Qualitative study

Tyldesley-Marshall, Natalie; Greenfield, Sheila; Neilson, Susan; English, Martin; Adamski, Jenny ; Peet, Andrew

DOI:
10.1136/archdischild-2019-317306

Title page

Title

Qualitative study: Patients' and parents' views on brain tumour MRIs

All authors:

Ms Natalie Tyldesley-Marshall. Institute of Cancer & Genomics / Institute of Applied Health Research, College of Medical and Dental Sciences, University of Birmingham, Birmingham, B15 2TT, UK n.g.tyldesley-marshall@bham.ac.uk

Prof. Sheila Greenfield. Institute of Applied Health Research, College of Medical and Dental Sciences, University of Birmingham, Birmingham, B15 2TT, UK s.m.greenfield@bham.ac.uk

Dr Susan Neilson. Institute of Clinical Sciences, College of Medical and Dental Sciences, University of Birmingham, Birmingham, B15 2TT, UK s.j.neilson@bham.ac.uk

Dr Martin English. Birmingham Women's and Children's NHS Foundation Trust, Steelhouse Lane, Birmingham, B4 6NH, UK martinenglish@nhs.net

Dr Jenny Adamski. Birmingham Women's and Children's NHS Foundation Trust, Steelhouse Lane, Birmingham, B4 6NH, UK jenny.adamski@nhs.net

Prof. Andrew Peet. Institute of Cancer & Genomics, College of Medical and Dental Sciences, University of Birmingham, Birmingham, B15 2TT, UK a.peet@bham.ac.uk

Corresponding author:

Prof. Andrew Peet. Institute of Cancer & Genomics, College of Medical and Dental Sciences, University of Birmingham, Birmingham, B15 2TT, UK a.peet@bham.ac.uk 0121 333 8711

Word count: 2498

Keywords Qualitative research, patient perspectives, imaging, oncology, paediatric practice

ABSTRACT

Background

Magnetic Resonance Imaging (MRI) is essential to the clinical management of children and young people with brain tumours. Advances in technology have made images more complicated to interpret, yet more easily available digitally. It is common practice to show these to patients and families, but how they emotionally respond to, understand and value, seeing brain tumour MRIs has not been formally studied.

Methods

Qualitative semi-structured interviews were undertaken with fourteen families (eight patients, fifteen parents) purposively sampled from paediatric patients (0-18 years) attending a large UK children's hospital for treatment or monitoring of a brain tumour. Transcripts were analysed thematically using the Framework Method.

Results

Four themes were identified: Receiving results (waiting for results, getting results back, preferences to see images); Emotional responses to MRIs; Understanding of images (what they can show, what they cannot show, confusion); and Value of MRIs (aesthetics, aiding understanding, contextualised knowledge / emotional benefits, enhanced control, enhanced working relationships, no value). All families found value in seeing MRIs, including reassurance, hope, improved understanding, and enhanced feeling of control over the condition. However emotional responses varied enormously.

Conclusions

Clinical teams should always explain MRIs after 'framing' the information. This should minimise participant confusion around meaning, periodically evident even after many years. Patient and parent preferences for being shown MRIs varied, and often changed over time, therefore clinicians should identify, record and update these preferences. Time between scanning and receiving the result was stressful causing 'scanxiety', but most prioritised accuracy over speed of receiving results.

INTRODUCTION

Medical imaging such as Magnetic Resonance Imaging (MRI) is a vital part of part of the detection, diagnosis and clinical management of brain tumours.[1] Each MRI scan of the patient produces hundreds and often thousands of images (MRIs), and doctors want to show patients these to improve communication.[2]

Showing patients their medical images aids understanding;[3-5] 'brings home' the reality of their condition;[3,6] and makes them feel more involved in their healthcare;[3] though may produce a strong emotional impact - positive or negative.[4,7-9] Given the choice, many, but not all, patients want to view their medical images.[4,10] There is a paucity of paediatric patients' (under 18 years) views,[4] despite their feeling particularly vulnerable after diagnosis.[11] This study aimed firstly, to

gain perspectives from young patients, and their parents, about the value and emotional impact from viewing brain tumour MRIs. Secondly, to explore what families understand from viewing MRIs, especially concerning the inherent uncertainty of the results.

METHODS

Participant selection and recruitment

Patients with brain tumours, and their parents, were recruited from the Neuro-oncology Clinic at Birmingham Children's Hospital which treats around 50 new brain tumours in children and young people under 16 years annually. Paediatric oncologists approached eligible families, giving an overview, information sheet/s, and gaining permission to pass on the parent's contact details. After gaining written consent, NT conducted interviews in the participants' preferred venue from May 2017 to March 2018. Purposive maximum variation sampling was used to provide the "broadest practicable range of participants"[12, p.564] in demographic variables such as age, gender, ethnicity, diagnosis, and socio-economic status (using postcode as a proxy).[13]

Patients were eligible if they had a brain tumour, were at least three months from diagnosis, not deemed by their clinician to be going through an acutely challenging period, and either: on active treatment (up to 3 months following completion), or undergoing MRI surveillance of residual tumour. Thus this study does not include patients with low-grade tumours treated with complete surgical excision. Participants needed to be able to see the prompt (Supplementary Figure), and respond verbally to questions. Patients with severe learning difficulties, and those under 8 years, were excluded due to anticipated communication difficulties, though their parents were eligible.

