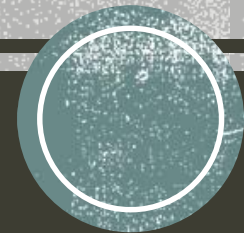


# Psychosocial impacts of a Renal Supportive Care Multidisciplinary Team

Reflections using the iPOS-Renal



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# Presentation Outline

- Why the iPOS-Renal?
- Brief review of last year's findings
- How does the data relate to empirical understandings and research?
- How can we respond?



IPOS-Renal Patient Version

Date: \_\_\_\_\_

Patient ID

eGFR: \_\_\_\_\_ Karnofsky: \_\_\_\_\_

**Highest level of Education Completed**

Primary School       Completed Diploma/ TAFE

Some High School     Completed University Degree

Completed High School

Q1. What have been your main problems or concerns over the past week??

1. ....
2. ....
3. ....

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick the box that best describes how it has affected you over the past week?

	Not at all	Slightly	Moderately	Severely	Overwhelmingly
Pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shortness of breath	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Weakness or lack of energy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nausea (feeling like you are going to be sick)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vomiting (being sick)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constipation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sore or dry mouth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drowsiness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor mobility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
itching	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty Sleeping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless legs or difficulty keeping legs still	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Changes in skin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diarrhoea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please list any other symptoms not mentioned above, and tick the box to show how they have affected you over the past week?

1. **Taste Changes (please describe)**
2. \_\_\_\_\_
3. \_\_\_\_\_



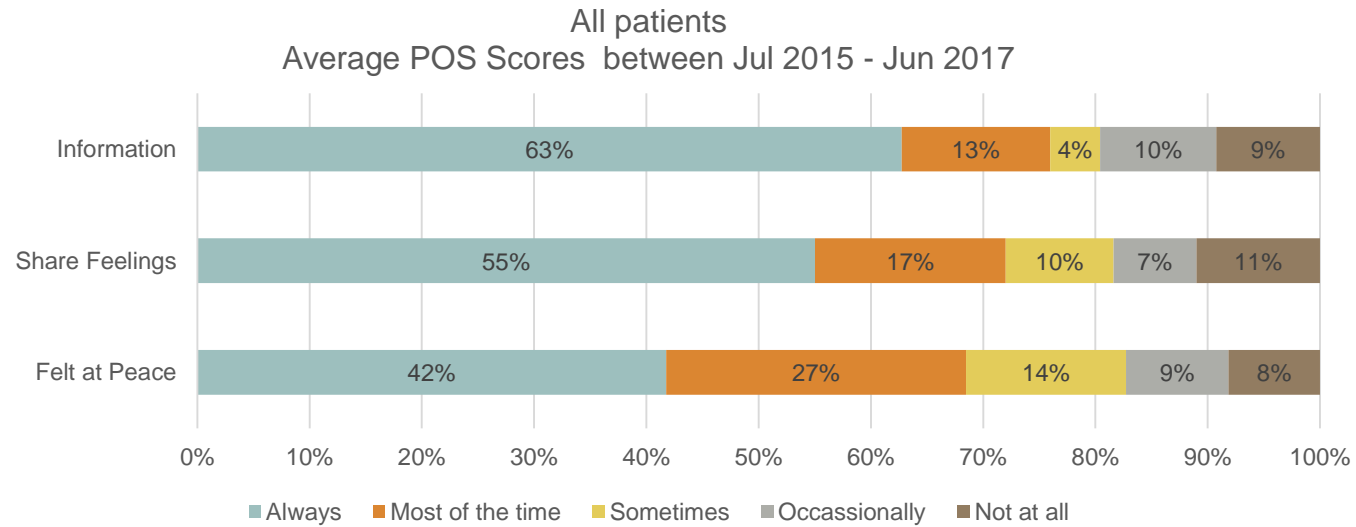
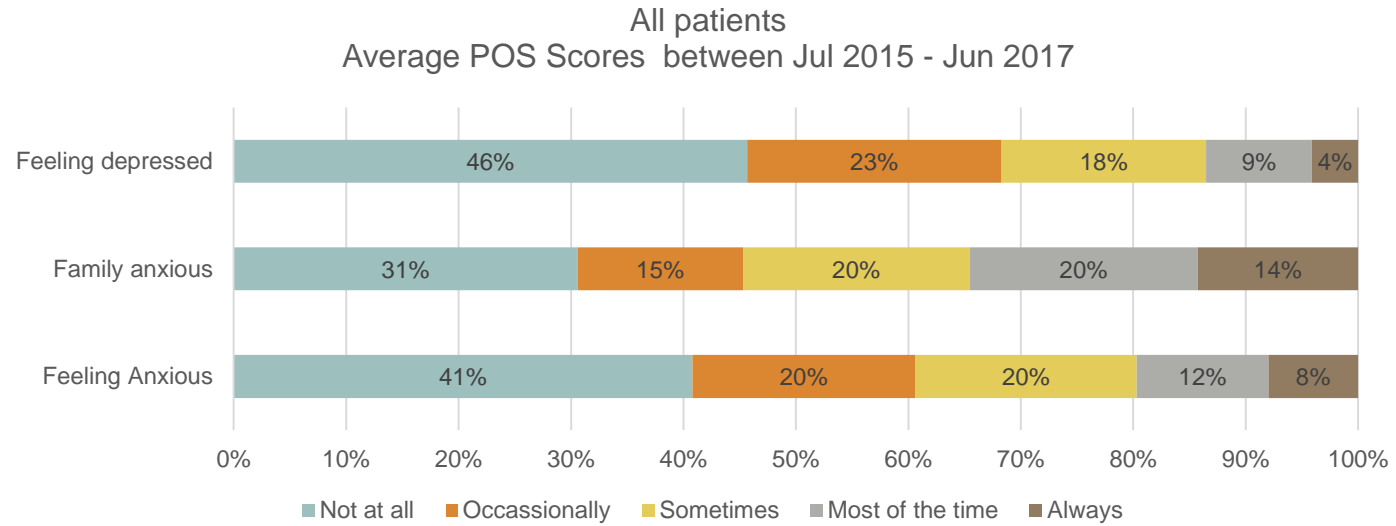
**Over the past week:**

