

Managing Post- Transplantation Late Effects: a Multidisciplinary Approach

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Outline

- Late Post-Transplant Effects
- The Late Effects Clinic at Guy's & St Thomas'
- Evaluating Psychological Late Effects
- Clinical Data
- Reflections & Recommendations



Chronic Graft *vs* Host Disease

- Donor lymphocytes recognise host (patient) as foreign and attack
- A degree of GvHD is desirable as donor lymphocytes also “fight off” the disease
- Primarily manifests in lungs/liver/gut and skin to varying degrees
- Other organs affected include musculoskeletal system and mucous membranes e.g. eyes, mouth, sinuses
- Severity ranges from minor aches and pains, dry skin and dry eyes to life threatening chest and liver problems
- Treated with immunosuppression e.g. steroids, ECP

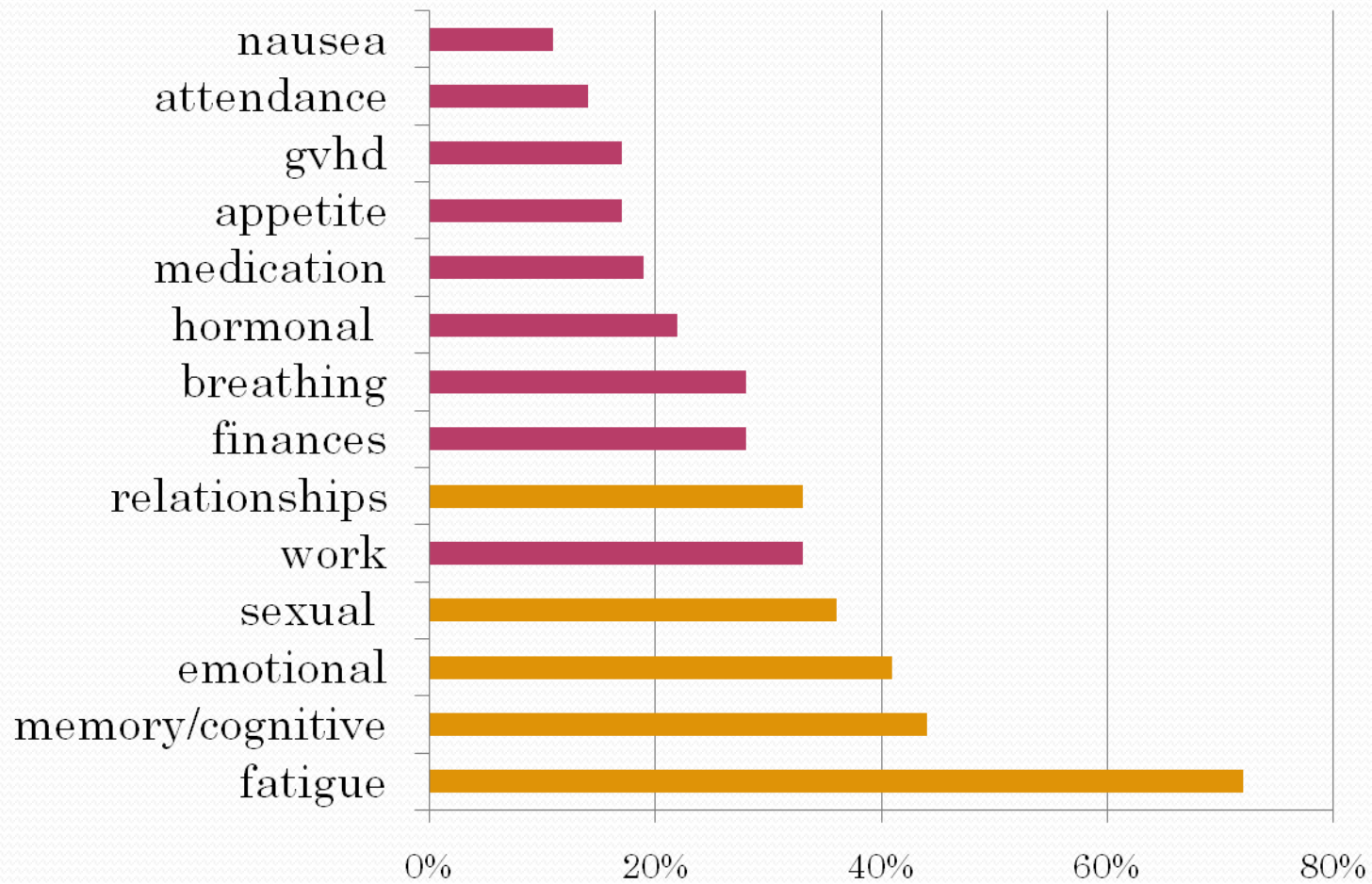


Psychological

- Mosher et al. (2009) Psycho-Oncology - Review
 - “A major psychosocial transition”
 - 25-35% moderate-severe distress in 1st year
 - 5-20% post-traumatic stress symptoms
 - distress not related to transplant type
- Grulke et al. (2008) Psycho-Oncology
 - Pre-transplant depression case on HADS → 2x mortality

Mendeley.com – free online reference app

<http://www.mendeley.com/collections/31430/Transplantation/>



The Late Effects Clinic

- A single point of contact
- Multidisciplinary, biopsychosocial care
- Views post-transplant as a long-term condition
- Systematically investigates medical late effects & psychosocial consequences
- Proactive surveillance & vaccination program
- Facilitate specialist referrals e.g. Assisted Conception Unit, Endocrinology, Ophthalmology, Benefits Advisors
- Offers open-ended patient support

Assessment

- Extensive patient questionnaire/checklist
 - At first visit and yearly
 - Based on Seattle Fred Hutchinson Centre protocols
 - Comprehensively covers functioning, current signs & symptoms, lifestyle
 - Complements clinical examination, scans, bloods etc
- Additional psychological adjustment section
 - 12 items VAS + free text reflections
 - Aim is **not** diagnostic/prognostic/psychometric