Data collection

Interview questions (Supplementary File) were informed by clinical experiences of the paediatric oncologists caring for the patients, literature review, and the Research Advisory Group (RAG)

(parents of current and former patients), then piloted with the target population. Questions covered initial responses to, usefulness of, and what could be shown from MRIs.

Patients (accompanied by parent) were met twice. Firstly, a session where they drew, played or talked with NT to become more comfortable around her.[14] Secondly, a semi-structured interview, where a prompt (Supplementary Figure) of another patient's anonymised brain tumour MRI provided a focus,[15] prompted memories, and made it less intimidating.[14] Interviews were audiotaped and transcribed verbatim (except one where notes were taken), with each question directed to patient, then parent. Fieldnotes were taken immediately afterwards.

Data analysis

Transcripts were thematically analysed [16] according to Grounded Theory,[17] with the Framework Method.[18] NT analysed transcripts line-by-line. Coding from early interviews was discussed among the research team – NT (female Sociology research fellow), AP (male professor in Paediatric Oncology / clinician, SG (female professor in Medical Sociology), and SN (female lecturer in Nursing / former palliative nurse) - (investigator triangulation);[19] as well as another clinician (GM), and the RAG to enhance "trustworthiness".[17] NT later compared codes across all participants, and grouped into themes.[16] Participants had opportunity to give feedback on findings.

FINDINGS

Participants

35 families agreed to be contacted. 11 later declined participation. 10 were uncontactable, ineligible or unavailable within the timeframe. 14 families participated: 15 parents (13 mothers) and 8 patients. Interviewing continued until theoretical saturation: "new interviews produced little or no change" to the codes.[20]

Patients' mean age was 12 years (range 8-15), and participant characteristics are given (Table 1). Interviews were held at home (n=9) or hospital (n=5), lasting on average approximately 38 minutes (range 8-80).

[Table 1 – Participant characteristics at time of interview]

Thematic analysis

Four themes emerged from the data: Receiving results; Emotional responses to MRIs; Understanding of images; and Value of MRIs. Each had a range of sub-themes (Figures 1 and 2), and illustrative quotations are provided (Table 2). Few differences were found based on ethnicity; parent's gender; socioeconomic status; and being on treatment or surveillance. Results presented are for all participants, though differences between patients and parents discussed.

[Figure 1 – Thematic schema 1]

[Figure 2 – Thematic schema 2]

Emotional responses to seeing MRIs

Almost all parents said that they felt confused, worried, distressed, scared, shocked, or overwhelmed on first seeing their child's MRI. Some felt nothing or calmed. None wished that they had not seen MRIs, or been given the choice. Some parents would demand to see them or 'freak out' if they could not. While nearly half of the patients did not remember first seeing their MRIs, one found it 'funny'.

Most of those who initially felt more painful emotions also mentioned feeling calmed, or becoming 'hardened' to these over time. Longer-term, many felt relief, reassurance and hope for the future from MRIs.

Receiving results

Waiting for results

All but two parents found this a long, difficult time to bear, though both reported that they initially found it hard. Just under half of patients found the wait long, although no patients on the autistic spectrum reported this. When presented with a hypothetical choice of potentially less accurate but faster results, a strong majority of parents chose accuracy over speed. Half the patients were unsure, with nearly half preferring accuracy.

[Table 2 – Illustrative quotes]

Uncertainty

Every parent mentioned the uncertainty of the condition and the future; almost all mentioned anxiety related to MRIs and the results ('Scanxiety').[21-22]

Coping and strategies

Virtually all participants mentioned using cognitive processes to "put up with", or actions to cope with the difficult times of the condition,[23, p.460] such as receiving the diagnosis, relapse, or facing surgery, and we intend to explore these in a future paper.

Preferences to see MRIs

This varied greatly, ranging from always to never seeing the image. Some wanted to see only 'significant' changes; 'good news'; or 'bad news'.

Understanding of images

What images can and cannot show

The vast majority of responses regarding what MRIs *could* show were correct: structures of the brain; anomalies; the size, shape, location and presence (or absence) of the tumour; and effects of treatment. Half the patients referred to tumour size, as did all the parents; though often with the implicit understanding that the bigger the tumour, the more life-threatening.

Generally, participants were clear what images could *not* show: the future; the cause, type, and *all* the effects of the tumour; the patient's feelings; when the patient was cured; or next treatment needed.

Confusion

Most could remember an occasion when they found MRIs confusing. Nearly half expressed doubt that they understood what was being shown; even after viewing for many years. Many commented that MRIs were immediately 'obvious', even to people without a medical background. MRIs were often described as 'black-and-white proof'; something seen in the images *was* real. Showing MRIs in context (side-by-side with previous MRIs) improved understanding, as did 'framing' the information first,[24] for example, "Good news".

Value of MRIs

Aesthetics

Half the participants wanted to view images out of curiosity, or fascination, as did some family and friends.

Aiding understanding

Almost every participant found MRIs aided their understanding (and that of loved ones) by visualising an 'invisible' condition; even the parent who had not seen any, believed MRIs would enhance understanding. Parents sometimes wanted to show their child MRIs when they were older and could understand what the child had been through.

