

What are the views of childhood cancer survivors on receiving lifestyle advice at their follow-up appointments?

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1. Background

Childhood cancer survivors (CCS) are more at risk of long-term diseases than the general population, some of which are shown in Figure 1. Approximately 60% will have at least one chronic (ongoing) health condition as a result of treatment¹. Survivors have a long-term-term-follow-up (LTFU) appointment, usually yearly, with one of the aims being to diagnose and manage any late effects of treatment at an early stage. Another crucial part of these appointments is providing lifestyle advice to prevent some of these side effects - diseases such as diabetes and high blood pressure can be prevented or delayed with healthy lifestyle. However, it is not clear how survivors feel about receiving this advice at their LTFU appointment. Their age can also be a challenge to effectively delivering this information, since the diseases that they are at risk of, tend to occur in the older population so the way in which the advice is given is very important.

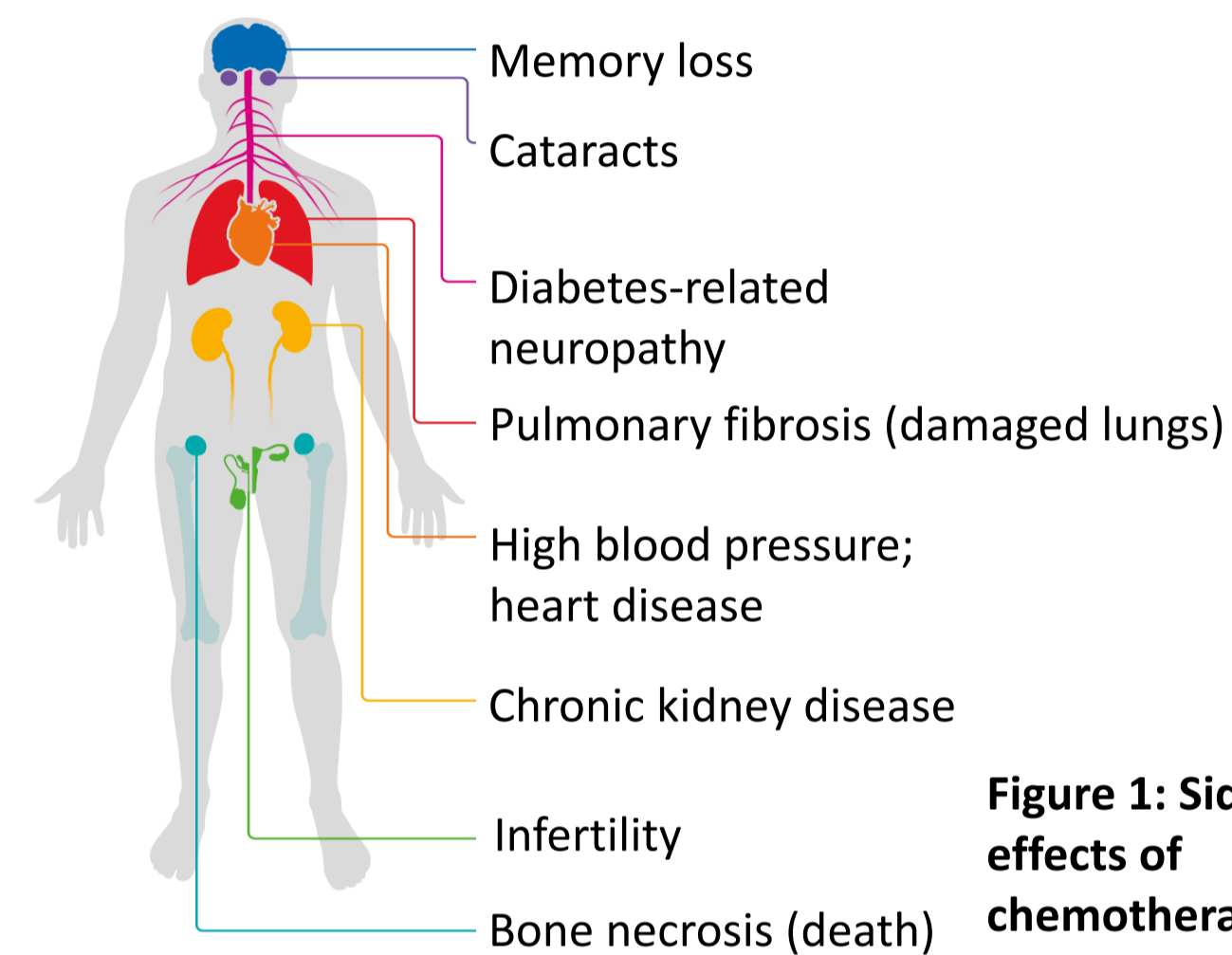


Figure 1: Side effects of chemotherapy²

Aims:

