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# Living with the Risk of Sudden Death: Psychology of Mortality

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CARDIOVASCULAR  
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# **With colleagues and patients we can talk about:**

Risk stratification for sudden death

The use of ECMO

Indications for ICD implantation

## **How do we answer when a patient asks:**

“How long do I have to live?”

“How am I supposed to manage this anxiety knowing I could drop dead at any minute?”

“I survived sudden cardiac arrest. What do I do now?”



**A few studies...**



# Living With Prophylactic ICD Therapy and the Risk of Sudden Cardiac Death: How Patients Negotiate Solutions and Problems

Qualitative Health Research  
2017, Vol. 27(14) 2128–2137  
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- Ethnographic study conducted in Danish hospitals
- At the time of ICD implantation, patients were grateful when offered an ICD to reduce the risk of SCD
- The following concerns emerged several months later: anxiety about ICD technology and the risk of death



# Living With Prophylactic ICD Therapy and the Risk of Sudden Cardiac Death: How Patients Negotiate Solutions and Problems

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“Clinicians create a narrative containing a problem of a significant risk of SCD and a solution in the form of a benign therapy that provides the good life.”

“ICD technology is not neutral but shapes patient life-worlds in unexpected and undesirable ways.”

“[Patients] experience the ICD both as an assurance of immortality and a reminder of their mortality, a harbinger of death.”

**What about patients who are at risk of SCD but do not receive an ICD?**



# Coping with the increased risk of SCD (associated with LQTS)

Qualitative  
interviews with  
7 patients with  
LQTS (23-76 yrs);  
4 had ICDs

- **ICD = safety measure + new source of anxiety**
- **Most participants reported that they were not afraid of their own deaths**
- **Most patients reported limitations in daily lives and dissatisfaction with health care providers**



# Heart-focused anxiety in patients living with the risk of serious arrhythmias & sudden cardiac death

- 126 patients (mean = 45 years) at risk for SCD due to personal/family history (Long QT/HCM)
- Completed: Hospital Anxiety & Depression Scale, SF-36, Cardiac Anxiety Questionnaire (*avoidance, attention, fear*)

Predictors of Anxiety Symptoms	Predictors of Depressive Symptoms
Female Recent SCD in family Avoidance Fear	Recent SCD in family Avoidance Fear

**Avoidance and fear are modifiable**



# Cardiac anxiety post sudden cardiac arrest

188 survivors of sudden cardiac arrest (55 ± 12 yrs) completed the Cardiac Anxiety Questionnaire

**Survivors showed high levels of fear, avoidance & focus on cardiac symptoms**

**Table 4**

Predictors of cardiac anxiety secondary to SCA.

	$\beta$ (SE)	Standardized $\beta$	p
Demographic variables			
Age	-0.01 (0.01)	-0.20	0.02*
Female	0.21 (0.12)	0.15	0.08
Cardiac history			
History of heart disease	-0.13 (0.13)	-0.08	0.31
Heart murmur	0.30 (0.12)	0.20	0.02*
ICD	0.08 (0.14)	0.05	0.55
ICD shock $\geq$ 1	0.28 (0.11)	0.21	0.01*
Psychosocial adjustment			
Depression	0.22 (0.12)	0.17	0.06
Generalized anxiety	0.35 (0.13)	0.25	0.008*

\*  $p < .05$ .





# Facilitators and barriers to end-of-life discussions in adult congenital heart disease

200 patients recruited from outpatient clinic (35 ± 15 years; 58% female; 81% with CHD of moderate/great complexity)

**Table 2.** Patient-Reported Facilitators to End-of-Life Discussions

	Applies	Does not Apply	Do not Know/ No Answer
I trust my doctor	85% (170)	6% (11)	10% (19)
My doctor is very good at taking care of congenital heart disease	78% (156)	6% (12)	16% (32)
I feel sure that my doctor will be there for me if I get very sick	69% (137)	9% (17)	23% (46)
My doctor cares about me as a person	68% (135)	8% (15)	25% (50)
I worry about the quality of life in the future	68% (135)	23% (45)	10% (20)
I have had family or friends who have died	63% (126)	26% (52)	11% (22)
I worry that I could be a burden on my friends and family if I got very sick	58% (115)	28% (55)	15% (30)
My doctor is very good at talking about end-of-life care	16% (32)	27% (54)	57% (114)
My doctor often asks me about end-of-life care.	8% (15)	64% (127)	29% (58)

