

Attitudes towards pain expression and pain management in parents of children with cancer

Roses Parker; Stephen McKeever;
Theresa Wiseman; Alison Twycross.

RN PG Dip (child), BSc, Doctoral candidate

parker@lsbu.ac.uk

 @Roses_Parker

Outline

Background

Aim

Methods

Results

Discussion

Take home message

Background

Children experience pain throughout their cancer journey
(Olsen & Amari, 2015; Twycross *et al.* 2015)

Pain has negative consequences
(Berger *et al.*, 2007; Huth *et al.*, 2003)

Pain is treatable
(Fortier *et al.*, 2011)

Care location is changing
(Fortier *et al.*, 2014)

Parental pain management?
(Flury *et al.*, 2011; Twycross *et al.*, 2015)



Aim

To explore attitudes of parents of children with cancer towards children's pain and analgesic medications



SURVEY

Knowledge
and attitudes



PAIN DIARY

Baseline
measurements



INTERVIEW

Understanding

Methods

Parental Pain Expression Perceptions questionnaire (PPEP)

- Zisk-Rony *et al.*, 2007
- Pain assessment attitudes in parents
- Likert-type scale:
 - Strongly agree → strongly disagree
- 3 subscales

Medication Attitudes Questionnaire (MAQ)

- Forward *et al.*, 1996
- Attitudes toward paracetamol and opioid administration
- Likert-type scale:
 - Strongly agree → strongly disagree
- 3 subscales

Demographic information

Inclusion criteria

- Parents of children with cancer
- Parent:
 - Mother, father, guardian, any individual with primary caregiving responsibility
 - 18 years old and over
 - Sufficient English language and literacy to completed survey
- Child:
 - Aged from birth – 16 years old
 - Any cancer diagnosis
 - On curative treatment
- Recruited from a tertiary cancer centre within the UK
- Target sample size: 100

Analysis

- SPSS
- Attrition
 - Chi squared
- Demographics and descriptive statistics
 - Tables, graphs, frequencies and percentages
- Inferential statistics
 - Time since diagnosis, Diagnosis, Parent ethnicity – Kruskal-Wallis
 - Gender – Student's t-test
 - Child age – Pearson's correlation
 - Parent age – Spearman's rho