Contextualised knowledge / emotional benefits

Many found seeing the images reassured them that the prognosis was better than they feared, or had previously been. Seeing the images gave some parents perspective, making the tumour a more tangible problem to solve, and reducing anxiety, fear, or distress. For a few participants, MRIs made

the condition ‘more real’. One parent reported MRIs eased grieving for their anticipated healthy child and aided acceptance of the situation.

Enhanced control

Most parents felt more informed about the condition and better prepared emotionally to handle it; being ‘in the dark’ without MRIs. Only parents (half), wanted to keep images for their personal records. A strong majority recognised that others would have different preferences for viewing MRIs (all / no / specific images), so the choice was important.

Enhanced working relationships

Being able to view the same images as their clinical team made a few parents feel more involved in their child’s healthcare, promoting transparency and increasing trust.

No value

Patients not wanting to view MRIs believed it would not bring any benefits. The one parent that did not view MRIs believed that any benefits would be outweighed by increased distress.

DISCUSSION

This study gained perspectives from young patients and parents on how they emotionally respond to, understand, and value seeing brain tumour MRIs. Feelings on first seeing MRIs varied, though patients often did not remember. Feelings often changed over time, as did preferences to see MRIs. All families that viewed these found some value in it. The one parent that had not viewed MRIs presumed that they would increase their understanding, and valued having had the choice. Generally, patients and parents understood what could and could not be seen from MRIs, though there was an assumption, mostly by parents, that the bigger the tumour, the more life-threatening.

Though there are similarities to adult patients viewing their medical images, there are also differences. Similar to previous studies, this study found that there was a strong sense that what could be seen in them was real [6,8] and self-evident.[6] Though almost all the parents and nearly

half the patients suggested that what was shown was 'obvious',[6] over half the parents and all the patients doubted their understanding of, or were incorrect regarding, what the images showed. Half the parents and a quarter of the patients expressed *both* of these contradictory views. This may show the power of the image,[4,6,8] which suggests an exact correspondence with the body,[6] or trust in MRIs from their being used as 'proof' of disease by doctors when visible symptoms are absent.[8]

Patients mostly mentioned being confused when first viewing MRIs, while parents tended to mention ambiguity, such as borderline changes, viewing from a different angle, or unfamiliar medical terminology. Though almost all participants found MRIs confusing at some point, almost all found MRIs aided their understanding.[3-5] 'Framing' the information,[24] and viewing the MRI side-by-side with a previous one,[6] helped clarify ambiguities.

Past research has found that with cancer: "uncertainty characterises the entire experience…to the period after treatment, when recurrence is a threat…Patients feel a loss of control".[25, p.2655] Parents of patients with paediatric brain tumours also experience this uncertainty.[26] It is perhaps unsurprising that parents' most common response about what images *did not* show was the future, suggesting their desire for certainty regarding their child's condition. (MRIs often enhanced coping, which a future analysis will explore.)

This explains also why only two parents would prefer faster MRI results at the cost of accuracy. No patients wanted this, though many were unsure about prioritising speed or accuracy, or did not want any additional information. Interestingly, nearly half the parents would be keen to know the results from emerging MRI techniques providing information on tumour type, growth and seriousness. Advances in MRI are increasingly giving this information, raising the important question of how to incorporate this knowledge in clinical practice.[27]

Previous studies have found 'scanxiety' or "fear and worry associated with imaging, both before and after a test (before the results are revealed)"[22] in adolescents with cancer.[21] Only 13-15 year old

patients mentioned scanxiety, while almost all parents did. Most patients now paid attention to MRIs when previously they had not; having not understood their importance when younger. Parents' preferences for seeing MRIs were more varied, and for some, had changed over the years, often due to a more stable or positive prognosis.

Over half of both patients and parents wanted to view their images for aesthetic reasons, found previously with adult patients.[28] Only parents (one third) found that MRIs made the tumour a more tangible problem to solve,[6] or lost some of its power to, for example, distress, terrify, or overwhelm.

None of the participants talked about MRIs taking the focus away from them in consultations, or feeling more valued or respected by their doctor from having the images shared.[4] Nearly a third of parents suggested that they had a *right* to see their child's images. Only parents, *not* patients, reported feeling more involved,[3,6] as well as a sense of transparency and trust, from viewing the same images as their clinical team.

RECOMMENDATIONS

- Families should have the option to view their MRIs, though be aware that it may cause a range of unpleasant emotions (often reducing over time). Clinical teams should therefore identify, record and regularly update, each family member's preferences regarding seeing MRIs.
- Patient families may value a preliminary report by the clinical team ahead of the consultation or radiology report, despite reduced accuracy.
- MRIs can be confusing, even after many years, so clinical teams should initially 'frame' their information-giving, e.g. "Good news" and always make results as clear and unambiguous as possible.

- Clinicians should regularly clarify that the size of the brain tumour, or an increase in size, does not automatically mean a poor, or worse, prognosis.
- Future research is needed to explore factors that impact upon, and address, misunderstandings and the challenges of uncertainty in test results; and how medical images can be resources for patient families.