1. What are their preferences of receiving lifestyle advice in clinic?
2. How much do they need this based on their current lifestyle?

2. Method

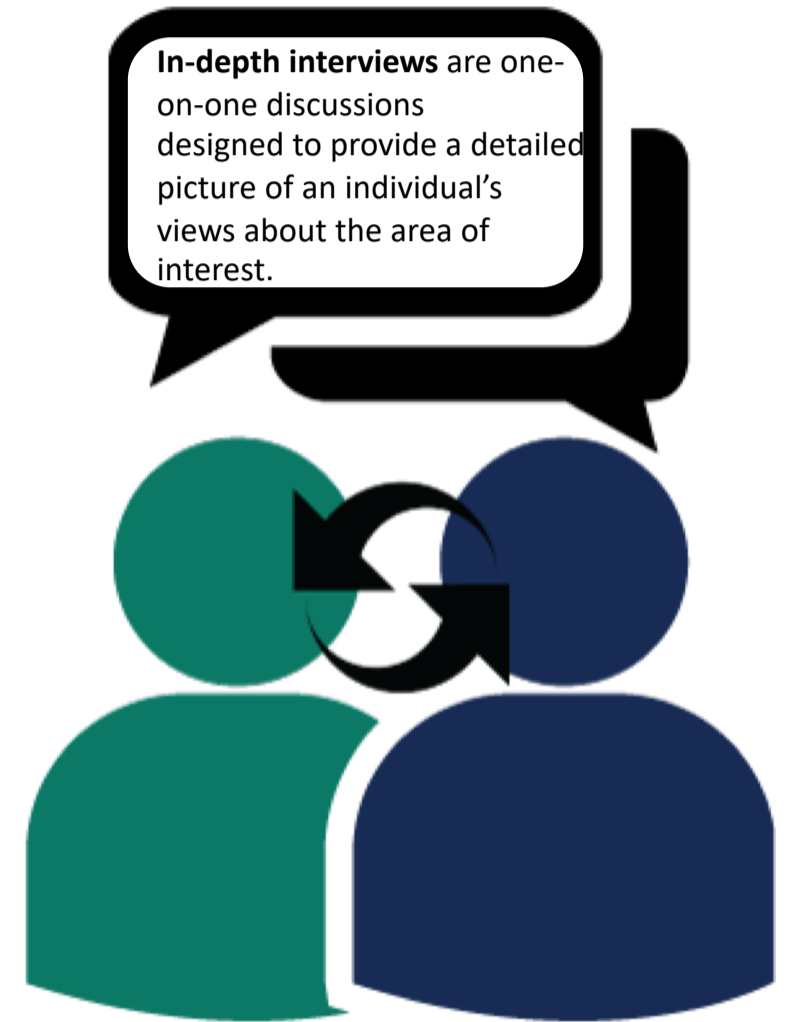