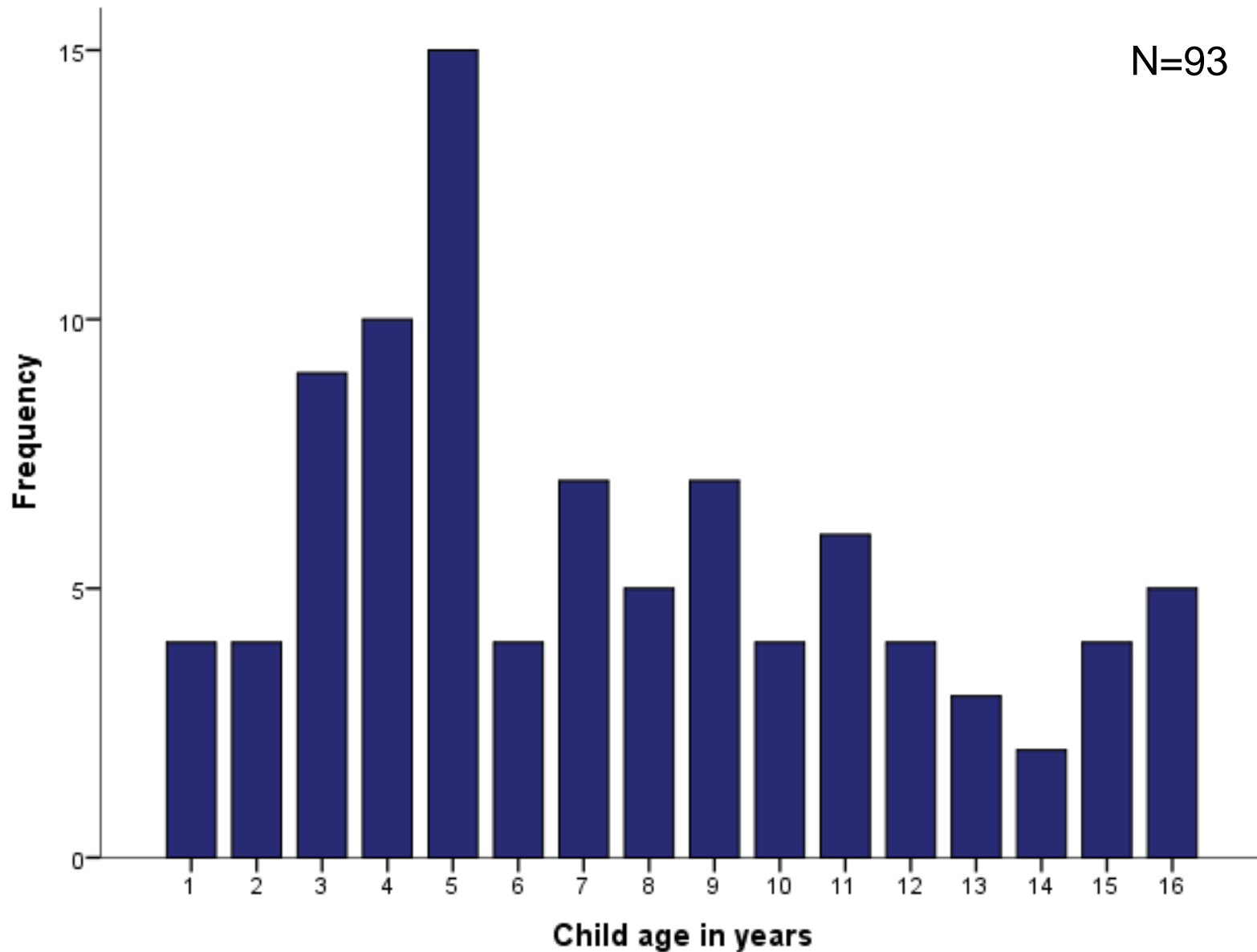
Analysis based on type of data and analysis of normal distribution
Statistical significance at $p \leq .05$

Sample

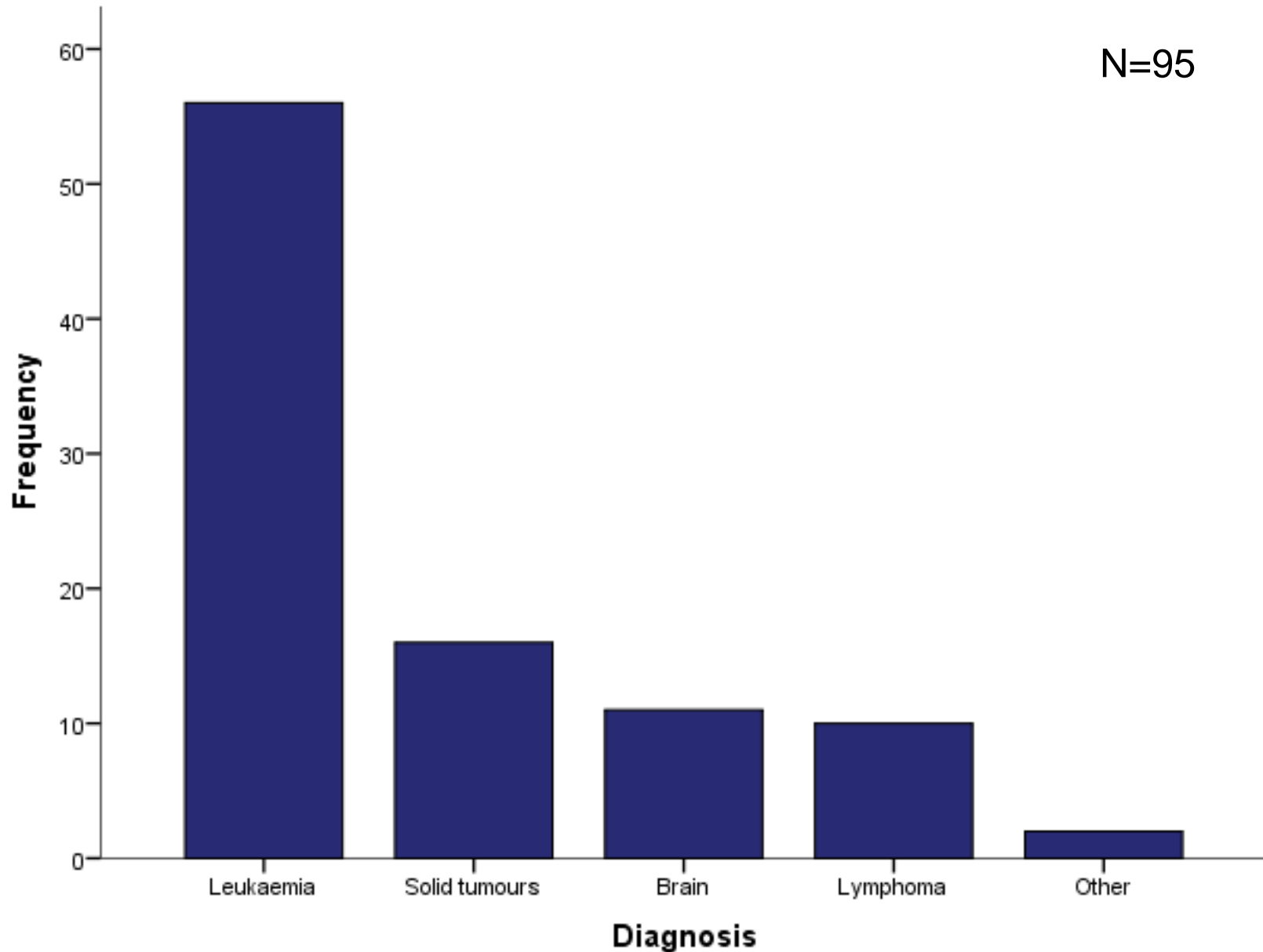
- 101/161 (63%) participants who were approached returned a survey.
- 75 mothers, 20 fathers*
- 27 pre-school, 42 primary, 24 secondary*
- 60 boys, 36 girls*

