

How do patients manage side effects during melanoma treatment? The importance of social support and doctor–patient communication

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Background and Objectives

The Melanoma UK digital registry, founded in collaboration with Melanoma UK, captures the real-world patient-reported impacts of melanoma and its treatment using a mobile application.

This study's objective was to explore patients' management of symptoms and side effects of melanoma treatment, particularly fever, and to evaluate the role of support from caregivers and clinicians.

Methods

Four registry participants took part in a focus group, primarily held to understand fever as a treatment side effect. A thematic analysis was conducted to identify themes from the discussion.

Results

Focus group participants were aged 33–66 years; all had Stage 4 melanoma and received either immunotherapy or targeted therapy. One participant reported being in remission.

Alongside their experience of fever and other treatment side effects, a key theme was participants' management of fever. Most participants expressed a preference for home-based management, most commonly taking paracetamol and calling the treatment hotline. Most also reported being hospitalized at least once with fever. One participant described the emotional challenges of being hospitalized; another noted that when hospitalized, they were unable to manage their fever symptoms as they would prefer to at home, particularly when feeling extremely cold. One participant reported being reluctant to treat their fever in hospital due to the COVID-19 pandemic.

Participants relied on social support from their caregivers during treatment, including monitoring their fever, providing instrumental support (e.g. assisting with daily routine) and facilitating access to healthcare. The importance of aligned doctor–patient communication was highlighted, as participants sought expertise from their oncologist during treatment. One participant experienced conflicted feelings and a sense of helplessness when discussing low quality of life during treatment with their oncologist, and being advised to continue with the treatment to prevent reoccurrence of melanoma. This created cognitive dissonance in terms of knowing that although treatment was effective, the participant would have to endure its debilitating impact long-term.

Table 1: Quotes from focus group participants categorized by main themes and sub-themes

Sub-theme 1	Sub-theme 2	Quote(s)
Theme 1: Home-based management of fever		
Home-based management of fever	Treatment hotline	Participant 2: "I was told you had to ring the treatment line if you got a f- a temperature if you got a fever above a certain level so I did..." Participant 4: "I think every time I've always called the Royal Marsden helpline- Macmillan hotline um (.) first and just said what was going on and asked them for advice..."
	Paracetamol	Participant 1: "...my temperature wasn't as high (.) if I'm honest and it was controllable at home through taking paracetamols et cetera..." Participant 2: "I'd spoken to my oncologist in the meantime (.) and she told me to take loads of paracetamol and only go to hospital if the paracetamol didn't get the temperature to a certain sensible level..."
	Symptom management	Participant 4: "...but I don't go to hospital 'cause I've just learned to ride it out at home I just feel like actually that's best for me 'cause I do (.) make sure I get warm (.) when I get cold you know with the shaking I just put the hair dryer on me put the hot water bottle on me (.) just make sure I get hot..."
Theme 2: Hospital-based management of fever		
Impact of COVID-19	Reluctance to go to hospital due to COVID-19	Participant 4: "...they said (.) "come in because we think you might ha- know- you could have COVID 'cause it's- it's one of the symptoms and we'll put you on a COVID ward and give you a test" and I said "no thank you (.) I don't want to come into a COVID ward to have a test I think I don't have that I think it's just my usual (.) um (.) side effects of fe- fever from the dab and tram (.)"

Theme 3: Patients' preference for treatment of fever in melanoma	
Negative associations with hospitals	Participant 1: "...I must- I must confess um (.) I don't like going to hospital and I call them the child catcher, once he's got you he never lets you go." Participant 1: "...hospitals are very very good at fixing you physically (.) but mentally (.) they destroy you because it gives you lots of time to think about (.) your predicament and (.) and your illness and just gloom- gloom sets in (.) unfortunately and I- and I don't like them for that reason."
Apprehension about hospital-based treatment of fever	Participant 4: "Also I know the hospitals aren't allowed to warm you up with heat pads etc if you're feeling very cold when actually your temp is spiking but it is very miserable and impossible to sleep if you're shaking violently with cold! I have cried in the middle of the night just feeling desperate for a hot water bottle which I know I could get if I was at home. It's on occasions like that when hospital starts to feel like prison."
Clinician's approval to manage symptoms at home	Participant 3: "The second time I'd had a conversation with my oncologist and said I'd e- ended up in hospital and she said to me well it was known that you (.) could get fevers with treatment and that the best thing to try and do to avoid ending up in hospital was try and manage it at home with paracetamol (.)"
Theme 4: Importance of social support	
Instrumental support	Participant 4: "...I'm very grateful that somebody comes and gets me food (.) and water (.) 'cause it just feels like such an effort to go and do anything..."
Monitoring condition	Participant 3: "...my wife would know where to take the temperature..."
Facilitating access to healthcare	Participant 1: "...One of my last bouts of fever coincided with a really bad um episode of colitis and my partner actually called the hospital (.)" Participant 3: "...I was whisked into hospital by my wife."
Theme 5: Importance of doctor–patient communication	
Oncologist as an expert	Participant 2: "The second time I'd had a conversation with my oncologist and said I'd e- ended up in hospital and she said to me well it was known that you (.) could get fevers with treatment and that the best thing to try and do to avoid ending up in hospital was try and manage it at home with paracetamol..." Participant 3: "...sometimes your mind can run a little bit wild and probably best not to and probably best to ask questions which I do to the oncologists 'cause that's what they're there for."
Dissonance between clinicians' and patients' views	Participant 1: "I- I don't see an end to it (.) I've spoken to my oncologist about it and it- basically it's- well we're getting good scan results and it's a small price to pay for the good scan results we're getting (.) when I questioned when would be the end of my trial or would I take it for it was (.) well let's talk in another 3 years' time when you've had it for 5 years and I'm just thinking (.) another 3 years of this."

Discussion and Conclusions

Patients receiving melanoma treatment prefer to self-manage fever and side effects at home, if perceiving them as possible to control. The home setting provides psychological comfort and allows patients the freedom to choose how they manage fever. Hospital treatment is perceived as the last resort and is sought by patients or caregivers when symptoms become severe. Apprehension about hospital treatment relates to the fear of long-term admissions, contracting COVID-19 and experiencing isolation that incites negative, intrusive thoughts.

Caregiver support is crucial during melanoma treatment and promotes patients' well-being. Caregivers provide support and assist with decision-making about the optimal time for accessing healthcare services. Doctor–patient communication plays an important role in patients' perception of their illness and treatment; aligned communication between clinicians and patients reinforces patients' self-efficacy in managing their symptoms. On the other hand, communicating information that does not alleviate patients' concerns might cause psychological distress.

Clinicians need to consider patient preferences for managing fever and symptoms at home, and help increase patients' confidence in being able to manage their symptoms effectively. This can be done by discussing self-management options available to patients.

Psychological distress could be alleviated by carefully managing patients' expectations of treatment and side effects.