



# Toronto Aortic Stenosis Quality of Life Scale (TASQ): Development of a Scale Based on a Canadian Aortic Stenosis Population and TAVI Patients

RIMA STYRA, MICHELLE DIMAS, MAMTA KAPOOR, KATHY SVITAK,  
MARK OSTEN, MARAL OUZOUNIAN, GERALD DEVINS, ERIC  
HORLICK

**PETER MUNK CARDIAC CENTER, UNIVERSITY HEALTH NETWORK,  
TORONTO**

# Disclosure

I have the following relevant financial relationships to disclose:  
Investigator Initiated Research Grant – Edwards Lifesciences Inc.

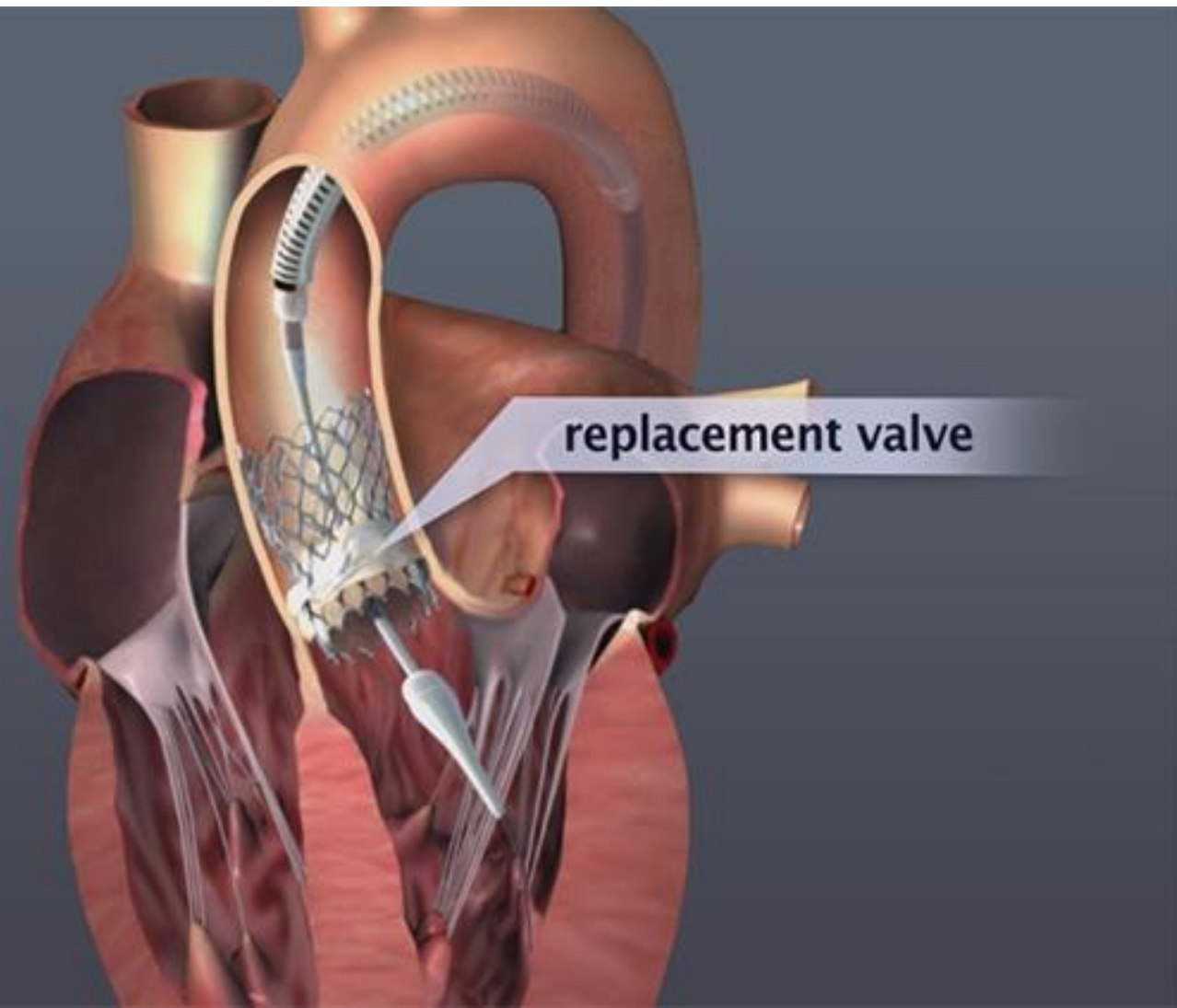
I have no relevant non-financial relationships to disclose.