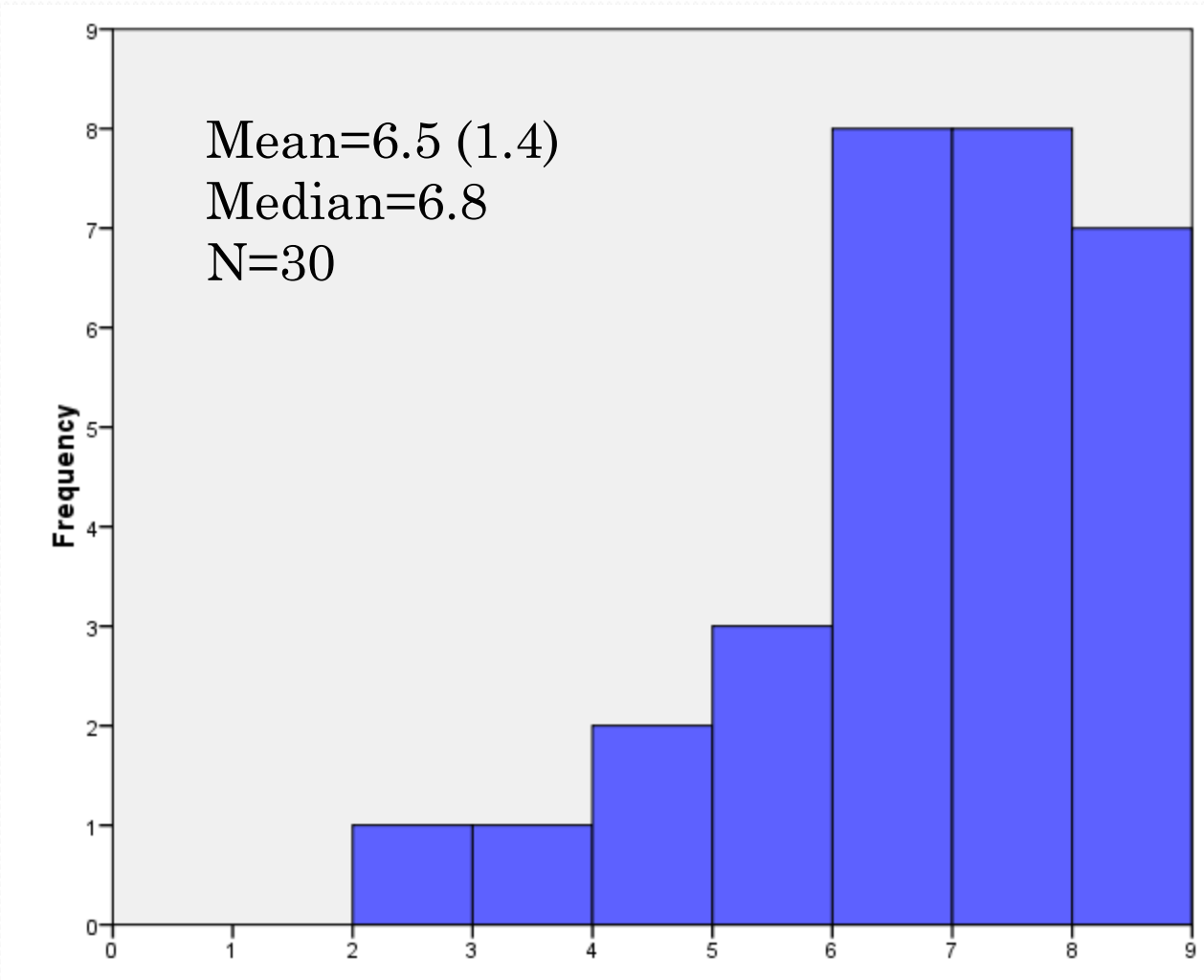
Psychological Adjustment

1. *How confident do you feel about dealing with the challenges of life after your transplant?*

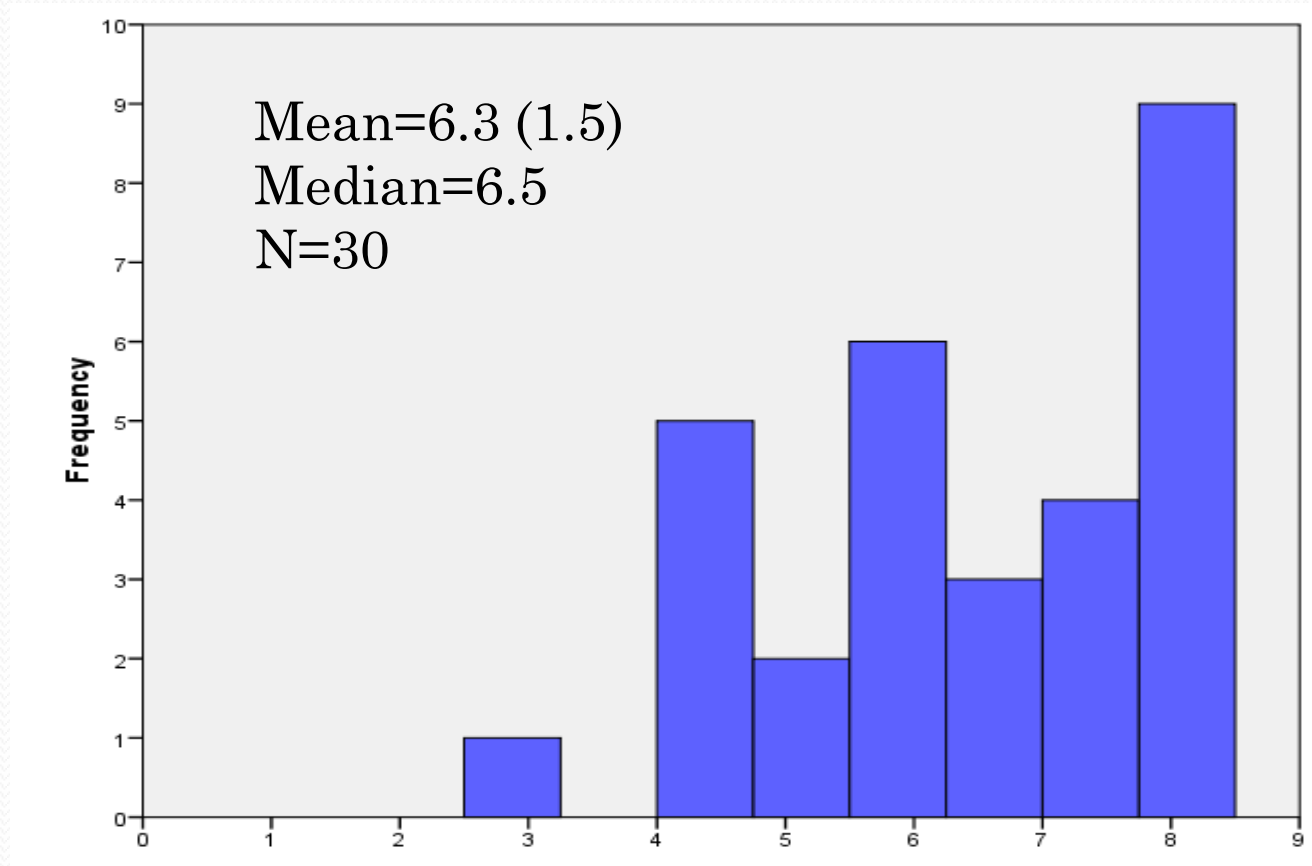


- This is a question about **general self-efficacy**, meant to give a global picture of confidence in dealing with adversity.
- It is as important to underline high ratings, as it is to investigate low ones.
- cf Hochhausen et al, 2007 (J. Psychosocial Onc.)

