Crotty, 1998)

Methods

- Small group sessions – 2 hours in length
 - 4 sessions
 - 3 with caregivers of recipients who survived
 - 1 with caregivers of recipients who died
- Two psychologists
- Semi-structured interview
 - Diagnosis, recovery, training, life at home

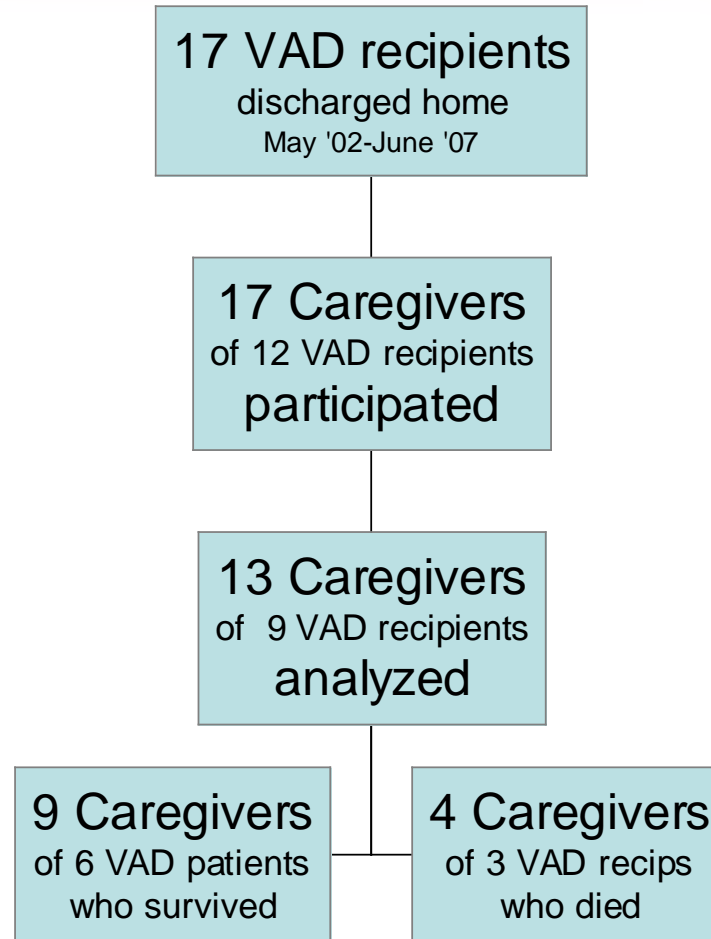
Methods

- 17 VAD patients discharged home between May 2002 and June 2007
- Caregivers invited to participate
- 13 caregivers of 9 patients agreed

Methods

- 4 x 2 hour sessions taped
- Taped sessions transcribed
 - 1 session was lost due to microphone problem
- Transcripts reviewed by authors and themes identified

Methods



Demographics

- Implant acuity
 - 2 Emergent
 - 3 Urgent
 - 4 Elective
- 8 F:5 M participants
 - 6 spouses
 - 4 children
 - 2 parents
 - 1 sibling

A

Pt #	Age	G	VAD	Diag	Urg	Support Days	Days at home	Outcome	Caregivers
1	46	M	P	DCM	Urg	519	488	HTx	Fem.partner
2	22	F	I	Myo	Emerg	106	72	Expl	Mother Father
3	55	M	XVE	Isch	Urg	392	325	HTx	Brother
4	57	F	XVE	Isch	Elect	248	179	HTx	Husband Daughter
5	66	M	I	Isch	Urg	107	40	Expl	Wife
6	58	M	XVE	Isch	Elect	228	186	HTx	Wife Daughter
7	61	F	P	Isch	Emerg	427	300	Died on VAD	Husband
8	64	M	XVE	Isch	Elect	101	62	Died HTx	Stepdaughter Husband
9	49	M	XVE	DCM	Elect	124	48	Died HTx	Wife

B

C

Findings

- Four themes were identified
 - Fear and anxiety
 - Loss
 - Burden
 - Coping

Fear and Anxiety

- Overarching theme throughout the VAD experience
- The intensity and manifestation changed with time
- Nature of initial fear/anxiety differed depending on the level of urgency of the implant

Fear and Anxiety

- At the time of implant – Mother of 22 y/o VAD recipient undergoing emergent implant:

“Well I think it’s like desperation you know, you don’t want to lose your child, you know this is the only thing being offered...”

and

“...I have no memory of time at all. I don’t remember, I remember getting off the plane and calling... I don’t remember anything else...”

Fear and Anxiety

- If the patient was able to consent, the level of fear and anxiety seemed less:

“... [the patient] was fully aware and capable of making decisions for herself at the time so we didn’t ... have to make that decision on our own, so we decided you know, we had to go ahead and have the VAD machine.”

Fear and Anxiety

- As time progressed the fear turned to anxiety, especially in relation to dressings and hygiene:

“Showering was one of the other biggest issues, it was like a two-hour ordeal...it was like oh my God, by the time we’d finished I was always exhausted”

Loss – of family roles

“...we didn't have much of a social life. We couldn't travel and I wasn't working. [Patient] wasn't working. I mean that was our life.”

and

“It was like having a kid”

Loss – of their loved one

- The fear of possibly losing their loved one was strong:

“For me, I think it was always in the back of my mind you know, something might happen and she will just die...”

“You are constantly losing your partner over and over and over again.”

Loss – of independence

“you totally change, from being carefree...”

“Our biggest thing was the loss of independence. She was a very independent person, and with the machine, she depended on me night and day and she didn’t care for that, but she had no choice.”

Burden – of responsibility

“I was scared, wondering if I was doing the right thing. I mean, it was for him, me, and the kids. It was like ... either way it turned out, I was the one that was going to take the brunt of everything, which was scary.”

“Well yeah, I mean I know he’s grateful I made the decision, but by the same token he was kind of like ‘maybe you should have just let me go’”.

Coping - faith

"...you probably have more spirituality than before...you have time to reflect on life...we were just in a rut before and this sort of thing helps you right the score..."

And in the health professionals

"You just put your faith into the hospital and just hope you've done everything right"

Coping - acceptance

“...when a fast ball is thrown at you, you have to take it and do the best you can with it, you know, you either swing the bat, or you keep the bat on your shoulder. We sort of ran with it. We knew we had to deal with it, and if we had to do it all over again, we’d probably be the same way with our emotions and everything else...”

Coping - support

“You’ve got to have somebody, you just can’t do it all on your own”

“ we’d go back to those books, [they were] so helpful...”

“Fortunately I have an employer who was kind enough to let me work from home...”

Summary

- Fear and anxiety underpinned the entire VAD trajectory
- Caregivers were faced with loss on multiple levels
- The burden of caring for a VAD patient was significant
- Caregivers employed a range of coping strategies

Implications for Practice

- Information absorption
 - Emergent vs. elective
- Identify and nurture coping strategies
 - Faith
 - Support
 - Emotional
 - Educational
 - Material
- Recognize and treat PTSD