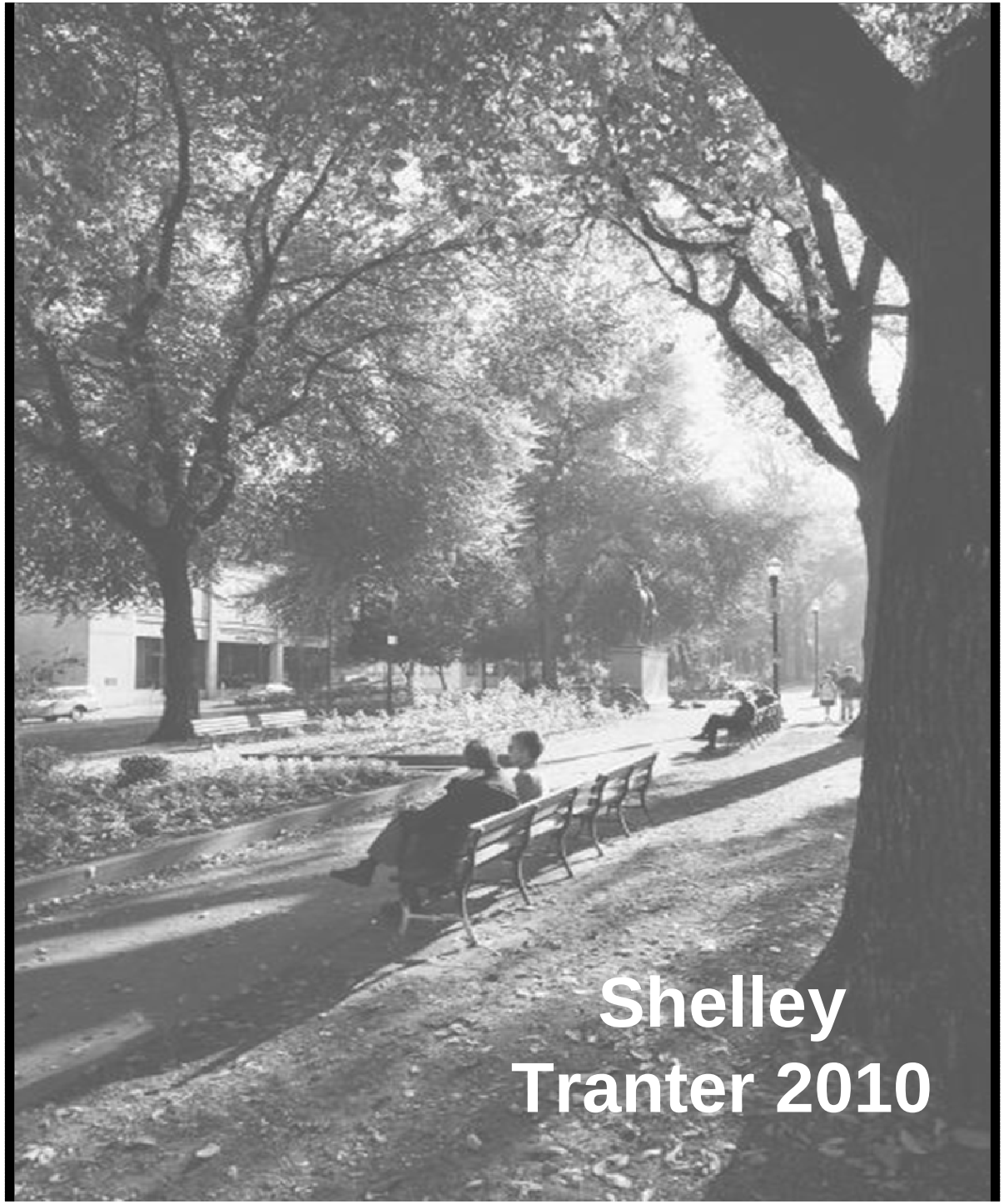
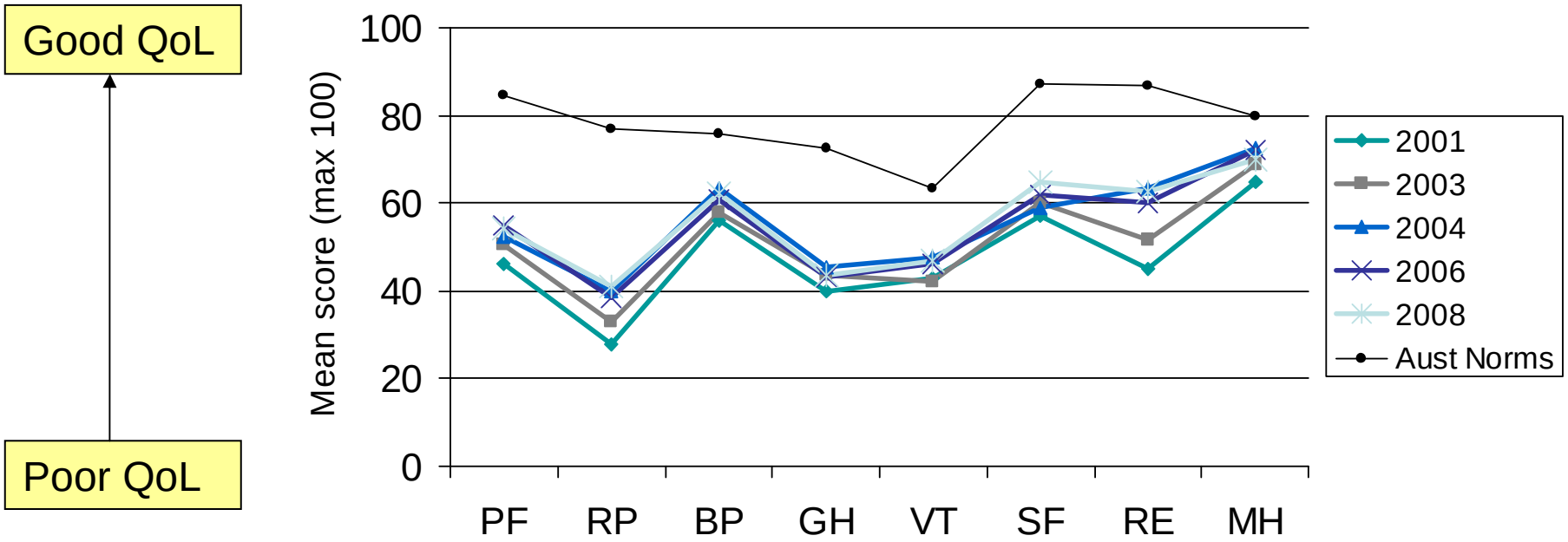
A new initiative: a renal palliative care clinic