LIMITATIONS

This was a single site study, so the ethos, procedures and processes of the particular organisation may have influenced participants' responses. Different responses may have been given if parents and patients were interviewed independently,[29] though questions were addressed to the patient first, so as to avoid them giving their perceived 'correct response', or attempting to 'shield' their parent from their worries. However, having a parent presence was thought to make the patients more comfortable, relaxed and more likely to provide answers, and support communication between participant and researcher.[30] Families were not approached for recruitment if they had recently experienced a relapse or a poor prognosis, so as not to increase their burden or distress, which may have narrowed the range of responses. Maximum variation sampling was used to capture a diversity of experience, given these limitations.[12]

"Recruitment challenges and sufficient sample sizes are a frequent dilemma" when researching a rare condition.[31, p.e216] Although 35 families initially expressed interest in the study, only 14 participated. 'Bad timing' and 'busy lives' were reasons typically given by parents that changed their mind. Last-minute cancellations of 'getting to know' sessions and interviews were common, highlighting how unpredictable lives can be for families of patients with brain tumours [32] Scheduling two sessions may have proved difficult, though concern around potential distress may also have been an underlying factor. However, the sample was large enough to capture a range of experience, yet small enough to analyse in-depth, [32] and reached theoretical saturation.[20]

List of abbreviations

MRI Magnetic Resonance Imaging

MRIs Magnetic Resonance Images

RAG Research Advisory Group

DECLARATIONS

Ethics approval and consent to participate

West Midlands - Black Country Research Ethics Committee WM/16/WM/0490.

Consent for publication

Parents consented for themselves and their child. Children signed a separate assent form.

Availability of data and material

Access to these is restricted to the steering group, or individuals granted permission by them, for the purposes of this or future research.

Competing interests

The authors declare that they have no competing interests.

Funding

The funding for the research was provided by an NIHR Research Professorship NIHR-RP-R2-12-019 awarded to Professor Peet. NIHR had no role in the study design; collection, analysis and interpretation of the data; the writing of this manuscript; or in the decision to submit for publication.

Authors' contributions

NT contributed to conception and design of study, carried out the data collection, analysis, drafted the manuscript and proofed the final manuscript as submitted. Contributions to conception and

design of study, input on initial data analysis and substantial guidance and input for developing the manuscript was given by AP, SG, SN, JA and ME. All authors read and approved the final manuscript.

Acknowledgements

Initial findings from this paper have been presented previously at conferences orally and through posters. We are grateful to all of our participants and the colleagues who helped us recruit them. We also thank the Specialist Nurses in Neuro-oncology (particularly Sharon Beardsmore), Dr Gerard Millen and our Research Advisory Group for their insights.

Author's information (optional)

What is already known on this topic

- Being diagnosed with cancer is an uncertain time for young patients and their parents.
- Waiting for MRI results is stressful for patient families.
- Adult patients can feel a range of emotions on seeing their medical images, especially reassurance.

What this study adds

- This study provides children and young people's perspectives (and their parents') on the impact and value of seeing medical images of their brain tumours.
- MRI scans and their interpretation are complex and can easily be misunderstood by families.
- Patient and parent views vary on how they would like information from scans given to them and these should be identified, documented and regularly updated.

REFERENCES

1 Kim MM, Parolia A, Dunphy, MP, et al. A non-invasive metabolic imaging of brain tumours in the era of precision medicine. *Nat Rev Clin Oncol* 2016;13(12):725-739 doi:10.1038/nrclinonc.2016.108 [Published Online First: 19 July 2016].

2 Carlin L, Smith H, Henwood F, et al. Double vision: An exploration of radiologists' and general practitioners' views on using picture archiving and communication systems. *Health Inform J* 2010;16(2):75-86 doi:10.1177/1460458210361935 [Published Online First: 23 June 2010].

3 Blaxter M. The case of the vanishing patient? Image and experience. *Sociol Health Ill* 2009;31(5):762-778 doi:10.1111/j.1437-9566.2009.01178.x [Published Online First: 29 July 2009].

4 Carlin LE, Smith HE, Henwood F. To see or not to see: A qualitative interview study of patients' views on their own diagnostic images. *BMJ Open* 2014;4(7) doi:10.1136/bmjopen-2014-004999 [Published Online First: 31 July 2014].

5 Makanjee CR, Bergh A, Hoffmann WA. Healthcare provider and patient perspectives on diagnostic imaging investigations. *Afr J Prm Health Care Fam Med* 2015;7(1) doi:10.4102/phcfm.v7i1.801 [Published Online First: 20 May 2015].

6 Rhodes LA, Phillips-Tangum CA, Markham C, et al. The power of the visible: The meaning of diagnostic test in chronic back pain. *Soc Sci Med* 2002;48(9):1189-1203 doi:10.1016/S0277-9536(98)00418-3 [Published Online First: 10 March 1999].

7 Kelly D, Pearson S, Mulhall, A. (2014) 'Being in the same boat': Ethnographic insights into an adolescent cancer unit. *Int J Nurs Stud* 2004;41(8):847-857 doi:10.1016/j.ijnurstu.2004.03.011 [Published Online First: 6 December 2016].

8 The A, Hak T, Koeter G, et al. Radiographic images and the emergence of optimism about recovery in patients with small cell lung cancer: An ethnographic study. *Lung Cancer* 2003;41:113-120 doi:10.1016/S0169-5002(03)00124-7

9 McNamara M, Arnold C, Sarma K, et al. Patient portal preferences: Perspectives on imaging information. *J Assoc Inf Sci Technol* 2015;66(8):1606-1615 doi:10.1002/asi.23269 [Published Online First: 18 July 2014].