# Objectives

- Brief introduction of aortic stenosis
- Review qualitative study used to identify patient concerns
- Development and validation of a QoL scale – Toronto Aortic Stenosis Quality of Life (TASQ)

# Aortic Stenosis

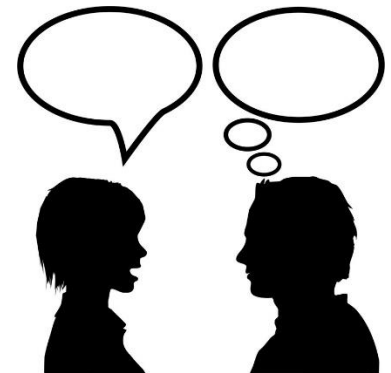
- Symptoms associated with severe aortic stenosis (AS):
  - shortness of breath
  - fatigue
  - dizziness, syncope
- Increases in incidence with age
  - 29% of individuals older than 65 years
  - 37% of individuals older than 75 years
- Interventions can be:
  - Medical treatment
  - Surgical - Surgical Aortic Valve Replacement (SAVR)
  - Minimally invasive - Transcatheter Aortic Valve Implantation (TAVI)



# Patient Reported Outcomes

Clinicians require a framework to understand the effects of an illness from a patient perspective

Physical domains are part of the picture but cannot capture the entire picture  
- shortness of breath, fatigue, dizziness, syncope



## Psychologically Meaningful Activities

**Interferes with capacity to engage in valued activities,  
interests and relationships**

## Qualitative Study

Objective: To explore the impact of aortic stenosis on patients

- Review of the literature
  - Identified patient and expert concerns
- Clinical practise
- Patients were interviewed regarding a number of areas identified:
  - Physical symptoms
  - Emotional symptoms
  - Impact on their function and activities
  - Expectations

# Demographics

- N = 333 patients
- Age:  $80.5 \pm 8.7$  years (range: 52 to 97)
- Males: N = 182 (54.5%)
- Widowed: N = 113 (33.9%)
- Married/common-law: N=184 (55.2%)
- Single/divorced: N = 36 (10.9%)



# Emotional impact

- Fears of a fatal cardiac event (echoed by family members)
- Fears of a myocardial infarction - non-fatal but further debilitating
- Frustration with repeated admissions or visits to the emergency department
  - Why can't they just fix it
  - I spend hours in the Emergency only to be sent away again
  - Every time I have to go to Emerg, my daughter has to take time off
- Inability to take care of their spouse or adult child with disability
  - main caregivers for their spouse who has dementia, or compromised with a chronic medical illness,
  - adult children who have disabilities

# Social Limitations

- Frustration with being unable to participate in social events or socialize with friends
- Interacting with family members was identified as an important priority
  - More effort and value was ascribed to interacting with family
  - Seeing grandchildren
  - Important family events
- Unable to plan for travel

# Measuring QOL

Conclusion from the CCS National Quality Report<sup>1</sup> - TAVI suggested a need to evaluate quality of life among patients with AS

“ Demonstrating improved quality of life as measured by the **patient’s direct perspective** is a pivotal component of the evaluation of appropriate case selection, procedural success and long term benefit of TAVI.”