Background – Quality of Life

- Regular Quality of Life (QoL) surveys collected from the St George dialysis patients since 2001 showed consistently low QoL scores despite improvements in:
  - Biochemical markers (Hb, Albumin)
  - Iron management
  - Dialysis adequacy



Palliative care and renal services

- We studied the introduction of palliative care as an adjunct to haemodialysis which showed:
  - High symptom burden in hospital Hd pts
  - High level of suffering and poor QoL
  - Difficultly in improving QoL
  - Although QoL did not improve, patients appreciated the service and contact with palliative care regardless of age.

Renal Pallcare Clinic

- High symptom burden of patients noted in literature and reflected also in our surveys;
- Increasing workload of renal consultants resulting in less time to adequately address complex symptom management;
- We have a palliative care consultant very interested in renal / palliative service along with a like-minded renal director.

Renal Pallcare Clinic

- Increasing need to manage conservative care patients so they are not ‘lost’ when in the final stage of renal disease.
  - Have often developed a good medical relationship with the renal staff;
  - Don’t have to develop new medical relationships at the end of life when palliative care is introduced early (patients and family have a better quality ‘end of life experience’).

Why a pallcare clinic?

- “Palliative Care is an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

  Palliative Care - WHO definition (2002)

Renal Pallcare Clinic

- Dedicated renal palliative care clinic
- Commenced March 2009
- Operates twice a month from 1300-1600 with 30 minute appointments
- Attended by palliative care consultant, renal registrar, renal CNC, social worker

The Staff

Social Work

Clientele

Four main categories of patients who are referred to the clinic:

- Patients who have chosen a not for dialysis pathway or need assistance in decision making around choosing dialysis or not;
- Patients who are on dialysis and have cancer or other terminal conditions;
- Patients on dialysis who are experiencing symptoms which are difficult to manage;
- Patients on dialysis who need assistance in decision making regarding withdrawing or continuing with dialysis.