*Chi-squared analysis comparing demographics of participation vs non-participation revealed no statistical significant differences

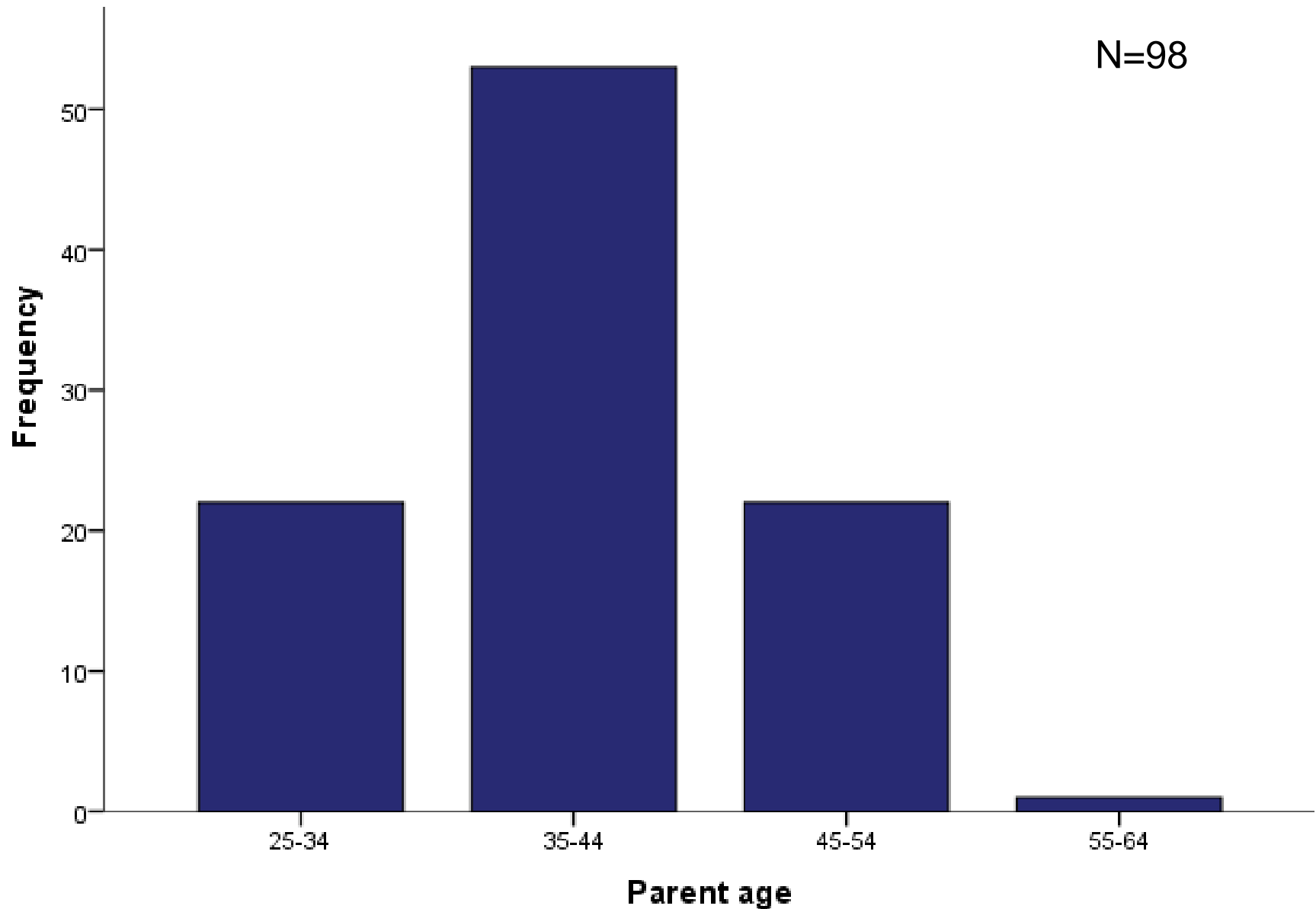
Child demographics – age



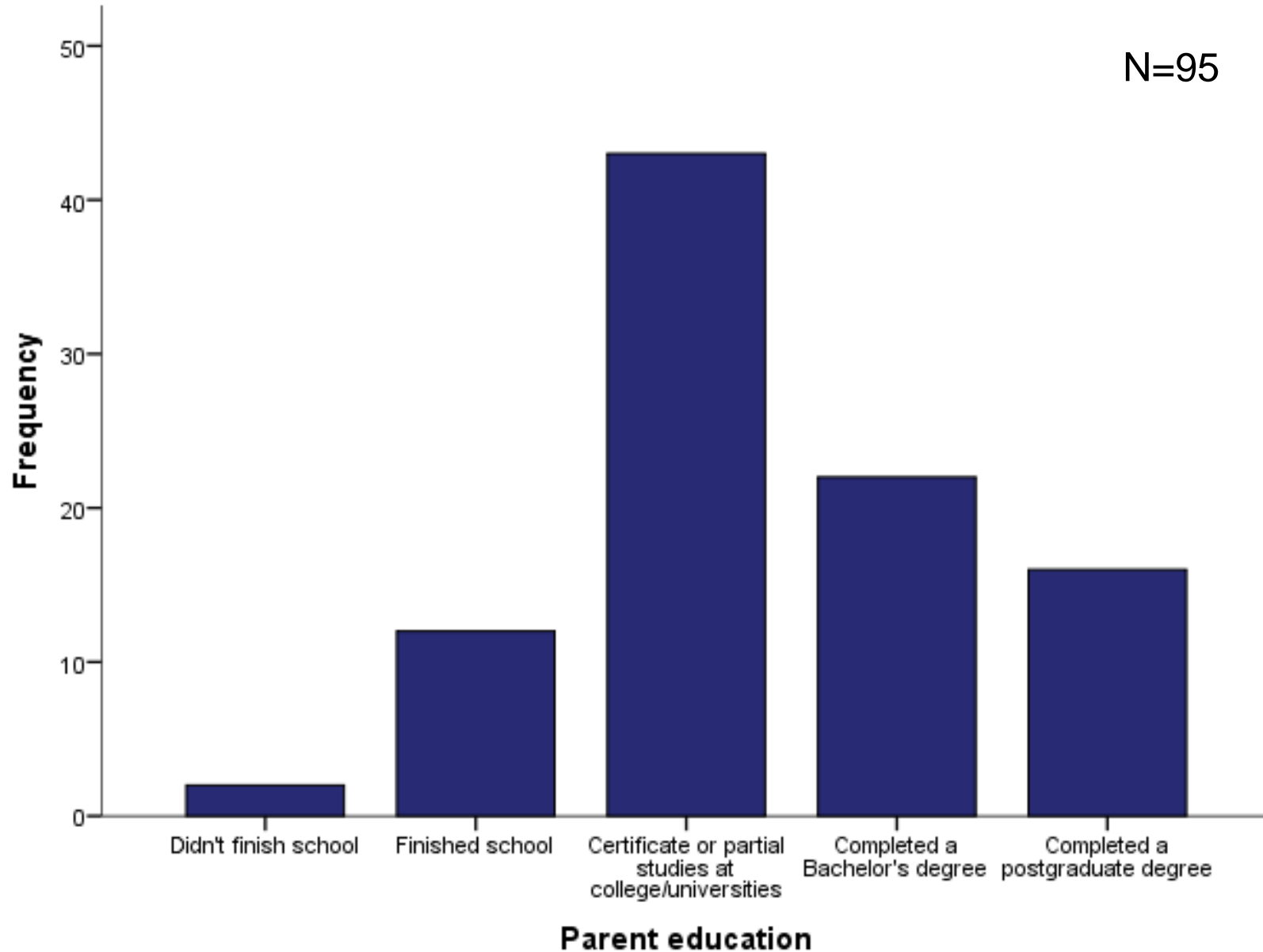
Child demographics - diagnosis



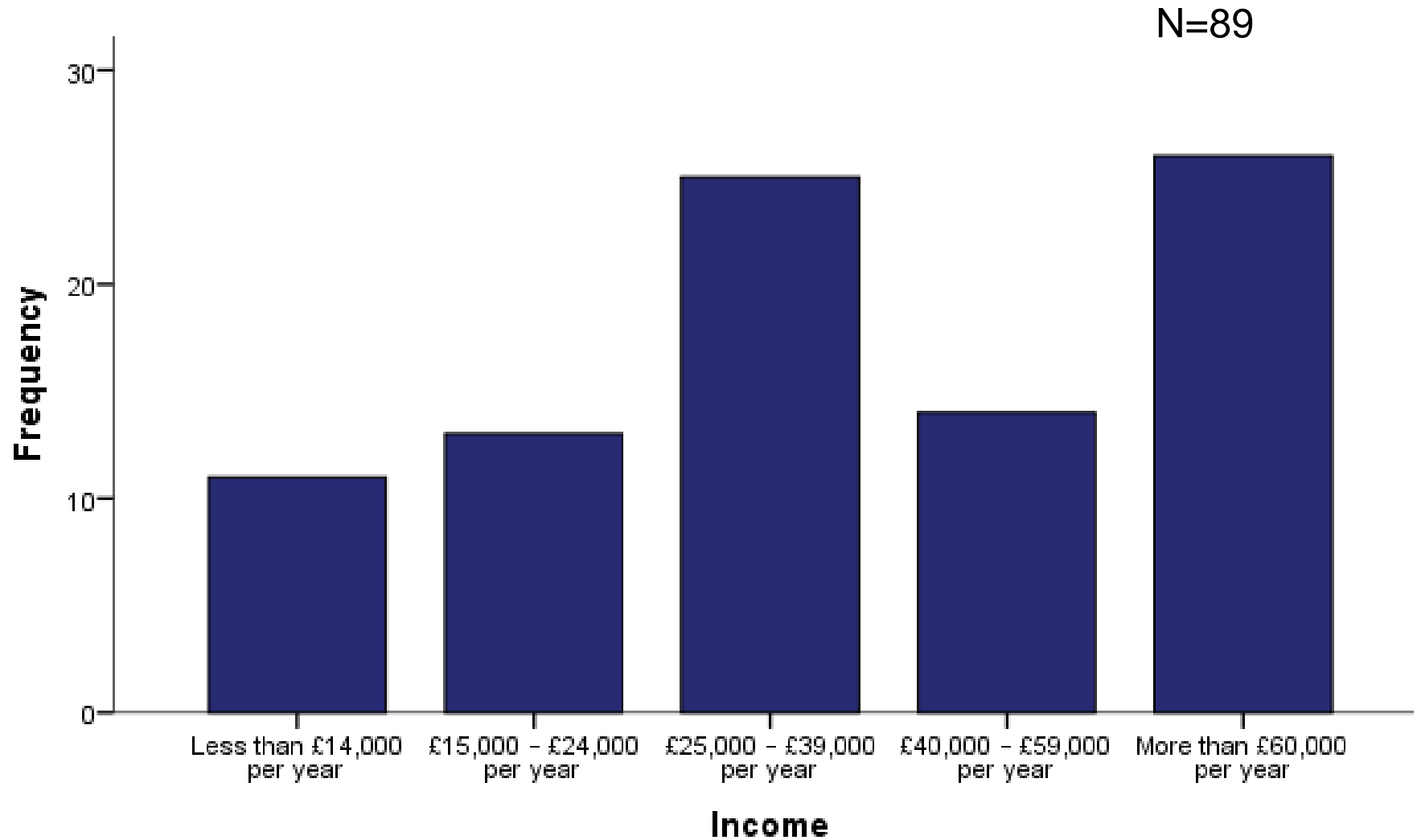
Parent demographics – age



Parent demographics – education



Parent demographics – income



Results – PPEP

| Statement on Parental Pain Expression Perceptions questionnaire | Disagree | Unsure | Agree |
|---|----------|--------|-------|
| Children always express pain by crying or whining | 48 | 1 | 51 |
| Children always tell their parents when they are in pain | 47 | 4 | 49 |
| Children who are quiet are not in pain | 62 | 3 | 34 |
| Children who are playing are not in pain | 59 | 1 | 40 |
| Children experiencing pain report it immediately | 56 | 5 | 40 |
| Children exaggerate pain | 46 | 15 | 39 |
| Children complain about pain to get attention | 52 | 6 | 42 |
| Children feel less pain than adults | 64 | 12 | 24 |
| Children in pain have trouble sleeping | 10 | 4 | 86 |