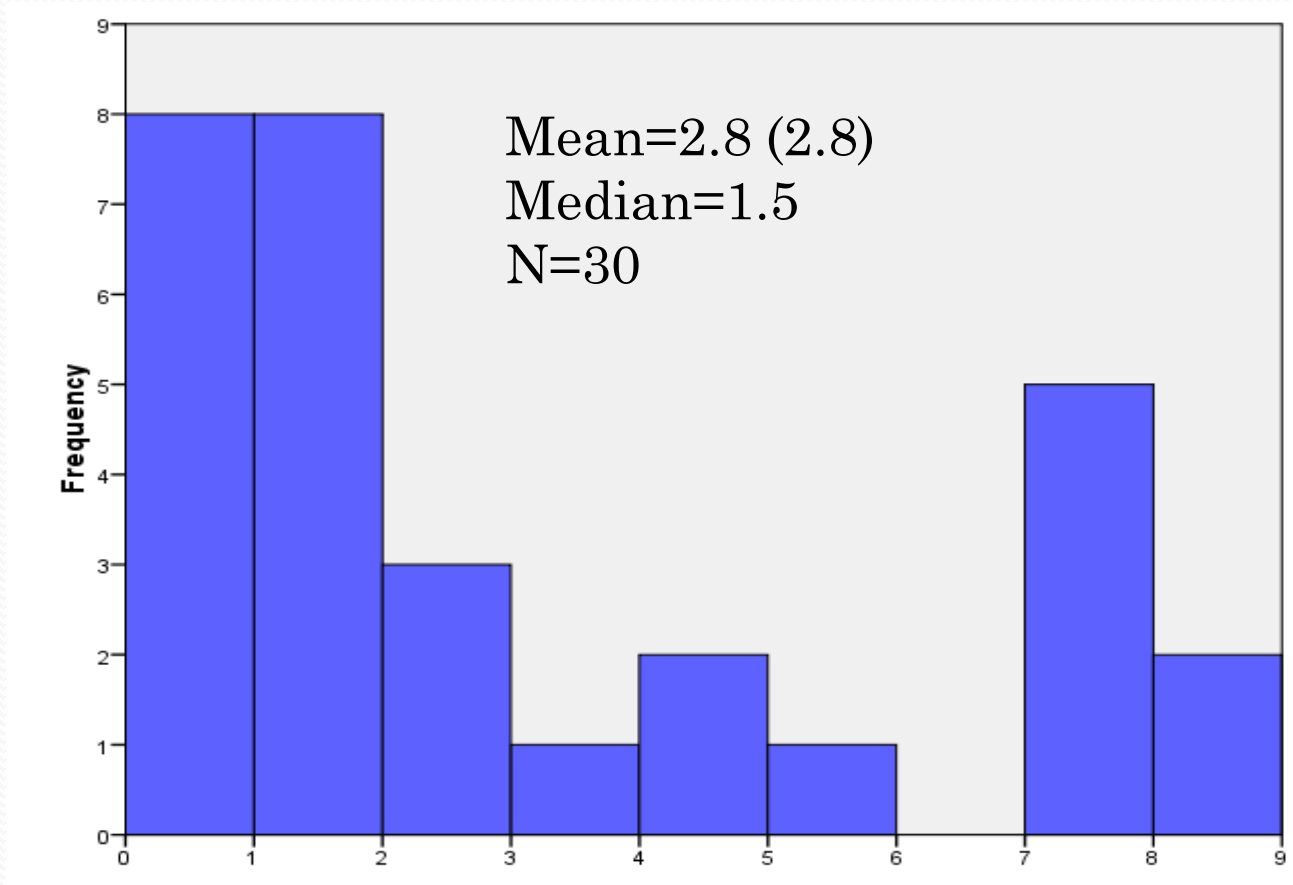
Confidence



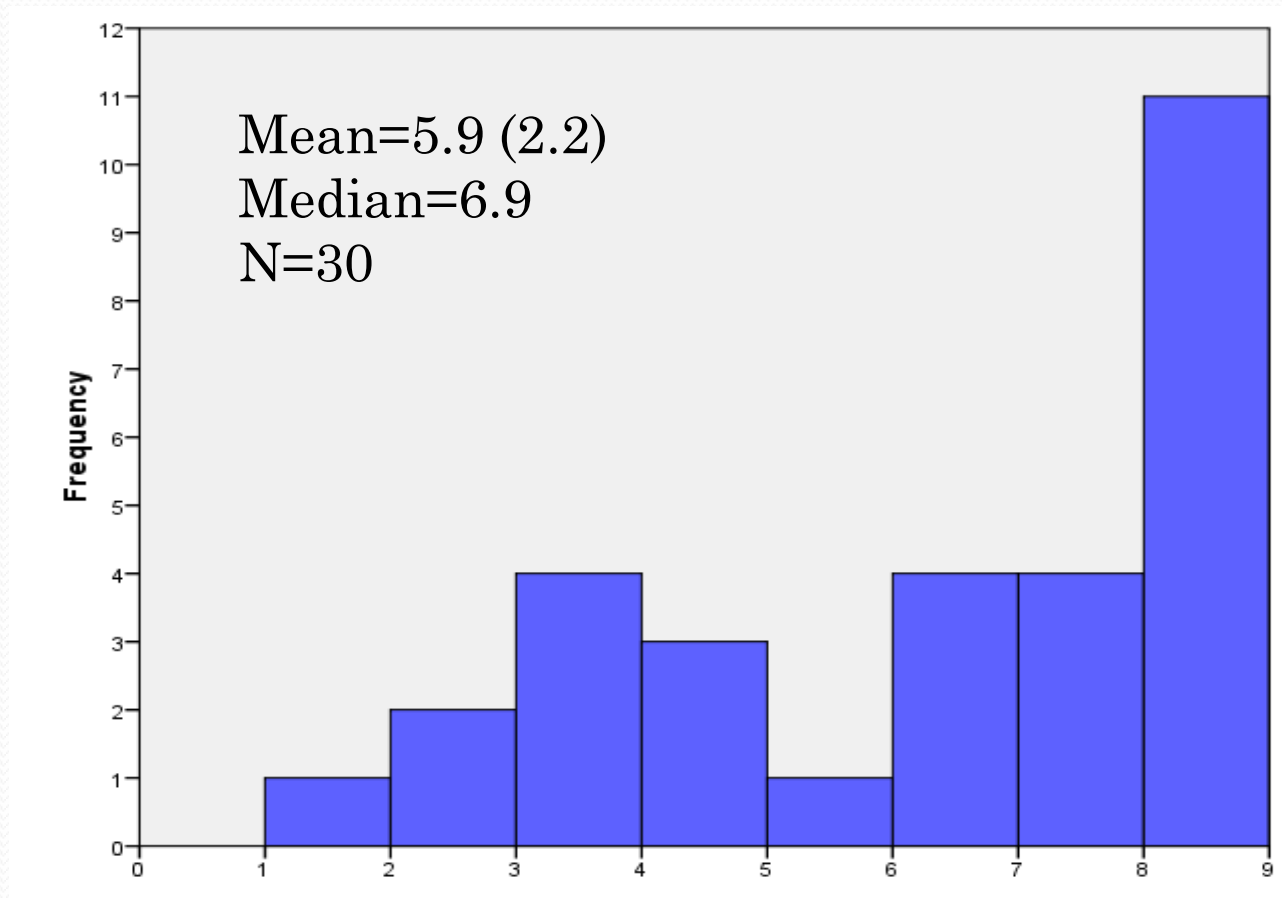
2. How clear is your understanding of your condition, your treatment, and any persistent side-effects?