Clinic discussions

- General wellbeing – patient and family
- Emphasis on symptoms
- Emphasis on QoL
- Feelings regarding requiring dialysis or not wanting to continue
- Advance care planning
- Referral as required

Clinic outcomes

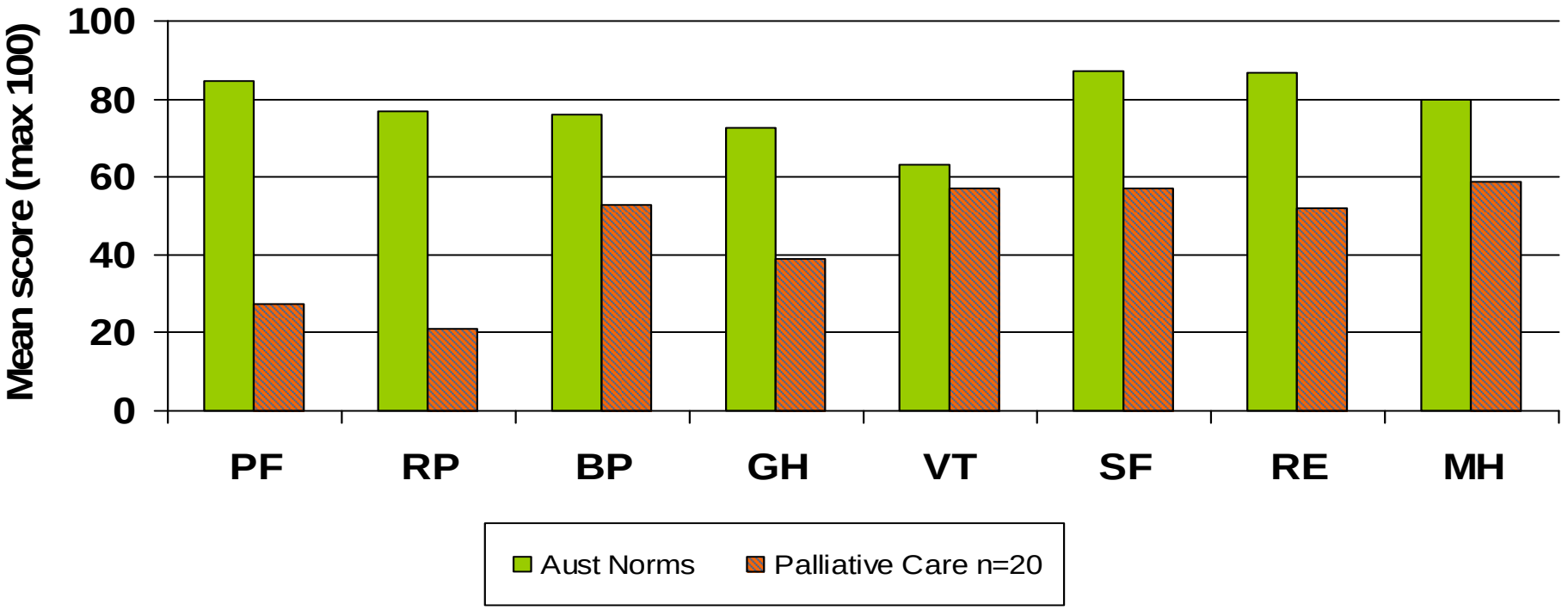
65 patients from March 09 to July 2010

Reason	%
Dialysis with Ca	10%
Dialysis with symptoms	18%
Dialysis-withdrawal	8%
NFD	64%

Clinic Mean Demographics at first visit Palliative Care

Age 1st visit	79yrs
BMI	29.6
Creatinine	379 umol/L
eGFR (MDRD)	16.3
Haemoglobin	108 g/L
Albumin	34 g/L
Male	63%

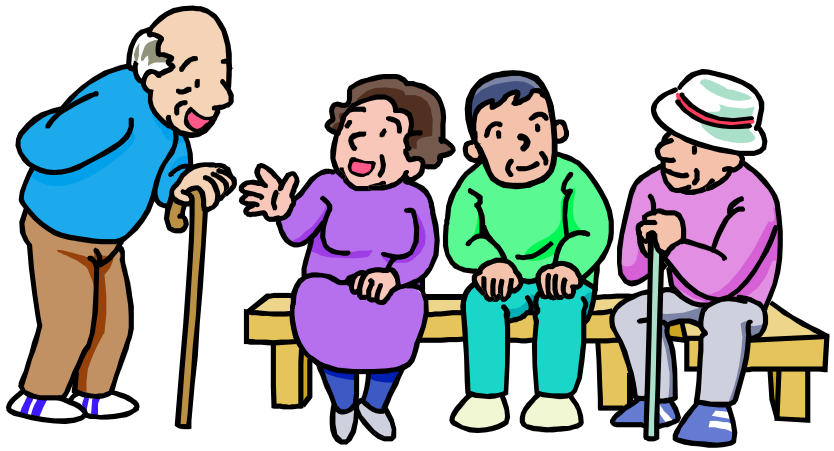
SF-36 scores compared to Australian Norm (July 10)



