

# Capturing patient experience to develop information that supports compliance with advice on neutropenic sepsis.

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**Background**

Neutropenic sepsis is a potentially life-threatening side effect of chemotherapy (Warnock 2016). Patients with neutropenic sepsis have a reduced ability to fight infection and can become seriously ill very quickly if sepsis is not detected and treated early. For most patients the onset of neutropenia occurs outside of the hospital setting so they need to be able to self-monitor and self-care (NICE 2012). A high temperature is one of the potential early warning sign of neutropenic sepsis and patients are asked to monitor their own temperature at home and contact the cancer centre immediately if it is raised or they develop any symptoms of infection. While patients play a vital role in detecting this side effect of chemotherapy, we know very little about the ways in which they monitor their own temperature, their understanding of neutropenic sepsis and the helpfulness of the advice we provide.

**Method**

Patients were recruited from out-patient and in-patient departments at a cancer centre in the north of England, UK. Initial interviews were carried out with 21 patients who had received a minimum of one cycle of chemotherapy, 14 had been admitted with neutropenic sepsis. Following first stage analysis a further 10 interviews were carried out with patients who had experienced neutropenic sepsis to explore themes identified in more depth. Interviews were carried out between July 2015 and September 2016, transcribed verbatim and analysed using framework analysis.

"If it went above 37.5, I would leave it for 4 to 6 hours, monitor it every hour and then ring as at least you would have a bit of information behind you when you rang. If I was feeling alright I would do this if I wasn't I would ring"

"I just wanted to lie down and go to sleep, I waited a whole day because I thought it was just a natural occurrence after chemo"

"I think they told me to take it every day but I don't because if I feel alright I don't bother"

"(husband) said, I'm just going to test it (temperature) again...and he said I'm going to ring and I was like, oh can we ring in the morning because I just want to go to sleep, and he was saying no because it says ring and I think its important that we don't leave it. So he rang"

"My daughter and niece; I don't take it in so they come to my appointments, they remember everything"

**Deviation from advice**

**Deviating from advice**

The interviews revealed a range of behaviours in relation to the advice received. Some followed it precisely. Others interpreted it in their own ways or knowingly deviated. This was seen in descriptions of the ways participants monitored their temperature and reacted to readings.

**Reasons for not following advice**

Some participants had delayed seeking advice or had only done so because a family member made them.

**Reasons for delaying included:**

- o Feeling too unwell to do anything about it
- o Not wanting to trouble anyone
- o Not wanting to go to hospital
- o Feeling well despite a high temperature
- o Poor insight into how unwell they were
- o Hoping symptoms will improve on their own
- o Attributing symptoms to chemotherapy side effects.

**Barriers**

- o Presenting symptoms are diverse and therefore difficult to interpret and convey
- o Inconsistent advice on monitoring from healthcare staff
- o Individual patient beliefs
- o Volume of information received in a stressful time

**Role of the family**

I didn't realise I was so poorly to be honest as I just felt this temperature. My husband pushed me to go, he told me lets go"

**Barriers and Facilitators**

**Facilitators**

- o Close involvement of family
- o Individual patient beliefs
- o Written information to refer to at home
- o Telephone triage advice line
- o Having advice reinforced/repeated by nurses at each visit
- o Provision of clear, consistent advice by healthcare staff

"It was a bit foggy for me when I came (for chemo) and I was a bit all over the place, but it was more than once I was told (to measure temperature)"

"I've got a whole booklet that tells me the symptoms that require me to phone up....Yeah, I'd just go and have a look at it, and if it's a request to go, to phone up I could"

**Family members provided essential support. They:**

- o Accompanied the patient during advice sessions and remembered the advice
- o Supported the patient in temperature monitoring
- o Recognised symptoms the patient was not aware of
- o Encouraged/made the patient seek advice if they were reluctant to do so.

"I'm really sure it was (the) doctor that said I must take my temperature, but when you go for these things, well I don't take it in. I've always got my, well I had my daughter for a while coming. She's gone back to (different city), so my niece normally comes, but they remember everything but I don't remember much about it"

**References**

Warnock C (2016) Neutropenic sepsis: prevention, identification and treatment. Nursing standard. 30, 35 51-58  
National Institute for Health and Care Excellence (NICE) (2012) *Neutropenic sepsis: prevention and management of neutropenic sepsis in cancer patients* NICE guidelines [CG151]

**Discussion/ Conclusion**

Providing information that is easily understood is essential for patients at risk of neutropenic sepsis. By exploring patient's perspectives we discovered insights into why it is not always understood or followed. These findings will inform the next stage of the project; co-producing information with patients that meets their needs.