Results – MAQ

| Statement on Medication Attitudes Questionnaire | Disagree | Unsure | Agree |
|--|----------|--------|-------|
| Children should be given pain medication as little as possible because of side effects | 37 | 24 | 38 |
| Children who take pain medication for pain may learn to take drugs to solve other problems | 43 | 23 | 34 |
| Pain medication works the same no matter how often it is used | 42 | 24 | 34 |
| Pain medication works best when it is given as little as possible | 40 | 22 | 38 |
| Pain medication has many side effects | 21 | 27 | 52 |
| Children will become addicted to pain medication if they take it for pain | 46 | 21 | 33 |
| There is little need to worry about side-effects from pain medication ** | 49 | 18 | 33 |
| It is unlikely a child will become addicted to pain medication if taken for pain ** | 17 | 33 | 50 |
| Pain medication is addictive | 29 | 28 | 42 |
| Pain medication works best if saved for when the pain is quite bad | 43 | 9 | 48 |
| Using pain medication for children's pain leads to later drug abuse | 55 | 17 | 28 |
| There is little risk of addiction when pain medication is given for pain ** | 21 | 18 | 60 |
| Children learn how to use pain medication responsibly when it is given for pain ** | 10 | 27 | 63 |
| Side effects are something to worry about when giving children pain medication | 16 | 11 | 73 |
| The less often children take pain medication for pain, the better the medicine works | 37 | 25 | 37 |
| Giving children pain medication for pain teaches proper use of drugs ** | 21 | 33 | 46 |

** Indicates reverse scored items

Results

Child factors

- Gender
- Age
- Diagnosis
- Time since diagnosis

→ No statistically significant differences



Parental factors

- Ethnicity.
 - A difference was found between Asian parents and white parents
 - A difference was found between Asian parents and parents of 'other' ethnicity
- Age
 - Spearman's rho revealed lower MAQ scores with higher age

Comparison to other populations

More negative attitudes and misconceptions than other studies using PPEP and MAQ

Example

55% disagree *“Using pain medication for children’s pain leads to later drug abuse”*