10 von Wagner C, Knight K, Halligan S et al. Patient experiences of colonography, barium enema and CT colonography: a qualitative study. *Br J Radiol* 2009;82(973):13-19 doi:10.1259/bjr/61732956. [Published Online First: 29 September 2008].

11 The Brain Tumour Charity. (2016) *Losing myself: The reality of life with a brain tumour.* Available at: https://www.thebraintumourcharity.org/about-us/our-publications/losing-my-place-reality-childhood-brain-tumour/ (accessed 18 October 2018).

12 Ziebland S, Chapple A, Dumelow C, et al. How the internet affects patients experience of cancer: a qualitative study. *BMJ* 2004;328:564-569 doi:10.1136/bmj.328.7439.564 [Published Online First: 4 March 2004].

13 OpenDataCommunities.org. (2016) *Indices of Deprivation 2015 explorer.* Available at: http://dclgapps.communities.gov.uk/imd/idmap.html/ (accessed 27 June 2018).

14 Flanagan SM, Greenfield S, Coad J, et al. An exploration of the data collection methods utilised with children, teenagers and young people (CTYPs). *BMC Research Notes 2013*;8:61 doi:10.1186/s13104-015-1018-y [Published Online First: 1 March 2015].

15 Coyne E, Hayes E, Gallagher P. Research with hospitalized children: Ethical, methodological and organizational challenges. *Childhood* 2009;16(3):413-429 doi:10.1177/0907568209335319 [Published Online First: 19 August 2009].

16 Braun V, Clarke, V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3(2):77-101 doi:10.1191/1478088706qp063oa [Published Online First: 21 July 2008].

17 Holloway I, Wheeler S. Qualitative research in nursing. Oxford: Blackwell Science Ltd 2002.

18 Gale NK, Heath G, Cameron E, et al. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* 2013;13:117 doi:10.1186/1471-2288-13-117 [Published Online First: 18 September 2013].

19 Hanson CS, Newsom J, Singh-Grewal D, et al. Children and adolescents' experiences of primary lymphoedema: Semistructured interview study. *Arch Dis Child* 2018;103:675-682 doi:10.1136/archdischild-2017-313856 [Published Online First: 17 February 2018].

20 Parslow RM, Anderson N, Byrne D, et al. Adolescent's descriptions of fatigue, fluctuation and payback in chronic fatigue syndrome/ myalgic encephalopathy (CFS/ME): interviews with adolescents and parents. BMJ Paediatrics Open 2018;2:e000281. doi:10.1136/bmjpo-2018-000281

21 Kent EE, Parry C, Montoya MJ, et al. "You're too young for this": Adolescent and young adults' perspectives on cancer survivorship. *J Psychosoc Oncol 2012;* 30(2):260-279 doi:10.1080/07347332.2011.644396 [Published Online First: 14 September 2011].

22 Mulcahy, N. (2017) *Cancer scanxiety is a real (terrifying) thing.* Available at: https://www.medscape.com/viewarticle/875634 (accessed: 6 August 2018).

23 Bury M. The sociology of chronic illness: a review of research and prospects. *Sociol Health Illn* 1991;13(4):451-468 doi:10.1111/j.1467-9566.1991.tb00522.x

24 Redshaw ME, Harvey ME. Explanations and information-giving; Clinician strategies used in talking to parents of preterm infants. *BMC Pediatrics* 2016;16:25 doi:10.1186/s12887-016-0561-6 [Published Online First: 11 February 2016].

25 Lang H, France E, Williams et al. The psychological experience of living with head and neck cancer: A systematic review and meta-synthesis. *Psycho-Oncology* 2013;22:2648-2663 doi:10.1002/pon.3343 [Published Online First: 10 July 2013]

26 Hutchinson KC, Willard VW, Hardy KK, et al. 2009 Adjustment of caregivers of pediatric patients with brain tumours: A cross-sectional analysis. *Psycho-Oncology* 2009;18:515-523 doi:10.1002/pon.1421 [Published Online First: 29 August 2008].

27 Peet AC, Arvanitis AN, Leach MO, et al. Functional imaging in adult and paediatric brain tumours. *Nat Rev Clin Oncol* 2012;9(12):700-711 doi:10.1038/nrclinonc.2012.187 [Published Online First: 13 November 2012].

28 Munn Z, Jordan Z. Patient experience of high technology medical imaging: A systematic review of the qualitative evidence. *Radiography* 2011;17:323-331 doi:10.1177/0907568209335319 [Published Online First: 18 July 2011].

29 Gardner H, Ranall D. The effects of the absence or presence of parents on interviews with children. *Nurse Res* 2016;31:e207-e218 doi:10.1016/j.pedn.2015.10.022 [Published Online First: 2 December 2015].

30 Pyer M, Campbell J. The 'other participant' in the room: The effect of significant adults in research with children. *Research Ethics* 2012;9(4):153-165 doi:10.1177/1747016112464721 [Published Online First: 6 December 2013].

31 Peletsov LJ, Fielder AL, Esterman AJ. The supportive care needs of parents with a child with a rare disease: A qualitative descriptive study. *J Pediatr Nurs* 2016;31:e207-e218 doi:10.1016/j.pedn.2015.10.022 [Published Online First: 2 December 2015].