	Not at all	Occasionally	Sometimes	Most of the time	Always
Q3. Have you been feeling anxious or worried about your illness or treatment?	1 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q4. Have any of your family or friends been anxious or worried about you?	2 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q5. Have you been feeling depressed?	1 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
	Always	Most of the time	Sometimes	Occasionally	Not at all
Q6. Have you felt at peace?	1 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	1 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q8. Have you had as much information as you wanted?	1 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
	Problems addressed/ No problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed
Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)	1 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
	None at all	Up to half a day wasted	More than half a day wasted		
Q10. How much time do you feel has been wasted on appointments relating to your healthcare, e.g. waiting around for transport or repeating tests	1 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>		
	On my own	With help from a friend or relative	With help from a member of staff		
Q11. How did you complete this questionnaire?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		

***If you are worried about any of the issues raised on this questionnaire then please speak to your doctor or nurse***



# All Patients' iPOS-Renal Emotional Data



# Chicken or the Egg?

Ryan et al (2013) highlights the strong evidence base pointing to a **rotational** relationship of physical and emotional burden in the chronic disease population.

Broken down, this can mean several things:

Some of our patients will report worsening physical discomfort when the real issue may be emotional or psychological.

Those without much of a physical symptom burden may under-report their emotional concerns if they are not able to identify a link to a physical symptom burden.

On the other hand, it is well known that physical symptom burden can cause or worsen poor emotional outcomes.

If a patient has a pre-existing emotional or mental health challenge, these patients are at risk of under-reporting any deterioration in their emotional symptoms if their physical symptoms are also worsening – with hope it may be so directly correlated that both would improve at the same time; Or, being accustomed to the highs and lows of their illness.