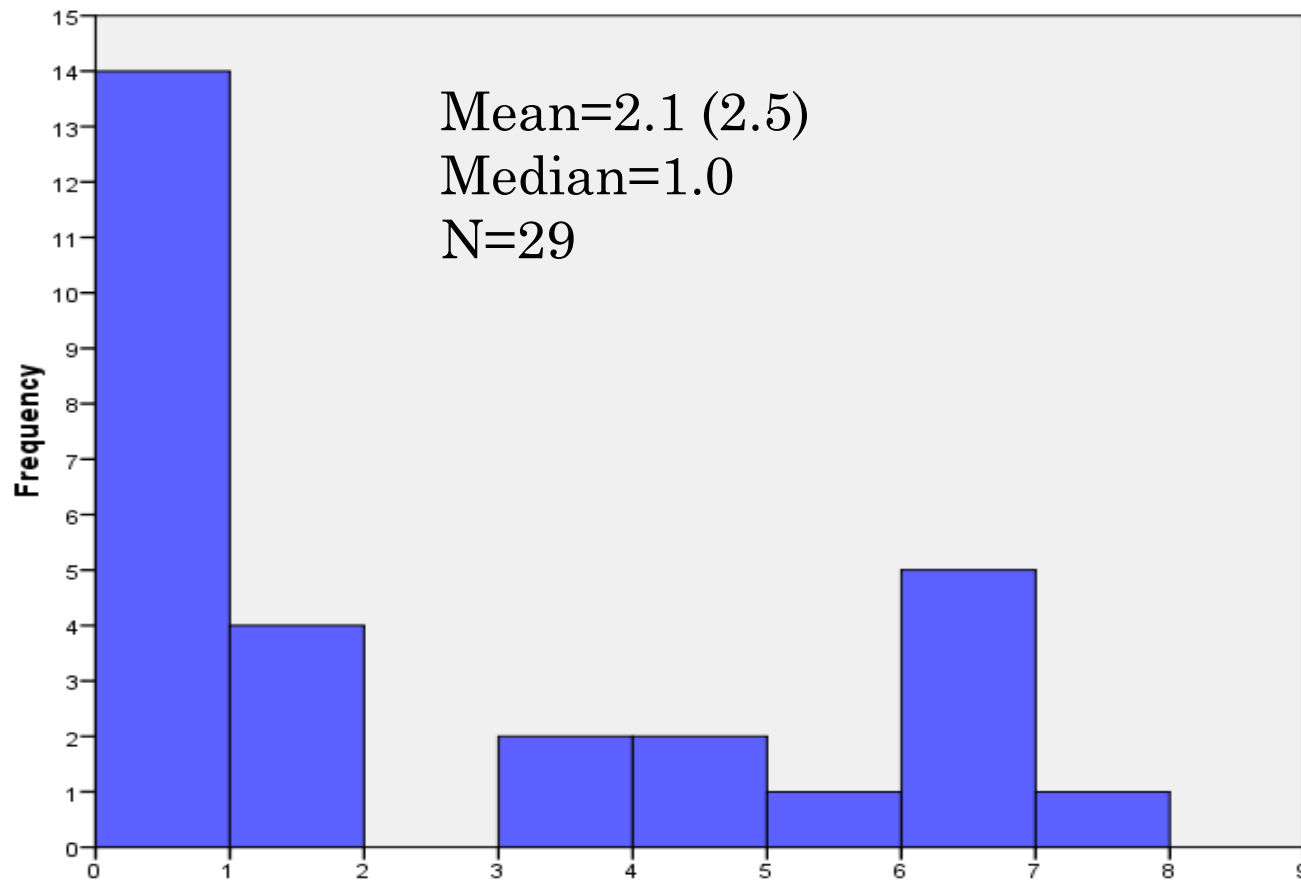
3. Are you distressed by any changes in your body or appearance since treatment?