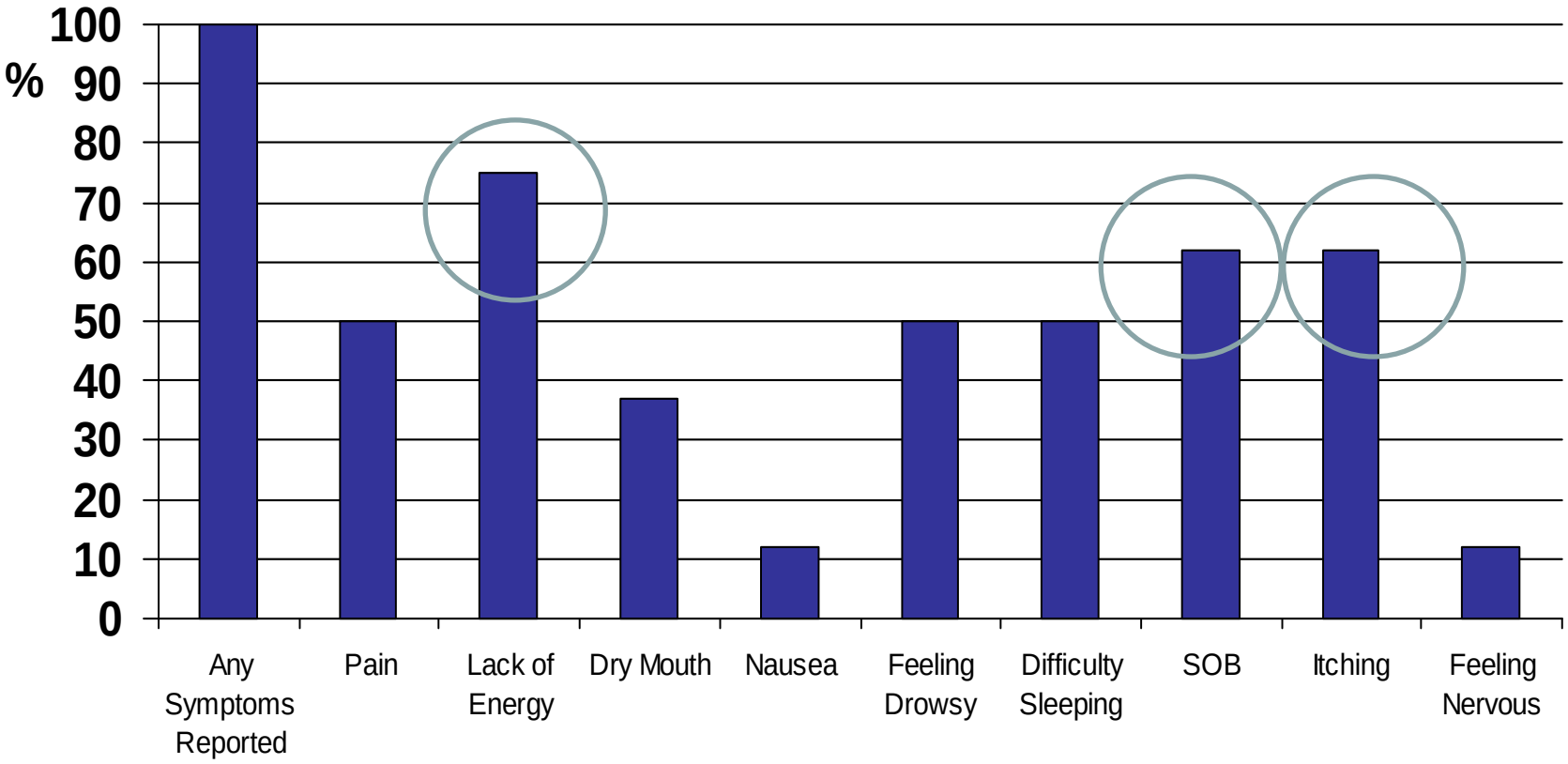
Expect QoL to be Unchanging as patients have ‘reframed’ their goals.