# What does this mean for practice?

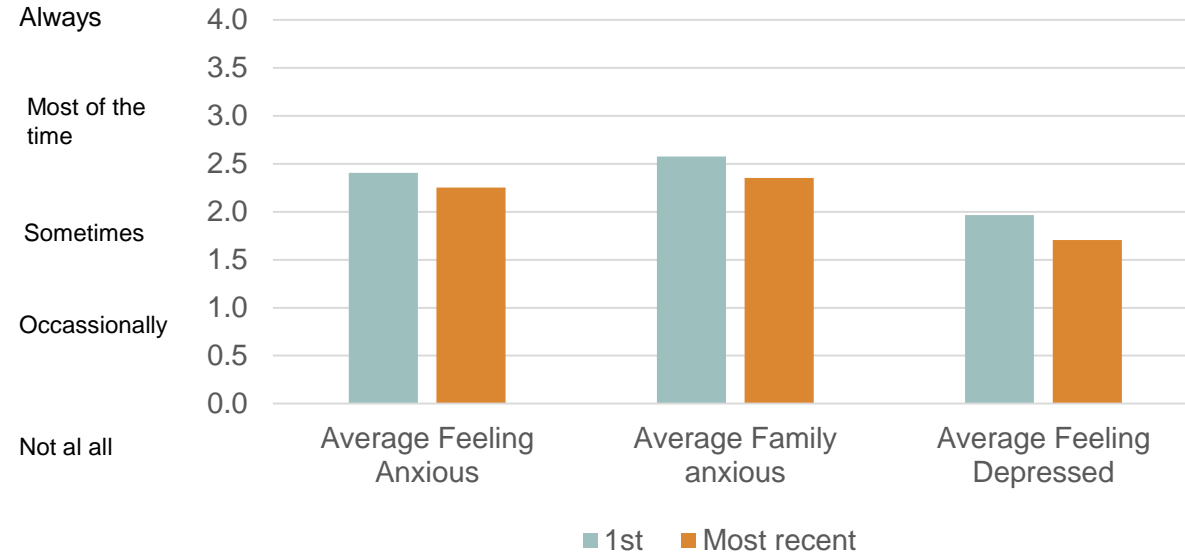
Brenes (2007) points to the need to emphasize care of anxiety and depression  
in chronic disease groups.

Attention to the iPOS-Renal back page

Attention to emotional symptoms alongside the physical **may** improve **some** patient's  
sense of their physical burden.

