Bootcongres 2019 ZELFMANAGEMENT NA

TRANSPLANTATIE

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Disclosure belangen spreker

(potentiële) belangenverstrengeling	Zie hieronder		
Voor bijeenkomst mogelijk relevante relaties met bedrijven	Bedrijfsnamen		
 Onderzoeksgeld 	 Nierstichting; ZonMW; Chiesi 		

Learning objectives

- To understand what self-management entails for kidney transplant recipients
- To gain insight into the gaps in knowledge in self-managent research

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- To gain insight into potential ways to improve self-management

Definition

"Self-management refers to the individuals ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition

Efficacious self-management encompasses ability to monitor one's condition and to effect the cognitive, behaviourals and emotional responses necessary to maintain a satisfactory quality of life"

(Barlow et al. 2002)





Among kidney recipients

Schmid-Mohler et al 2014 Interviews with 12 transplant recipients



on et al 2016; AJKD 0 qualitative studies



Prevalence of poor self-management



Dew et al., Transplantation, 2007

Prevalence of poor medication adherence



Impact of poor medication adherence



Impact of smoking, alcohol and exercise (B-SERIOUS consortium)

- Posttransplant smokers had higher odds of:
 - cardiovascular disease (OR, 1.41; 95% CI, 1.02-1.95)
 - nonskin malignancies (OR, 2.58; 95% CI, 1.26-5.29)
 - mortality (OR, 1.74; 95% CI, 1.21-2.48)

No significant association of alcohol with outcomes due to insufficient data

Low PA was significantly associated with low physical healthrelated quality of life (OR=0.172, 95% CI=0.08, 0.37) Review of 34 studies; 15 in meta-analysis

Duerinckx et al. 2016 Review of 73 studies

Dobbels et al. 2018 Review of 76 studies 93% on liver Tx recipients



Impact of depression

- > 10% of KTx recipients were depressed
- Depression associated with
 - Frailty
 - Longer length of stay
 - > Death censored graft failure

Konel et al 2018 773 KTx recipients

Mortality

How can we support self-management?

Patients' Needs

- More attention to psychological and social

needs

- Attitudes towards self-management support differ
- Tailoring of support
- First year post-transplant
- Shared-decision making

Nurses' Needs

- Varying views on SMS focus often medical
- Focus often on education rather than on patient
 - empowerment and coaching
- Need for confidence and communication skills

Been-Dahmen et al 2015; Ter Maten Speksnijder et al., 2016 Hoofd et al 2017; Grijpma et al 2016; Been-Dahmen et al 2018; Duprez et al 2018

Available interventions?

Self-management support programmes after KTx

Focus on medication adherence interventions

Effective self-management interventions for posttransplant care are scarce

Self-management support training most effective when based on theory, including (video) feedback and follow-up sessions

Low, 2015; De Bleser, 2009

Duprez et al 2017



Development of a nurse-led self-management support intervention

JMIR RESEARCH PROTOCOLS

Beck et al

<u>Protocol</u>



A Nurse-Led Self-Management Support Intervention (ZENN) for Kidney Transplant Recipients Using Intervention Mapping: Protocol for a Mixed-Methods Feasibility Study

Denise Beck¹, MSc; Janet Been-Dahmen², RN, PhD; Mariëlle Peeters², MSc; Jan Willem Grijpma¹, MSc; Heleen van der Stege², PhD; Mirjam Tielen¹, RN, PhD; Marleen van Buren¹, RN, MSc; Willem Weimar¹, MD, PhD; Erwin Ista³, RN, PhD; Emma Massey¹, PhD; AnneLoes van Staa^{2,4}, RN, MD, PhD

Support programme key elements

- Delivered by trained nurses
- Patient-centered, activating not informing
- Holistic
- Tailored
- Brief for implementation in clinical practice
 4 sessions during regular clinic visits
 - Solution-focused brief therapy & Motivational Interviewing

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Why solution focused?

Problem focus:	Solution focus:		
 Problems (duration, severity) What the patient does not want Causes Negative emotions Disadvantages Risks Weaknesses and limitations Undesired or feared outcomes 	 Successes What the patient does want Exceptions Positive emotions Advantages Chances Strengths and resources Desired outcomes 		





How to write SMART Goals





Motivation for change?

Current situation?



Desired situation / result?



Self-efficacy for change?

How confident are you?



Can you explain why it's a 4 and not a 3?



What does it look like in daily practice?

- Holistic assessment of life areas
- Goal setting
- Action plan
- Assess motivation
- Assess self-efficacy
- Monitoring of progress
- Success and failures (attributions)
- Adaptation goal / expectations / plans
- Relapse prevention
- Generalisation

Beck et al., 2019 JMIR; Been-Dahmen et al., BMC Nephrology

Four

sessions

Feasible in clinical practice?

Methods

- pilot test among 24 kidney transplant recipients
- ••• 16 completed the PRE and POST questionnaire
- interviews with patients and professionals
- video observations

Quantitative results

- Conclusion: acceptable and feasable satisfaction with care
- medication a
- self-manager

Question: but is it effective?

Been-Dahmen et al., BMC Nephrology



Patient: "Well, the difference between the beginning and the end was quite spectacular. In the beginning, I had of lot of domains scored as bad. But at the end, I also had good some scores. Given that I still have medical issues, it was very nice for me to see that I made progress."