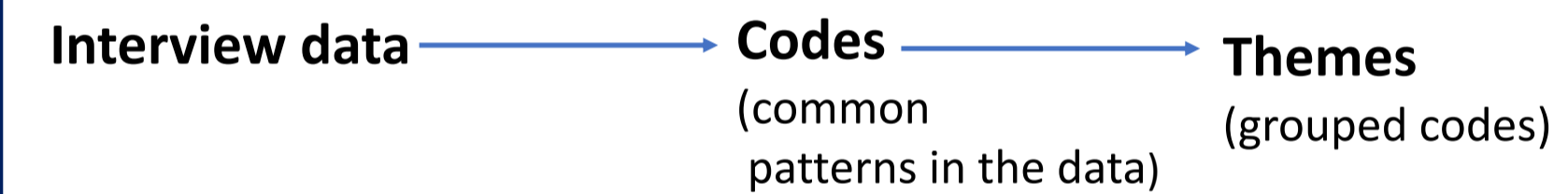
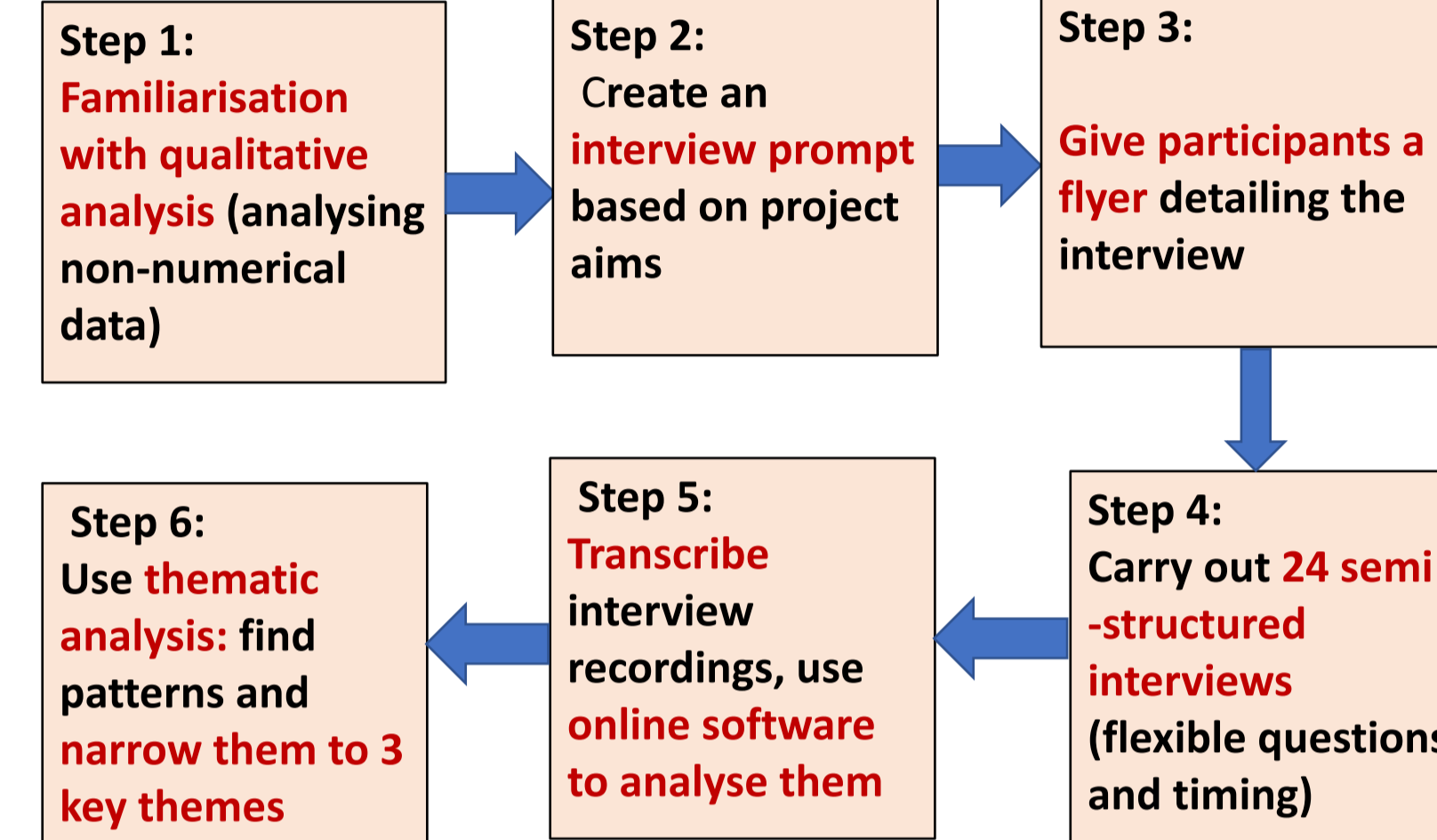


Figure 2: Detailing the purpose of a one-to-one interview³

Participants: Aged 14+, had a range of cancers and treatments.

