Background

Beatriz is a refugee from Chile, who during the civil unrest surrounding the 1973 coup d'état, witnessed violence and was tortured before she came to the UK in the late 1970s. She had cancer of the bladder and spent her last days in a hospice. In the final two weeks of her life, Beatriz became more sensitized and unsettled. She was given new drugs to relieve her increasing pain and symptoms. Hypersensitivity, agitation and paranoia are not uncommon with advanced disease, when patients can have complex physical and psychological symptoms and can be on several drugs, which carry the increased risk of adverse reactions.

SKIN

Beatriz Diaz had survived incarceration, torture and the clutches of a military junta. Her last protest was staged in her bed. Before she stopped talking, Beatriz turned her back on the English language, speaking only in her mother tongue. Then she began to refuse to be bathed; the hoist that lifted her into the bath made her feel unsafe, like a piece of meat. It was not long before even the gentlest of touches caused her excruciating pain. A nurse calling her name made her jump. The noises in the ward hurt her ears. She became irritable with everyone. The smell of coffee made Beatriz shudder and grimace.

Caffeine shots - coffee combined with Coca-Cola - had helped her to stay awake for 72 hours when the students took over the factories. At the end of three days when it was her turn to sleep, Beatriz lay on a bed and spasms rioted through her body. Those days flash into her thoughts sometimes, but no one could guess what was behind the glassy stare in her green eyes.

The care team discuss Beatriz, offering considered opinions and diagnoses. They know from her family that she was a fastidious woman, someone who liked to take care of herself. The photographs on her bedside table showed a stylish woman, full of life. Had she become difficult and mean? Perhaps she was suffering from paranoia with the change in her drugs? Could her behaviour be the symptoms of terminal restlessness?

"I think there's a lot to her case," says a nurse. "But I find it hard to read her, especially with the language difference."

"Yes, but she's had such a difficult life," a social worker reminds them.

With the uncertainty, the care team falls back upon trusted principles and agree that it is in Beatriz's best interests that they should respect her autonomy and choices. If she does not want to be bathed they will not try to wash her again. They will monitor her blood pressure once a day and move her only for comfort. It is important to respect a patient's choices and it isn't going to make much of a difference if she is a little smelly.

Activity (can be done alone and/or as part of a group discussion)

(i) Read the case story and identify Beatriz's symptoms. The symptoms include:

- hypersensitivity to touch, smell and sound
- agitation and irritability
- a retreat from language, beginning with English, Beatriz's second language
- a refusal of hands-on care

(ii) In thinking about the relationships between social and physical pain for Beatriz, there is a layering and intermixing of possible causes to consider:

- the biochemical changes brought on by advancing disease and adverse reactions to her drugs
- her past biographical experience in Chile and then as a refugee in the UK
- individual characteristics and habits (has Beatriz always been a person who becomes easily irritated by others?)

(iii) Think about the team's decision not to wash Beatriz. Why might a decision to respect patient 'choice' be problematic in this case? What care alternatives might there be?