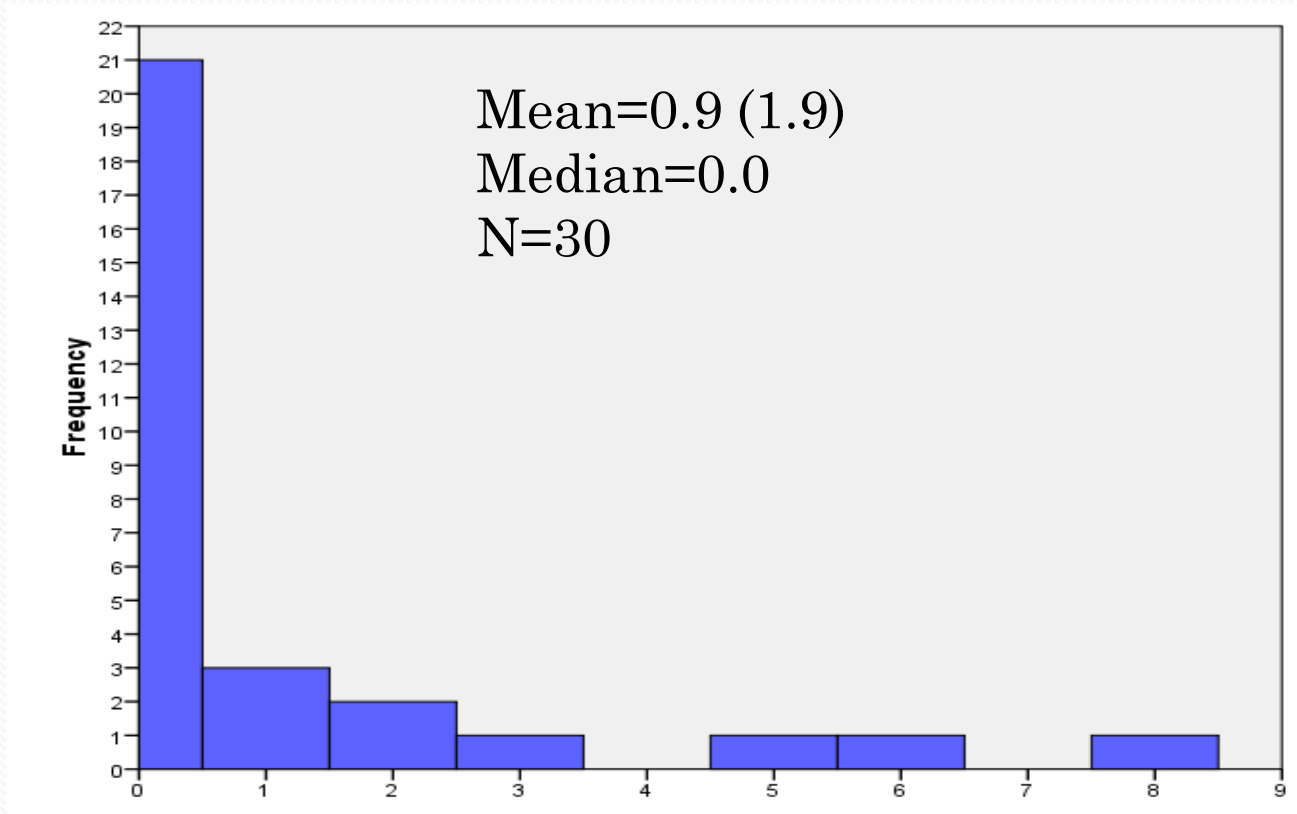
4. Do you feel able to **enjoy** things as much as you always did, e.g. a good meal, a movie, a social occasion etc?



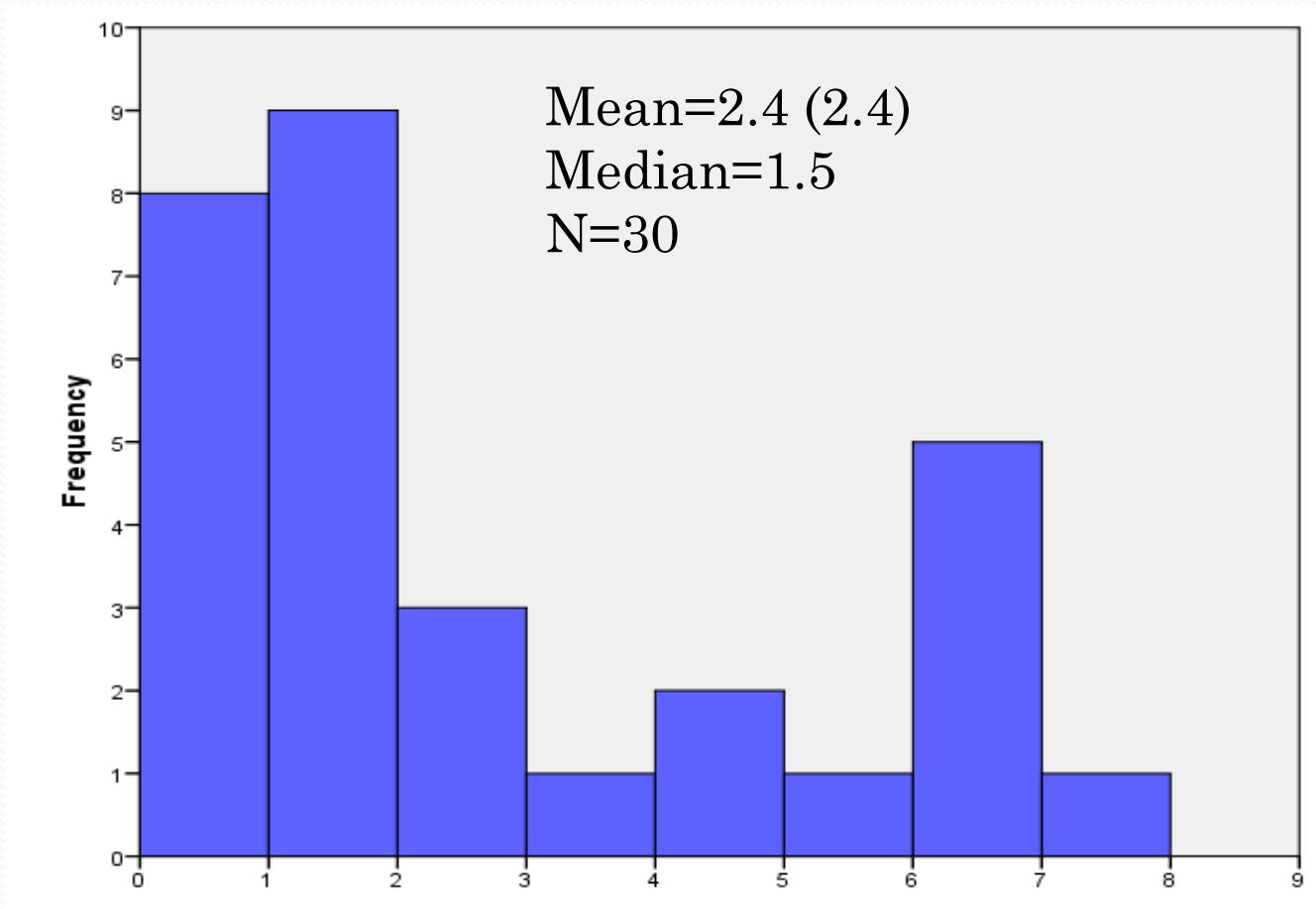
5. *Do you have sudden feelings of panic, anxiety or intense fear?*