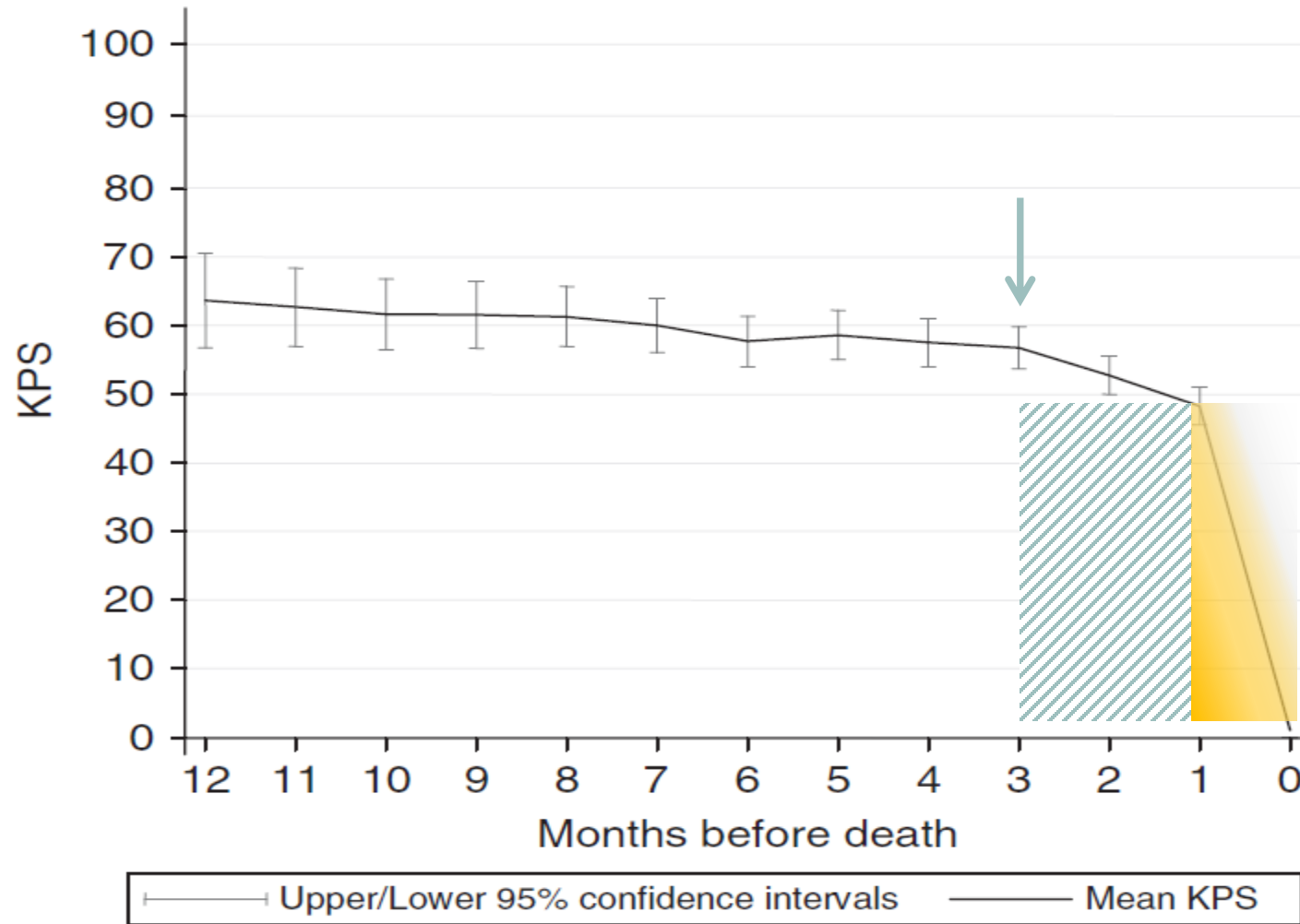


# Patients who scored negatively (between 2-4) at their first iPOS-Renal: Did their emotional symptoms improve over time?