32 Darcy L, Knutsson S, Huus K, et al. The everyday life of the young child shortly after receiving a cancer diagnosis, from both children's and parent's perspectives. *Cancer Nurs* 2014;37(6):445-456 doi:10.1097/NCC.0000000000000114 [Published Online First: 11 January 2014].

TABLES AND FIGURES

Table 1 Participant characteristics at time of interview

Table 1 Participant characteristics at interview			
Patients (n=8)		**Parents (n=15) (14 families)**	
Characteristics	N	Characteristics	N
Gender			
Female	4	Female	13
Male	4	Male	2
Percentage of deprivation (Assessed by Multiple Indices of Deprivation)			
10% least deprived	1	10% least deprived	2
20% least deprived	2	20% least deprived	2
30% least deprived	0	30% least deprived	0
40% least deprived	0	40% least deprived	1
50% least deprived	2	50% least deprived	2
50% most deprived	1	50% most deprived	3
40% most deprived	0	40% most deprived	0
30% most deprived	1	30% most deprived	2
20% most deprived	0	20% most deprived	0
10% most deprived	1	10% most deprived	3
Age (years)		*Age of child (years)*	
Under 8 (Interviewed parent only)		Under 8	6
8 – 12	4	8 – 12	4
13 – 15	4	13 – 15	4
Ethnicity		*Ethnicity of child*	
Caucasian	7	Caucasian	10
Asian	1	Asian	2
Mixed	0	Mixed	1
Unknown	0	Unknown	1
Diagnosis (patient may have more than 1)		*Diagnosis of child (may have more than 1)*	
Glioma	4	Glioma	6
Astrocytoma	3	Astrocytoma	4
NF1	3	NF1	4
Medulloblastoma	2	Medulloblastoma	3
Other	0	Other	1
Years since diagnosis		*Years since child's diagnosis*	
< 1 year	1	< 1 year	3

1 < 2 years	1	1 < 2 years	2
2 < 5 years	0	2 < 5 years	2
5 < 10 years	4	5 < 10 years	5
> 10 years	2	> 10 years	2
Age at diagnosis		*Child's age at diagnosis*	
< 1 year	0	< 1 year	2
1 < 2 years	2	1 < 2 years	3
2 < 5 years	2	2 < 5 years	4
5 < 10 years	3	5 < 10 years	4
> 10 years	1	> 10 years	1

Figure 1 Thematic schema 1

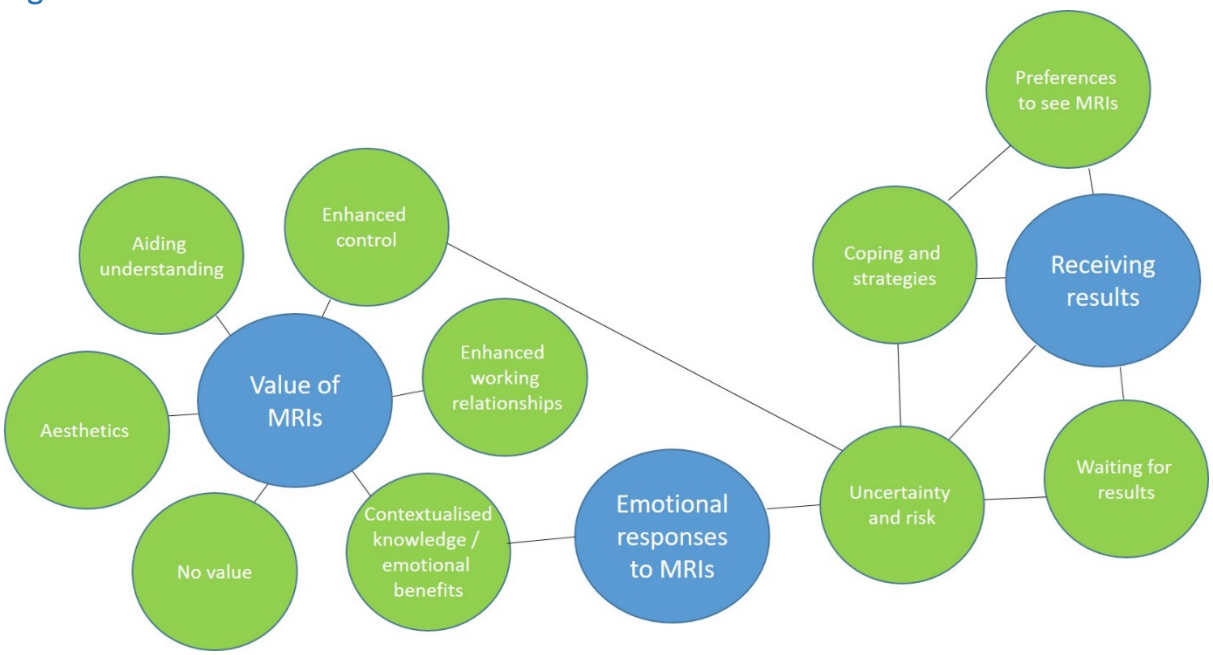

Figure 1 Legend

Though initial emotional responses to seeing MRIs varied, participants tended to 'harden' to more painful feelings over time, and find emotional benefits, and other values, in seeing MRIs. The uncertainty and risk with their condition, especially receiving results, was mitigated for some by the feeling of control, and reassurance provided by the images. Many mentioned strategies to cope.