3. Results/Data themes

The three themes of the data, which highlight preferences of the CCS, are written below along with a few quotes to represent some key findings.

Theme 1: Patient-centred care

- People have barriers to a healthy lifestyle- should take this into account when giving advice
- Advice should be based on patient's health worries
- Age and patient's stage of life affects what advice should be given

Theme 2: Personal responsibility

- Some think lifestyle advice is intimidating so choices should be made independently
- There is a limit to the difference lifestyle advice in clinic makes; it requires patient engagement

"(Lifestyle advice) should be different for everyone depending on your treatment."

"A lot of lifestyle things weren't relevant because it was very light chemotherapy."

"I don't like getting told off."

"I think a good lifestyle is something I have to do for myself"

"I am quite responsible when it comes to lifestyle"

"I try my best not to drink excessively but I'm 19 and a student"

"It's easier coming from someone you have known throughout the whole thing"

"I haven't made any changes because I only come to the clinic once a year and after, I forget to do what they say."

"Leaflets would be helpful because I don't want to be bombarded."

"When I read something, it takes too long and I would like someone there if I have questions."

Theme 3: Formats of advice

- 20 participants preferred that their consultant gave them the information
- Mixed preferences on whether to have verbal or written information

Is there a need for the advice?

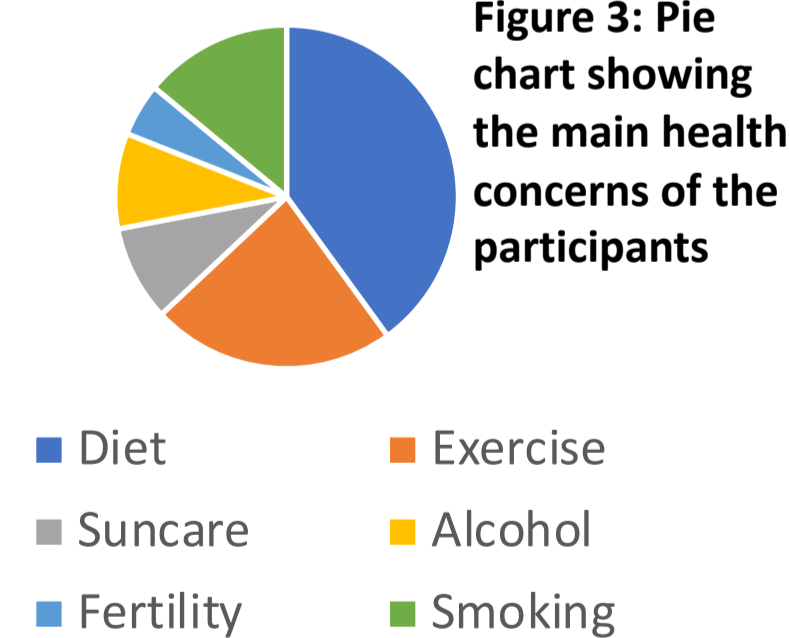


Figure 3: Pie chart showing the main health concerns of the participants

- 22 of the 24 participants claimed to have worries about lifestyle and identified changes to make
- 17 mentioned they were more concerned about lifestyle after their diagnosis and treatment
- Diet and exercise were the biggest concerns, as shown in the chart

4. Conclusions

The findings of the project suggest that childhood cancer survivors prefer information tailored to them, their diagnosis and their treatment. The information should be given in a variety of formats, in a more informal way, during their appointment, but ultimately from the consultant who has lead their care. It also requires the patient to act on this advice in the long-term.

There is a need for lifestyle advice as survivors tend to link the importance of a healthy lifestyle to their cancer and the majority were worried about at least one aspect of their current lifestyle.

More research is needed into what the most efficient ways to personalise lifestyle advice for this patient group are.

5. References

1. Oeffinger KC, Mertens AC, Sklar CA, et al. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med.* 2006;355:1572-1582.
2. Figure 1: Adapted from- Anticancer chemotherapy in teenagers and young adults: managing long term side effects- *BMJ* 2016. www.bmj.com/content/354/bmj.i4567
3. Figure 2: Image from: www.thecompassforsbc.org/how-to-guides/how-conduct-qualitative-formative-research