

Paws for thought ..?

A case study of a breast cancer patient with Asperger's Syndrome and her experience of radiotherapy

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Case History

44 year old female diagnosed with invasive ductal grade 3 carcinoma of the left breast. Treated with wide local excision, 6 cycles of FEC-T and post-operative radiotherapy to the left breast, axilla and supra-clavicular fossa, 40Gy in 15 fractions followed by a boost to the surgical bed – 10Gy in 5 fractions. Comorbidities: Asperger's/autism, dyslexia, learning disability, polyneuropathy with non-dermatomal distribution (of unknown aetiology). The patient cannot read and has no concept of time, her mother is her main carer.

Background

In the UK there are 700,000 adults and children approximately who are diagnosed with autism⁽¹⁾. The National Autistic Society has a helpful set of guidance for healthcare professionals. Every autistic person has an individual set of difficulties that bring challenges for them on a daily basis. The Society of Radiographers (SoR) has general advice for diagnostic radiographers regarding how to meet the needs of autistic patients⁽²⁾. As a therapy radiographer this has been helpful in meeting the needs of a patient with Asperger's syndrome. It would be helpful to have advice for therapy radiographers as in practice most patients will attend for a number of daily fractions.

Barriers

On their first on treatment review I realised the patients needs were not being met (see figure 1).

- **Time** - This was needed for the patient to be able to process what was being said in a conversation. The patient has no concept of time, saying 'I will be back in a few minutes' confused the patient.
- **Environment** - The patient complained about the noise. It wasn't until her third week of treatment that the patient told me she was anxious sitting in the waiting area in an unfamiliar space, sounds and too many people.

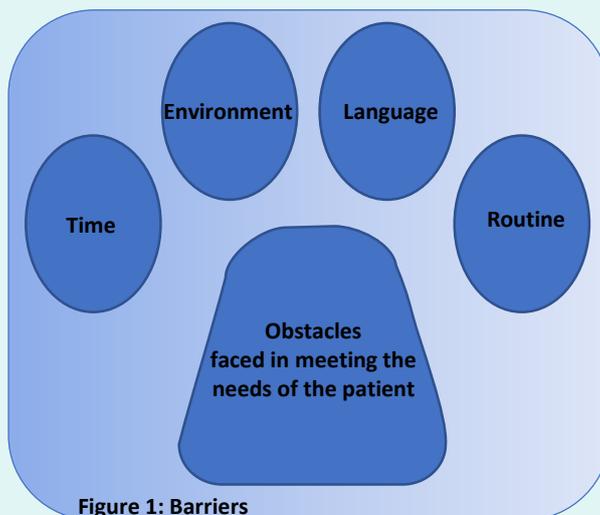


Figure 1: Barriers

- **Language** - The patient got upset after a review with the Doctor as they could not understand some of the words that were used. On another occasion the patient didn't understand phrases like 'Top form' and I found it tricky myself to explain this phrase to her.
- **Routine** - The patient got upset when her treatment room was changed due to the lineac being on service. They got confused in the room and were embarrassed as they got off the treatment couch. This was due to the room being a mirror image of the one they were used to being in. The change in staff made them uncomfortable too.

Lessons learnt

- Speak to the patients carer – the patients mum helped in explaining time by comparing it to how long a TV advert is. We applied this whenever we had to refer to times in daily conversation. Take the time for the patient to process what has been said to them or asked of them.
- An unfamiliar environment adds anxiety as well as the unusual sounds the patient is not used to. A small waiting room is more appropriate. The patient used squishies to help them with their anxiety each day.
- Do not use phrases or sayings. Use short clear plain sentences. When I asked if the patient 'was she in pain?' she replied 'she doesn't get pain.' There are studies that suggest people with autism can have a higher pain threshold. I observed how she was with her body language – she kept rubbing her skin around her left SCF. There was erythema in this area and I gave her skincare advice.
- Routine is important – patient more comfortable with familiar staff. The change of room was not communicated to the patient, if this was explained beforehand to her she would have not been so upset.

Developing practice

- More knowledge of how to support patients with autism through the radiotherapy pathway
- Given squishies to anxious patients to help with their anxiety whilst on treatment (see figure 2 and 3)
- Applied for funding for squishies to give to anxious patients
- Awareness of the barriers facing patients with autism and learning difficulties
- Develop a guide on patients with autism for therapy radiographers

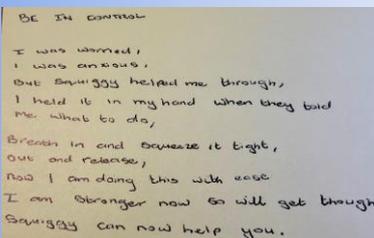


Figure 2: Poem by a patient



Figure 3: Slow release squishy

Acknowledgements

A special thank you to the patient who wanted to share her experience of radiotherapy so that health professionals will have more awareness and knowledge to support patients with autism.

Thank you to Carolyn Costigan for your support and guidance.

I couldn't have produced this poster with out the gracious funding of our hospital charity, thank you

References

1. <https://www.autism.org.uk/asperger>
2. <https://www.sor.org>
3. <https://www.nice.org.uk/guidance/cg142>
4. <https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/asd-toolkit.aspx>