Figure 2 Thematic schema 2

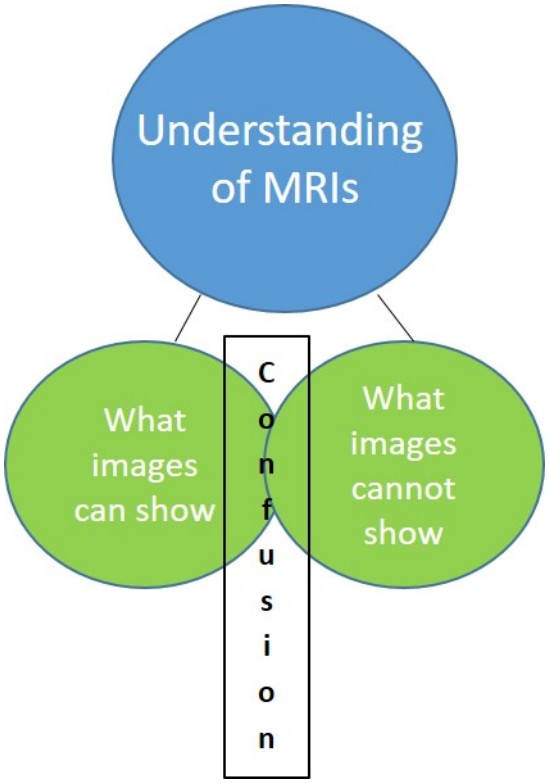

Figure 2 Legend

Generally, participants were clear on what MRI could and could not show. Though a few participants were unclear on whether the MRI could show the cause of the tumour, or 'everything', led to confusion.

Table 2 Illustrative quotations

Table 2 Illustrative quotations	
Receiving results	
Waiting for results	
	"C: I need the results. But if it means I've gotta wait, then you sortof have to." P2, p5, 165
Uncertainty and risk	
	"C: I felt worried because there was a lump and worried what it would do when I get older." P9, p2, 62
	"P: There's no hundred percent in anything." P5, p5, 151
Accuracy or speed in reporting?	
Accuracy over speed	"C: Obviously it's, quite, like daunting, the wait you have to have. 'Cos' you wanna, I sortof wanna know, like 'Is anything different'?" P2, p4, 156
Speed over accuracy	"P: Even if they, someone gave ya a phone call. [NT: Mmmm.] Just to say, 'We've had a, quick scan. We think everything's okay, but, we're not puttin' our name against it, until ya come in'. It's just that, not knowing, [NT: Mmmm.] that's the thing an' it, an' it's awful." P10, p13, 488
Preferences to see images	
	"P: We don't look at the scans any more. We just go in and discuss the changes." P2, p2, 54 "P: I always want to see them, obviously." P7, p2, 50 "P: Couldn't care less, whether we had a picture or not." P10, p11, 377 "C: Now when I go, I prefer seeing the scans." P12, p2, 53
Emotional responses to first seeing MRIs	
Positive	"P: You were giggling [when first shown MRI]? [NT laughs. C: Yeah.] […] C: 'Cos' um, 'cos' it was fun-ny." P6, p2, 60