Nurse: "I really liked this. Especially the Self-Management Web is a nice opening to start the conversation. Discussing all these topics helped me to create a complete picture of my recipients and to get insight into their problems"

Nephrologist: "I think that this intervention has an added value for recipients' quality of life. I do not think we get better functioning kidneys, but we will get better functioning recipients."



What's new?

Protocol adapted for other departments
Training at Erasmus MC for nurses
New grant
New colleague
Multi-center c-RCT



umcg



Radboudumc





Conclusions

- Knowledge gaps on the impact of self-management on transplant outcomes
- Patients report self-management challenges and need for support (tailored and holistic)
- Professionals report need for skills training to provide better support
- Need for (research on) effective strategies to improve selfmanagement after kidney transplantation
 - ZENN c-RCT we need you!



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Thanks to my team and collaborators

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Erasmus MC University Medical Center Rotterdam



Developing Dialogue-Pioneering Practice

26 - 29 April 2019 Krakow, Poland

Auditorium Maximum of the Jagiellonian University

Keynote Lectures:

Current and emerging challenges in transplantation ethics James Childress (USA)

The ethics of organoid transplantation: how should one launch a first in human trial? Annelien Bredenoord (Netherlands)

Plenary Dialogues:

International kidney exchange: opportunity or exploitation? Is opting out the solution for the organ shortage? Challenges and opportunities in vascularized composite allotransplantation Living donor organ banking: a worthwhile investment?



Emma Massey e.massey@erasmusmc.nl

Erasmus MC Cafung

Session 4





Intervention mapping

Bartholomew, Parcel, & Kok, 1998 www.interventionmapping.com

Step 1	 Create logic model of problem: Establish patient advisory committee; patient needs assessment; nurses needs assessment
Step 2	Creat logic model of change: Specify performance objectives (Self-regulation Theory & 5A model); select determinants; state change objectives
Step 3	Programme design: Choose evidence-based and theory-based methods of change; select practical applications for implementation, determine scope and sequence
Step 4	 Programme production: Develop programme materials, manual, checklist, training syllabus, pre-testing
Step 5	• Programme implementation plan: Carry out training, implementation of intervention with ongoing evaluation
Step_6	• Evaluation plan: plan effect and process evaluation, define measures and indicators Erasmus MC

How can we support selfmanagement?

Patient needs

- Focus groups among 41 kidney transplant recipients
- Medical care satisfactory- > ••• need for greater support of emotional and social challenges

Self-management support programmes

- Focus on medication adherence interventions
- HUDer for holistic approach Need for Effective self-management interventions are

One-size does not fit all -> need for tailored education support

Been-Dahmen et al 201

Low, 2015; De Bleser, 2009

Patient attitudes towards self-management support?

Key components of the four profiles.

	Profile A transplant-focused	Profile B bolistic and	Profile C life-focused and self-	Profile D+ minimalizing and	Profile D— coping-focused and need	v
	and obedient	collaborative	determined	disengaged	coping rocused and need	<i>,</i>
Attitude towards life	Preserving kidney	Re-establishing	Integrating life and	Minimizing impact of	Coping with demands an	d
		quality of life	treatment goals	transplantation	consequences	
Responsibility for health and	Health professionals	Shared	Patient	Patient	Health professionals	
decision-making	Modical	responsibility	As indicated by patient	Modical	Holistia	
content	wedical	Holisue	As mulcaled by patient	weuldi	HUIISUC	
Self-management Support:	Extensive	As indicated by	As indicated by patient	Minimal	Extensive	
amount		patient				
Attitude towards health	Tractable	Cooperative	Assertive	Resistant		
professionals						
professionars					app	
			-1	reu		
			401			
						Erasmus N
						tool

Griipma et al 2016

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Why solution focused?

- Effect found in with limited number of sessions
- Applicability among ethnic minorities and those with low health literacy
- Less burn-out among therapists
- Patient-centered and guarantees autonomy of patient

Effective when there is resistance for change

Burns, 2016; Medina & Beyebach, 2014; Franklin et al., 2012; Cladder, Nijhoff-Huysse, & Mulder, 2009;

Brief for implementation in clinical practice

- Recently tranplanted patients (first year after transplantation)
- Nurses trained and supervised in techniques
- > Four sessions of 15 minutes coupled with regular visits

Not...



Impact of alcohol (all organs; B-SERIOUS consortium)

> 23 studies on alcohol use posttransplant

On average 24% of transplant recipients use alcohol posttranplant
 15% at-risk drinking

- 93 correlates investigated over 76 studies
 - 9 significant (e.g. male gender, smoking pre-transplant/posttransplant, sobriety <6 months prior to transplant)</p>

No significant association of alcohol with outcomes due to insufficient data

Dobbels et al. 2018 Transplant Review Review of 76 studies 93% on liver Tx recipients

Impact of physical activity

(all organs; B-SERIOUS consortium)

Berben et al. In press

Review of 34 studies: 15 in meta-analysis

- > 30 correlates investigated
 - No correlations found with PA
- > 19 outcomes investigated
 - Low PA was significantly associated with low physical health-related quality of life (OR=0.172, 95% CI=0.08, 0.37)