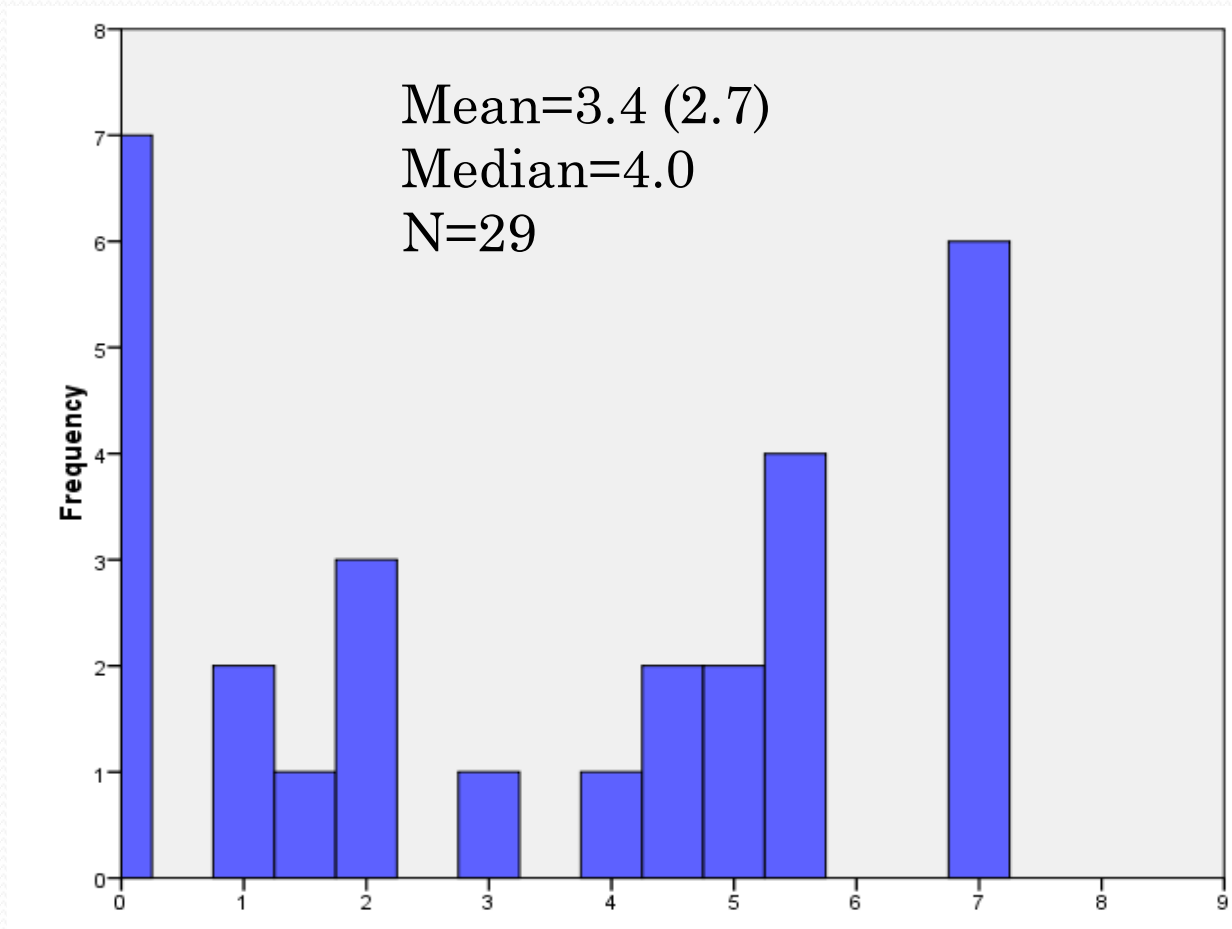
6. *Do you ever get so upset or worried that you **avoid or miss** hospital appointments or taking medication?*



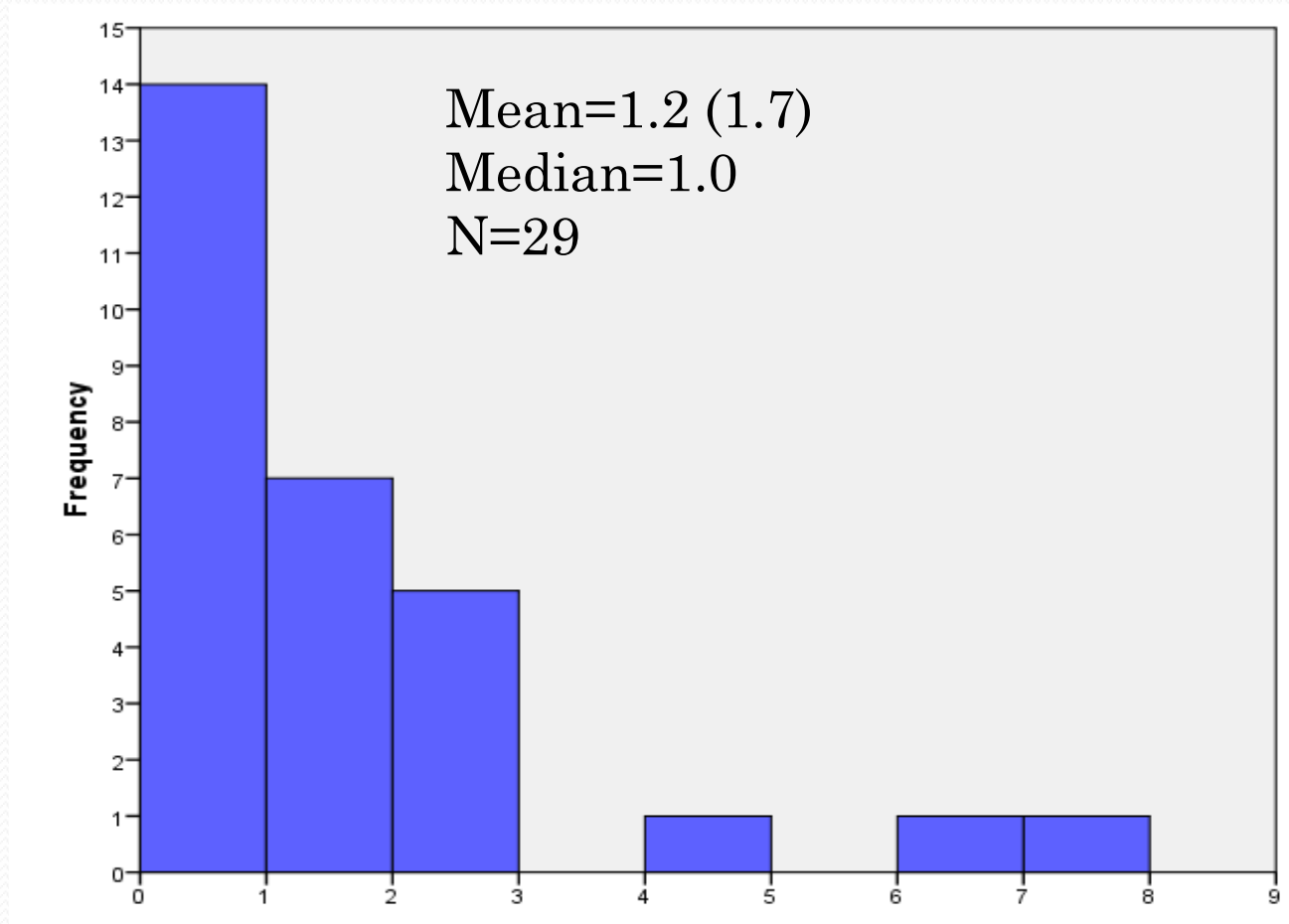
7. Do you find yourself feeling very low, “flat”, **depressed** or frequently tearful?