	"P: Sometimes I do think… images of your brain are really intrusive. 'Cos' I think it's so personal. But then, at the same time, erm…. I was happy to see it" P14, p3, 90
Neutral	"P: And then when I actually went into the room and saw the scan, it didn't really mean a lot to me, what I saw." P11, p3, 83
Negative	"C: I could see the scans and I knew what it meanttt. I'd… get a little bit worried and I would cry or something, cos it made me feel upset, 'cos' obviously I knew what I'd have to go through again." P12, p2, 63
	"P: I just remember my first thought, thinking 'That's it. There you go. [They]'ll um, erm… That's it. That the end of [Child]', and knowing that [they]'ll die. […] Because the tumour was massive." P12, p2, 78
Understanding of images	
Images can show	
Functioning of the brain	"P: it was interesting to see where the er, yaknow the brain, the water brain, the water of [their] brain goes and that." P8, p5,161
Anomalies	"P: If there is an abnormality, somewhere else as well, like… one side of the head, s'like side of your brain is slightly bigger than the other as well or misshapen, it shows that as well." P13, p2, 50
Tumour present or not	"NT: Is it [the tumour] the smaller circle or the bigger circle? C: Little one." P6, p4, 144
Tumour size	"C: I like to know, where it is it in the head, what size is it, is it okay." P2, p3, 87
Tumour shape	"P: I, I found it really informative to see [the doctor] and then to be able, for [them], to show me, especially with the MRIs with the different dimensions of it. [Child]'s was always changing shape." P7, p2, 66
Tumour location	"C: So for me, it's just showing me where the *brain* tumour isss, in, my head…, really… " P2, p1, 78
Origins / How long tumour there	"C: Ermmm, it [the MRI] can tell you, like what, they, what they need to get rid of [NT: Mmmm.], why it's *there*… […] Erm, how it's caused, and things like that." P8, p2, 66
Next treatment	"C: Erm, they [MRIs] might, they might tell you things like chemotherapy and things like that." P8, p2, 70
Healing	"P: Everything we needed to know regarding the tumour and [their] healing process and if it spread, we knew from, the MRI." P6, p12, 398
Everything	"NT: Is there anything you think the scans, don't tell you? C: No. Like it's all there. Good." P5, p4, 118
Images cannot show	
The future	"C: Can't tell youuuu, ummm, whether it'll come back or not." P8, p3, 92
	"P: (Pauses) It can't forecast anything for you. So it's only showing a picture of there and now." P7, p3, 78
Next treatment	"C: It can't tell you how long it will be, to wait, for your op ter, actually take place. (pauses)" P8, p3, 93
When tumour active or not	"C: Say if my tumour's growing when they'd taken a scan, and they can see it over time on the scan, how it grows, without like on the same photo." P12, p5, 166
Feelings	"C: It, it, it cannot tell how I'm feeling. [Coughs] [NT: Mmmm.]" (Silence) P3, p5, 183
Origins / How long tumour there	"C: (Pauses) Errr, they can't tell you how…, like, why it's there, and how -. So, like, so why it's happened to you… and not someone else." P8, p3, 91
When cured	"C: (Pauses.) Can't tell youuuu, ummm, whether it'll come back or not. [NT: Mmmm. Mmmm.]" P8, p3, 91
	"P: But what else does it not tell me? Erm. [Silence] I don't know. I, I'm not sure. […] Ya know if it's gone, or whatever." P11, p5, 169
All the effects from the tumour	"P: Can't show side-effects. Mmmm […] It shows, what's goin' on in the brain physically, but not all the, 'motions, and the, all theee… that type of side of things." P3, p10, 351
Tumour type	"P: Don't know if they could, they wouldn't be able to tell what sort of tumour it was." P8, p3, 85
Confusion	
Limits of understanding	"C: It cannot ssshow me, my… Um. I dunno." P3, p6, 186
	"P: I wouldn't, I wouldn't er, be able to read a scan." P8, p4, 114
Obviousness	"C: Obviously to me, a simple scan is easier for me to understand, 'cos' I can just, look and understand it straightaway then, 'cos' obviously I've saw a couple now." P2, p4, 142
'Seeing is believing' or proof	"P: I don't like just being told 'No. Everything's fine'. [NT laughs] I'm like, 'Well, hang on, prove to me that it's fine, first'." P13, p2, 57
Putting the image in context	"C: My doctor, [they'll] explain to me, like, how it's grown and you'll be able to see 'cos' [they'll] put the photos side to side and you'll be able to see how they've grown, so it's a *lot* easier to understand." P12, p3, 94
Value of MRIs	
Aesthetics	
Want to see images	"P: [They're] quite keen to see them, aren't you? [to child] C: Yeah. Yes." P5, p3, 87

Friends and family want to see	"NT: And then would you show it [printouts of MRIs] to friends or family or…? C: Yeah. [NT laughs]" P6, p16, 573
Aiding understanding	
Visualising the condition	"C: Every time I can remember, they've been, quite easy to understand, when I see them. Really, like, for me. 'Cos' it's just, laid out as, where it is in the head" P2, p3, 110
Aiding others' understanding	"C: I mean I do *show* my friends, […] I'll more-or-less just say 'Yeah. It's fine.', 'It's grown a little bit, it's shrunk a little bit.'" P12, p6, 241
'This is what you went through'	"P: And when [they're] old-er, I could say to [my child], this is what you went through, this is how you started, this is how it finished. So [they know] it…" P13, p3, 87
Contextualised knowledge / emotional benefits	
Made it 'real'	"C: As you get older, […] you realise, what, what can happen, and you realise the situation you're in, like, this scan shows what, what can 'appen. So like how it can still affect you." P12, p4, 135
Gave 'perspective'	"P: Quite shocking, when I was first told. But to actually see the picture puts things into perspective" P7, p2, 57
Aids grieving	"P: I think, clearly seeing it makes ya- the grieving process a little bit easier." P10, p4, 145
Reassurance	"C: It's just nice ter, look at them and see that there's no change." P2, p3, 84
Enhanced control	
Feeling more informed and better prepared	"P: And then obviously with the pictures, you see a lot clearer 'cos' it's like you know what's going on. 'Cos' otherwise if you didn't know, then, you'd just be panicking, like 'What's going on?' 'How are they doing stuff?' So obviously you have to prepare yourselves, as well, so." P6, p4, 138
Keeping for their 'records'	"P: [Child's] got a medical drawer, with the letters and thing. We'd probably keep them in there, rather than going to look at them, but they're there." P12, p7, 263
Respecting patient choice	"P: I wanna see what's going on inside. Just ter, peace of mind. But not everybody gonna feel that way. Which is fine." P14, p5, 188
Enhanced working relationships	
More involved with child's care	"P: It makes you feel that you're part of the actual… kind of setup. Even though obviously we are part of it, to actually see what's going on instead of just 'This is what's happening'" P10, p3, 111
Increased transparency	"P: So even though your doctors are saying something, for you to actually see, and see that they's telling you the right thing… Okay. I, that, that builds even more trust." P3, p7, 256
No value	
	"C: Just not really useful to me [to see the MRIs]" P7, p4, 108

Table 2 Legend

Key: Parents are anonymised as P1, P2… and Children as C1, C2… These are followed by the page and line number from the transcript for the beginning of the quotation.