**Identified Need**

**Confirmed what we had found in our literature review and clinical practice**

# TASQ (Toronto Aortic Stenosis Quality of Life)

- Content analysis of the information obtained from our qualitative study to identify QoL domains and items by a multidisciplinary team
- 5 domains:
  - emotional impact
  - social limitations
  - physical limitations
  - health expectations
  - physical symptoms
- 16 item self-administered scale based on patient identified issues
- Piloting with 12 patients (content and face validity)
- Scale takes approximately 5 minutes to complete (consider patient burden)
- Each item is scored on a 7 point scale; scores range from 16 to 112

# Study of pre-TAVI and follow-up

- 62 patients meeting criteria for the TAVI procedure
- TASQ (Toronto Aortic Stenosis Quality of Life)
- KCCQ (Kansas City Cardiomyopathy Questionnaire) – condition specific questionnaire
- IIS (Illness Intrusiveness Scale) – generic instrument
- Pre-TAVI, at discharge, 1 month and 3 month follow-up

## Participant characteristics at baseline (N = 62)

Variable	No. of patients		Range
<b>Age (years)</b>	62	83.45 ± 5.45	70-95
<b>Sex</b>			
<b>Male</b>	40	64.5%	
<b>Marital status</b>			
<b>Married/common law</b>	34	54.8%	
<b>Divorced</b>	3	4.8%	
<b>Widowed</b>	23	37.1%	
<b>Single</b>	2	3.2%	
<b>Living arrangements</b>			
<b>Living alone</b>	15	24.2%	
<b>Living with spouse/partner</b>	29	46.7%	
<b>Living with family</b>	16	25.8%	
<b>Living in retirement or long-term care facility</b>	2	3.2%	
<b>Caregiver role</b>	8	12.9%	
<b>Activities of daily living*</b>			
<b>Completely independent</b>	45	72.5%	
<b>Needs help with physical chores</b>	14	22.6%	

# General Overview of Construct Validity: Pearson Correlation Coefficients between TASQ Scores and QOL Criterion Variables Over Four Measurement Occasions

	TASQ Physical Symptoms	TASQ Physical Limitations	TASQ Emotional Impact	TASQ Social Limitations	TASQ Health Expectations
KCCQ Physical Limitation	+	+	+	+	-
KCCQ Symptom Stability	+	+	+	+	
KCCQ Symptom Frequency	+	+	+	+	+
KCCQ Symptom Burden	+	+	+	+	
KCCQ Self-Efficacy	+	+	+		
KCCQ Quality of Life	+	+	+	+	+
KCCQ Social Limitation	+	+	+	+	
IIRS Instrumental	-	-	-	-	
IIRS Relationships and Personal Development	-	-	-	-	
IIRS Intimacy	-	-	-	-	