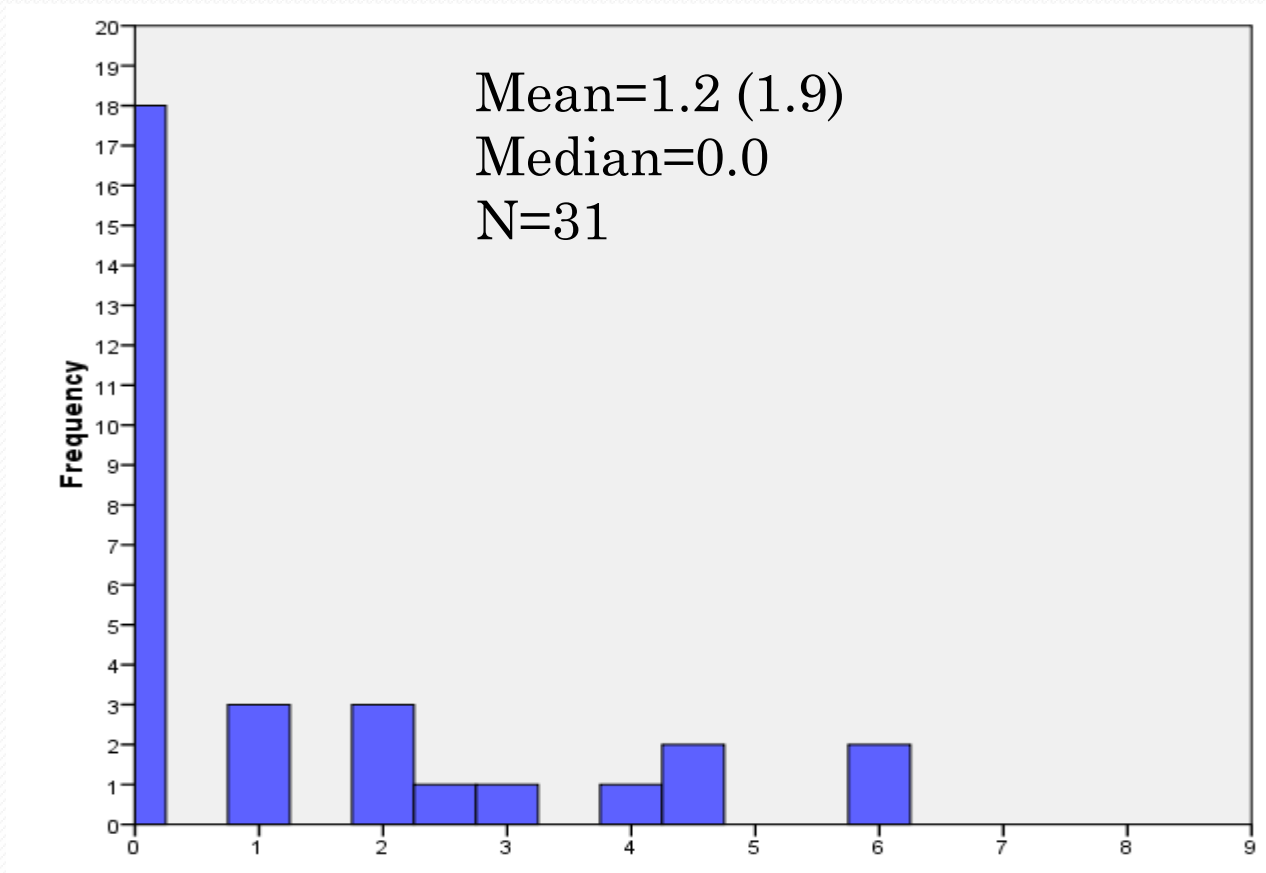
8. Do you find it harder than usual to **concentrate**, remember things, or think clearly?



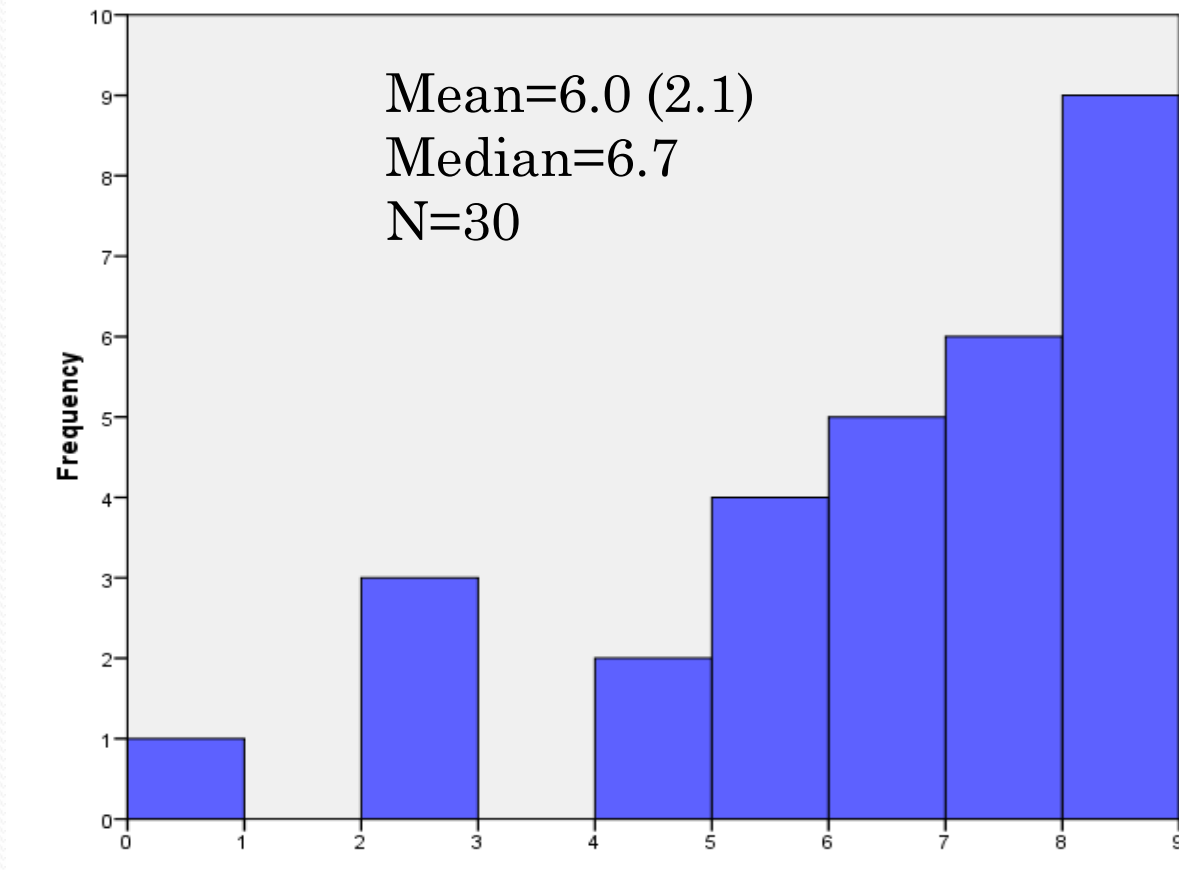
9. *Do you experience any distressing flashbacks, hallucinations or intrusive thoughts?*