## Conservatively managed ESKD patients

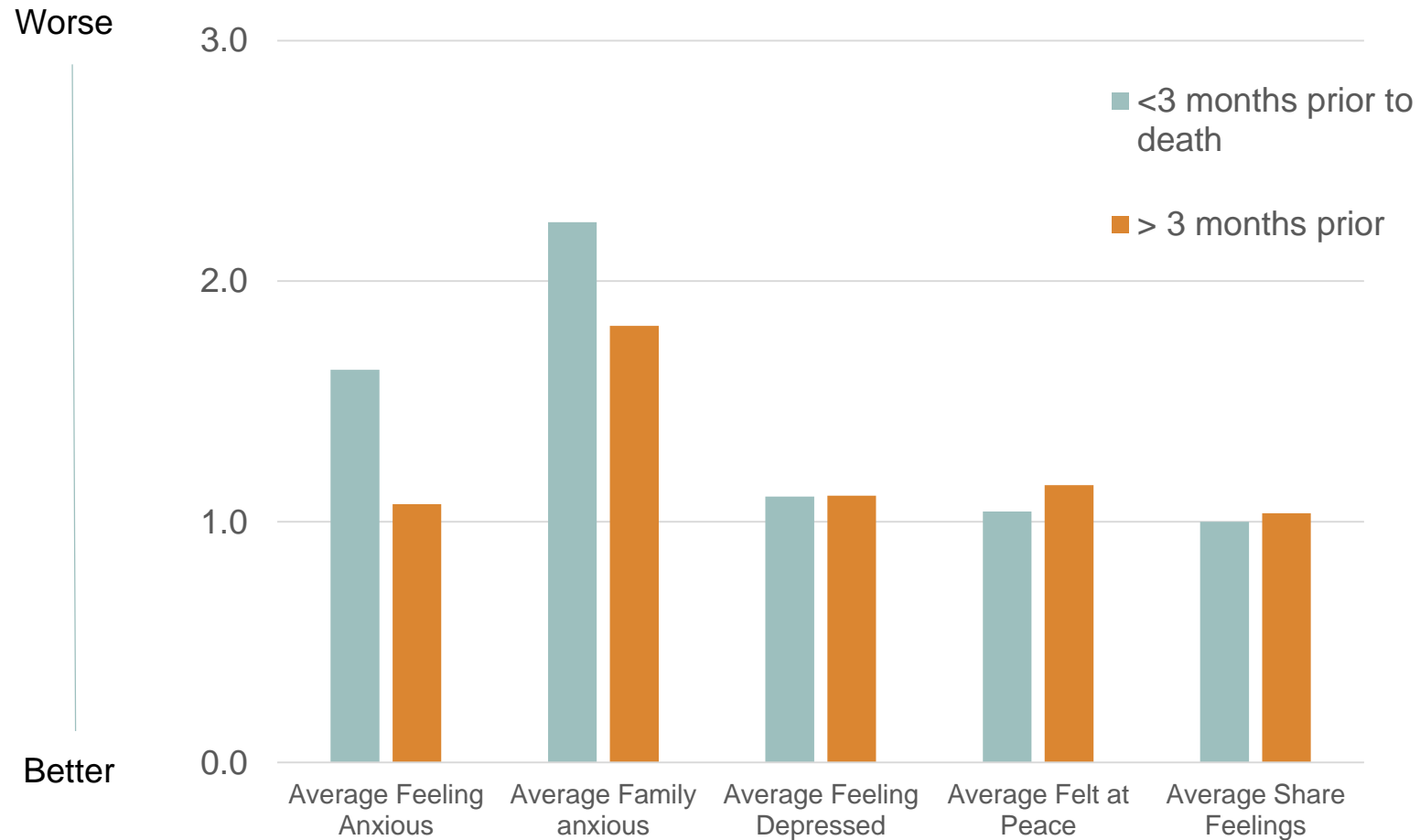


**Figure 2.** Trajectory of mean Karnofsky Performance Scale (KPS) score over the last year of life for those who died (N = 46).



# Seeking out trends

Average iPOSRenal scores for patients who died between July 2015 and June 2017



# How can we attend to those needs?

Clear communication about functional decline and what it signals



Anticipating and offering conversations on what the future may hold

Practical information about the processes

Reassurance of several options for location of EoL care

Reassurance of non-abandonment



Review / Reaffirmation of the Patient' and Carers' values, strengths, wishes & goals



# Carers' emotional outcomes

While the iPOS-Renal does not survey Carers and Family in-depth, Schulz & Beach' 1999 four-year study of 392 caregivers points to a

**mortality ratio up to 63% higher for Caregivers** experiencing Caregiver stress, compared to their non-Caregiving counterparts.

These findings were made specific to the renal population by Gayomali et al's US-based study in 2008. This study includes conservatively managed patients and in turn highlights the importance of supporting Carers in contexts such as Renal Supportive Care.

*There is hope*



# What can we bring to our practice to help?

Carer Research is expanding

Social Literacy and understanding is improving

**See Carers ALONE – normalise it**

**Employ ‘checkpoints’ as prompts to review Carers in same way we would with the Patients’ journeys**



# Take Home Messages

- Treat iPOS outcomes as one part of the whole
- Team Communication
- iPOS can be prompt for SW referral – Look at the Emotional alongside the Physical
- Good communication means using ‘checkpoints’
- Considerate communication and good management means ”always look ahead”
- No one goes through this alone
- Carers need private time for support
- Comfort with a treatment pathway decision does not necessarily translate to preparedness nor a sense of peace



# References & Recommended Readings

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