Symptoms

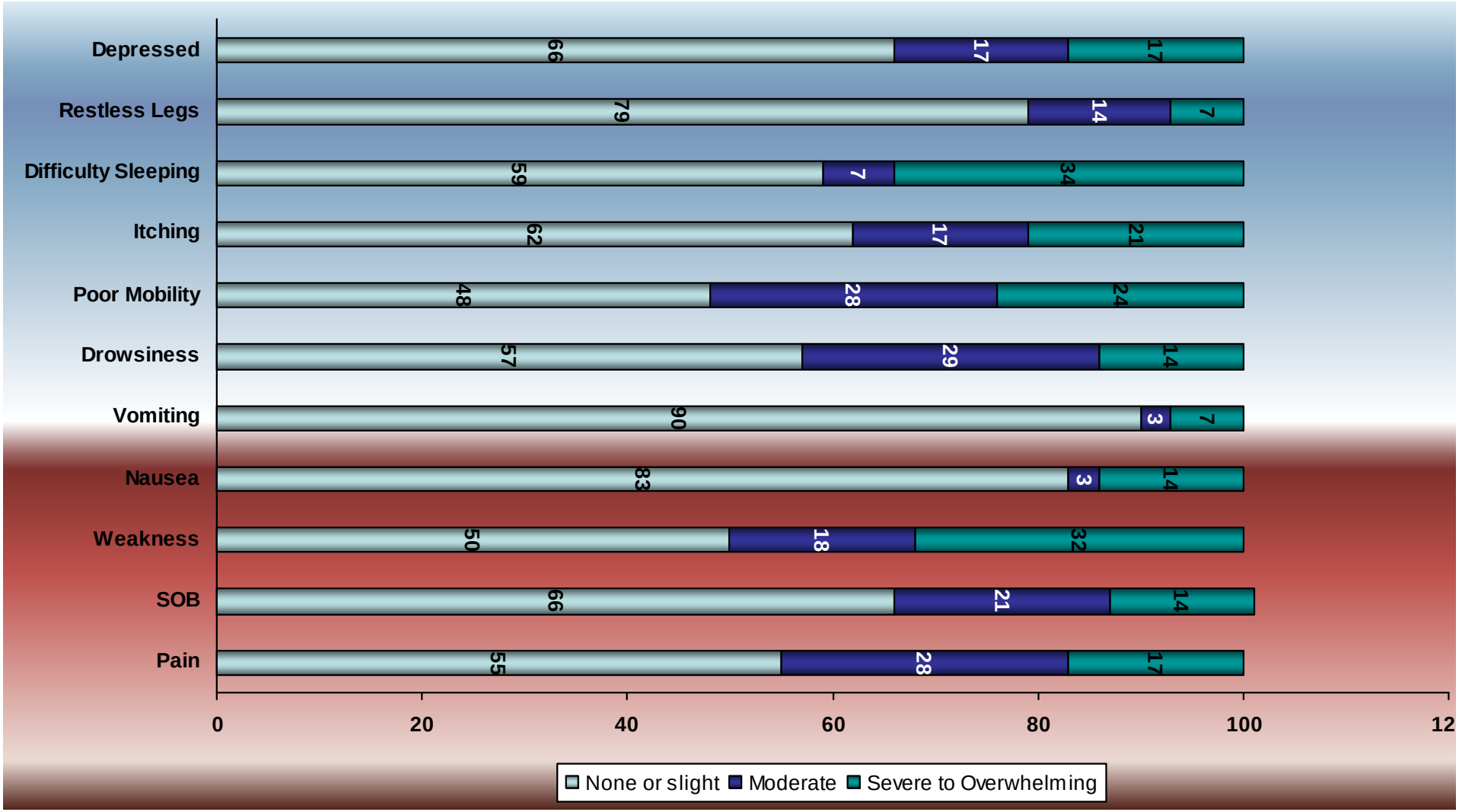
Each visit - fill out a symptom inventory



Reported Symptoms (MSAS) First Visit Renal/Palliative Care Clinic



POS results


Depressed
66
17
17
Restless Legs
79
14
7
Difficulty Sleeping
59
7
34
Itching
62
17
21
Poor Mobility
48
28
24
Drowsiness
57
29
14
Vomiting
90
3
7
Nausea
83
3
14
Weakness
50
18
32
SOB
66
21
14
Pain
55
28
17
0
20
40
60
80
100
12
None or slight
Moderate
Severe to Overwhelming

Clinic outcomes

The primary outcome measures will be:

- Survival from the time of 1st visit to clinic;
- Survival from 1st dialysis;
- QOL at baseline and at 6 monthly intervals
- Symptom scores at baseline and at 6 monthly intervals;
- Patient satisfaction measured after 2 visits and at 12 monthly intervals;
- Family satisfaction measured after 2 visits and at 12 monthly intervals.

Summary

- The clinic has worked well because of the support of the palliative care service which is severely under resourced in most hospitals.
- Anecdotally patients attend for clinics and enjoy interactions with the staff.
- Getting good results as far as symptom control.
- Formal evaluation in progress.

the end