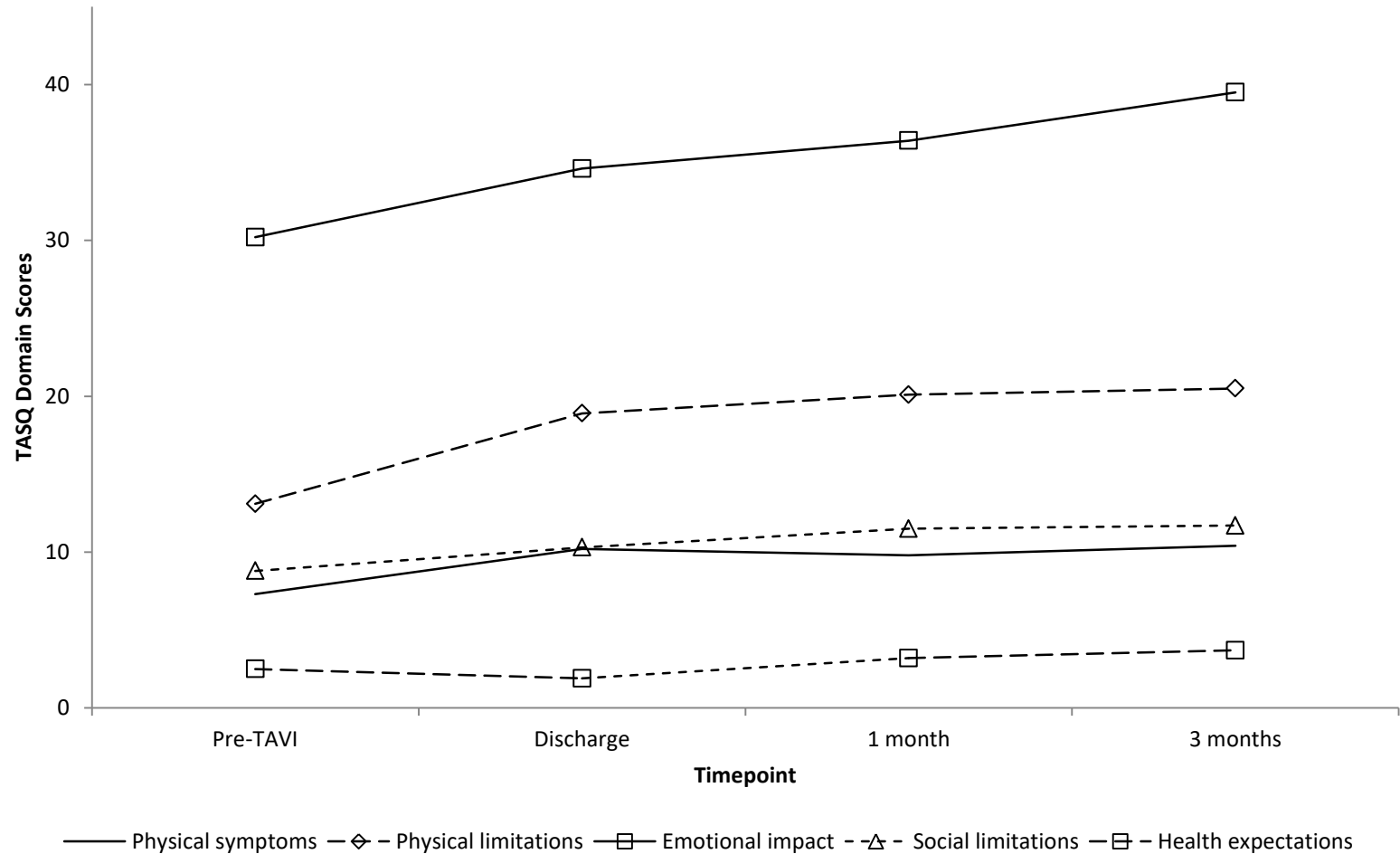
Note: Algebraic signs indicate whether the observed coefficient was positive (+) or negative (-)

# Responsiveness

- Sensitivity to change from baseline to each of the three measurement occasions
- Total scores improved significantly from baseline (Pre-TAVI) to all follow-up occasions :
  - Discharge ( $p < 0.0001$ ,  $d = 0.92$ )
  - 1 month ( $p < 0.0001$ ,  $d = 0.94$ )
  - 3 month ( $p < 0.0001$ ,  $d = 0.99$ )
- All domain scores improved significantly over time ( $p$ 's  $< 0.03$ ) with the exception of the 3 month follow-up of health expectations ( $p < .10$ )



# TASQ scores by domain over time



# Early Improvement

- Consistent with literature indicating significant recovery early on <sup>1</sup>
- Identification of early improvement is important to patients:
  - primary care givers
  - older deconditioned patients requiring rehabilitation
  - proceeding to other surgeries
  - need to return to work

Dauermann HL, Circ Cardiovasc Interv 2016

# Limitations

- Psychometric studies of the TASQ using a larger sample size in several centers
- Longer term follow-up
- Include a comparison group such as SAVR and medical treatment

# Summary

- TASQ was developed based on a large cohort of AS patients
- Factors impacting QoL identified as most important by patients were utilized
- TASQ is a brief, valid, self administered scale and easy to score
- The properties of the TASQ allow it to be incorporated into a busy clinical practice to monitor QoL
- The concerns and expectations of the patient can only be addressed if healthcare professionals are aware of the issues being faced by the patient
- Explore whether it might assist with decision making

“Listen to the patient”

- William Osler