- Zisk *et al.*, 2007 (Surgery, US): 80% disagree
- Zisk *et al.*, 2010 (Outpatient surgery, US): 86% disagree
- Fortier *et al.*, 2012 (Cancer, US): 70% disagree
- Twycross *et al.*, 2014 (General, UK): 84% disagree

Summary

- Parents of children with cancer hold negative attitudes and misconceptions
 - No improvements with time since diagnosis
 - Fewer with age
 - More in Asian populations
- More negative attitudes and misconceptions than other populations



Take home message

Awareness that more must be done to challenge negative attitudes and misconceptions of parents of children with cancer so that they do improve with exposure to healthcare settings

References

- Berger, A. M., Shuster, J. L. and Roenn, J. H. V. (2007) *Principles and Practice of Palliative Care and Supportive Oncology*. Lippincott Williams & Wilkins.
- Flury, M., Caflisch, U., Ullmann-Bremi, A. and Spichiger, E. (2011) Experiences of parents with caring for their child after a cancer diagnosis, *Journal of Pediatric Oncology Nursing*, 28 (3), pp. 143–153.
- Fortier, M. A., Martin, S. R., Kain, D. I. and Tan, E. T. (2011) Parental attitudes regarding analgesic use for children: differences in ethnicity and language, *Journal Of Pediatric Surgery*, 46 (11), pp. 2140–2145. DOI:10.1016/j.jpedsurg.2011.06.021.
- Fortier, M. A., Wahi, A., Bruce, C., Maurer, E. L. and Stevenson, R. (2014) Pain management at home in children with cancer: A daily diary study, *Pediatric Blood & Cancer*, 61 (6), pp. 1029–1033. DOI:10.1002/pbc.24907.
- Fortier, M. A., Wahi, A., Maurer, E. L., Tan, E. T., Sender, L. S. and Kain, Z. N. (2012) Attitudes regarding analgesic use and pain expression in parents of children with cancer, *Journal of Pediatric Hematology/Oncology*, 34 (4), pp. 257–262. DOI:10.1097/MPH.0b013e318241fd07.
- Forward, S. P., Brown, T. L. and McGrath, P. J. (1996) Mothers' attitudes and behavior toward medicating children's pain, *Pain*, 67 (2–3), pp. 469–474.
- Huth, M. M., Broome, M. E., Mussatto, K. A. and Morgan, S. W. (2003) A study of the effectiveness of a pain management education booklet for parents of children having cardiac surgery, *Pain Management Nursing*, 4 (1), pp. 31–39.
- Olson, K. and Amari, A. (2015) Self-reported pain in adolescents with leukemia or a brain tumor: A systematic review, *Cancer Nursing*, 38 (5), pp. E43–E53.
- Twycross, A. M., Williams, A. M., Bolland, R. E. and Sunderland, R. (2014) Parental attitudes to children's pain and analgesic drugs in the United Kingdom, *Journal of Child Health Care*, 19 (3), pp. 402–411.
- Twycross, A., Parker, R., Williams, A. and Gibson, F. (2015) Cancer-Related Pain and Pain Management Sources, Prevalence, and the Experiences of Children and Parents, *Journal of Pediatric Oncology Nursing*, 32 (6), pp. 369–384.
- Zisk, R. Y., Grey, M., Medoff-Cooper, B. and Kain, Z. N. (2007) Accuracy of parental-global-impression of children's acute pain, *Pain Management Nursing*, 8 (2), pp. 72–76. DOI:10.1016/j.pmn.2007.03.002.
- Zisk, R. Y. Z., Fortier, M. A., Chorney, J. M., Perret, D. and Kain, Z. N. (2010) Parental postoperative pain management: attitudes, assessment, and management, *Pediatrics*, 125 (6), pp. e1372–1378. DOI:10.1542/peds.2009-2632.

Thank you

- Supervisors: Alison Twycross, Theresa Wiseman, Stephen McKeever
- Staff, patients and families at The Royal Marsden

Any questions?

Roses Parker

parker11@lsbu.ac.uk

 @Roses_Parker

The ROYAL MARSDEN
NHS Foundation Trust



EST 1892

**London
South Bank
University**