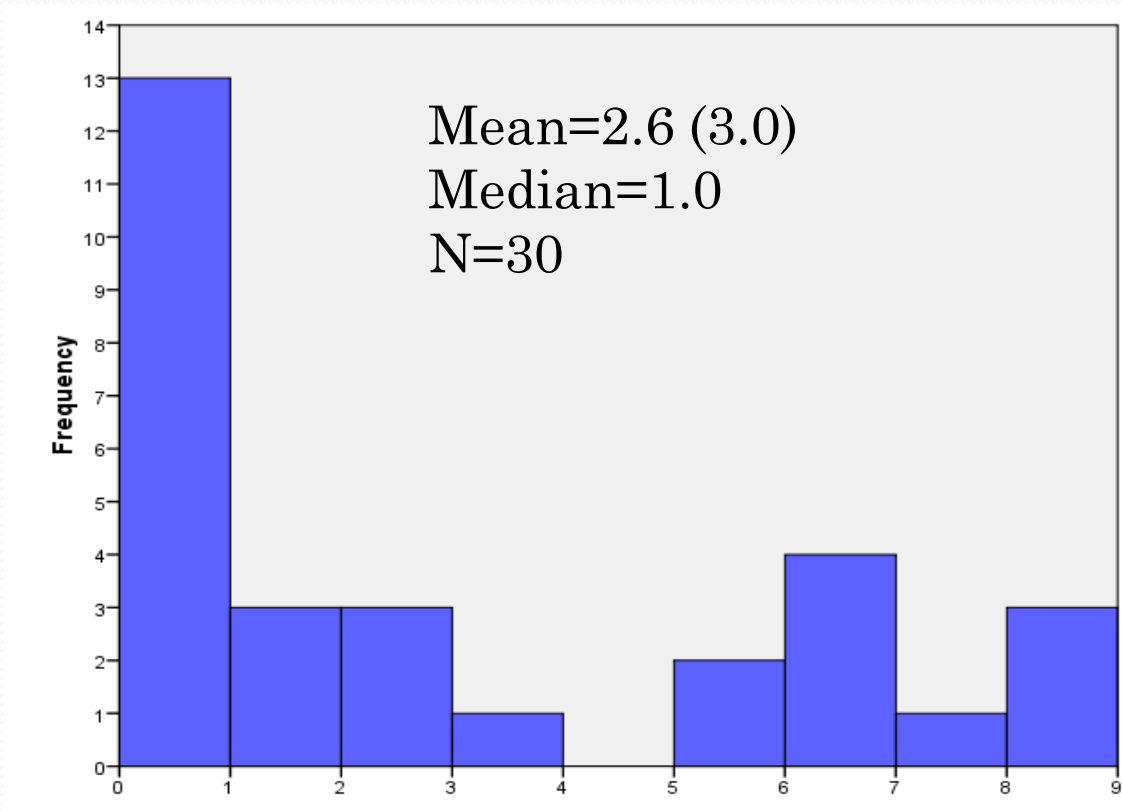
10. Do you ever feel very **hopeless**, like life is not worth living any more?



11. If you live with **others** (e.g. partner, family, parents), do you feel that they have adjusted well to your condition?



12. In your life up to having this illness, have you **ever experienced** times of feeling very low or anxious, or had any traumatic or overwhelming experiences?



Correlations

- It's not valid measurement, but..
 - Low mood and cognitive problems $r=.62$ ($p<.001$)
 - Low mood and hopelessness $r=.61$ ($p<.001$)
- and..
 - Confidence and understanding $r=.52$ ($p<.005$)
 - and negative correlations with mood ($r=-.41$, $p<.02$)
 - No variables linked to family adjustment or emotional distress history

Psychology Follow-up


- Responses explored in clinic
- May lead to referral (N=10, 26% of this sample)
- Full assessment in parallel psychology clinic
- Intervention draws on full Psycho-Oncology team, incl. counselling, psychotherapy, liaison psychiatry
- Issues of trauma, readjustment, symptom burden, anxiety, depression, avoidance, fertility; carers' issues

Reflections

- Input useful to frontline clinical colleagues
- As part of broader engagement with Haematology team (e.g. pre- screening, CNS reflective practice group, support group development, teaching, etc)
- Promotes attachment, systems and biopsychosocial perspectives
- Informs clinical practice pre-transplant; QoL and adjustment impact addressed earlier
- Staging post for supportive care (e.g. survivors groups, fatigue management, carer support)

Recommendations

- A biopsychosocial approach to late effects
- Integrated psychological screening
- Look for pre-transplant distress
- 1-3 years post-transplant most sensitive
- Actively query emotional, sexual & family adjustment issues
- Specialist psycho-oncology assessment



‘Given a second chance at life so I really want to make the most of my chance. I feel freer to say how I feel on certain issues which matter when before I would have held back, and don’t bother about small trivia anymore. I make sure I enjoy all I do, otherwise what’s the point?’

‘Strength gained from living through treatment is eroded by the grind of getting balanced follow-up treatment. Others tire of the continuing chronic after effects and can really only recognise and deal with acute issues.’

Thank You!

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