Data are presented as % (number), n = 200  
 Questions modified, with permission, from Knauft et al.<sup>10</sup>



# Facilitators and barriers to end-of-life discussions in adult congenital heart disease

**Table 4.** Patient-reported Barriers to End-of-life Discussions

	Applies	Does not Apply	Do not Know/ No Answer
I would rather concentrate on staying alive than talk about death	66% (132)	25% (50)	9% (18)
I do not know what kind of care I want if I get very sick	55% (109)	30% (60)	16% (31)
I am not sure which doctor will be taking care of me if I get very sick	49% (97)	36% (71)	16% (32)
I have not been very sick	47% (93)	41% (82)	13% (25)
My ideas about the kind of medical care I want change at different times	42% (84)	38% (75)	21% (41)
I do not like to talk about getting very sick	41% (81)	49% (98)	11% (21)
I am not ready to talk about the care I want if I get very sick.	24% (48)	60% (119)	17% (33)
My doctor never seems to have the time to talk about issues like end-of-life care.	22% (43)	52% (103)	27% (54)
I do not want to make plans for the future	20% (40)	64% (127)	17% (33)
I feel that talking about death can bring death closer	16% (31)	71% (141)	14% (28)
I have a living will, and that means I do not need to talk with my doctor about the care I want if I am too sick to speak for myself	13% (25)	69% (138)	19% (37)
My doctor does not like to talk about me getting very sick	11% (22)	60% (120)	29% (58)
I worry that talking about getting sick is too depressing for my doctor	6% (11)	69% (138)	26% (51)

Data are presented as % (number), n = 200.

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**Clinical experiences:  
What I've heard when I talk to  
patients about death and dying...**



**“I’m terrified of dying. I’m  
scared of missing all of the  
things I love in life.”**

**“I’m not afraid of dying. But I’m  
worried about how my family  
will cope when I’m gone.”**



**“I’ve grateful that I’ve lived much longer than anyone thought I would. I accept that I won’t live as long as other people.”**

**“As a kid, I always beat the odds. I thought I was in the clear. Nobody ever told me I would die young. I’m stunned.”**



**“I actually like the idea of a sudden, quick death. I don’t want a long drawn-out experience for me and my family.”**

**“I hate the idea of not knowing when it might happen and not being able to say proper good-byes.”**



**“I just know there is something waiting  
for me on the other side.”**

**“I think that when I die, I die,  
and that’s it.”**





**Because I don't have  
a crystal ball,  
I now ask...**



**Physical pain**

**Missing out on the  
rest of my life**

**Letting my family  
down**

**“When you think about death  
and dying, what are you most  
concerned about?”**

**Being alone at the  
time of death**

**Not knowing when &  
where it will happen**

**The unknown**



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## A good answer to: “How long do I have to live?”

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"The patient asked how long they would live.  
I answered as **honestly** as I could.

I explained that adults with CHD, in general, have reduced life expectancy. I also explained that it is **difficult to accurately predict** the patient's future outcomes and survival.

I explained that the patient is **at risk** of heart failure and sudden cardiac death. But their clinical trajectory is unknown and may be over many years.

I let them know that I would be pleased to **continue discussing these issues** and also encouraged them to continue leading a **full and active life.**"

# Take-Home Messages: The Psychology of Mortality

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- Being informed of the elevated risk of sudden death carries psychological implications.
- An ICD might alleviate some worries and lead to others.
- A strong patient-provider relationship fosters end-of-life discussions.
- Wanting to concentrate on staying alive and wanting to talk about end-of-life care are not mutually exclusive.
- The only way to know an individual patient's concerns regarding death and dying is to ask.
- These discussions take time.

