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

Martina Davies, Rachel Mead, Gail Lambarth, Will Leaver, Jamie-Lee Gynn, Angela Tod, Clare Warnock

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 signs 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.

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

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

“WARNING...”

“...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”

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

Barriers and Facilitators

Family members provided essential support. They:
- Accompanied the patient during advice sessions and remembered the advice
- Supported the patient in temperature monitoring
- Recognised symptoms the patient was not aware of
- Encouraged/made the patient seek advice if they were reluctant to do so.

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”

“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