

Cancer survivors' perspective on and input for a community pharmacy-based intervention for managing late effects of cancer (LEC)

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Background

- One in three Danes get cancer before they turn 75 years, and two-thirds of them survive cancer for at least five years.
- More than half of all cancer survivors in Denmark experience late effects of cancer or cancer treatment (LEC)
- More than 40 % of them state that they do not get the necessary help managing late effects through the existing rehabilitation services.
- LEC have an impact on the quality of life, health status and workability of the cancer survivor.
- Danish community pharmacies offer several health services, but none of these specifically target cancer survivors.

Objective

Based on the perspective of cancer survivors, the aim of the project is to:

1) provide input for a community pharmacy intervention for cancer survivors with LEC and 2) explore cancer survivors' view on community pharmacies' opportunities and limitations when dealing with LEC

Methods

A qualitative study design using focus group interviews was chosen. Participants were recruited through the Danish Cancer Society User Panel as well as through Facebook groups for cancer survivors experiencing LEC.

13 cancer survivors participated in two semistructured focus group interviews with 5 and 8 participants, respectively. Data were recorded, transcribed, and analyzed using thematic analysis.



Results

The thematic analysis resulted in two deductively determined themes:

- cancer survivors' wishes and needs for the intervention
- cancer survivors' challenges with the intervention

In addition to the deductively predetermined themes, during the thematic analysis of FGI-1, two additional themes were identified inductively:

- collaboration between health care providers
- counselling at the pharmacy

From FGI-2, the same two themes and a third theme "cancer survivors' perception of late effects after cancer" were inductively identified. In figure 1, the inductively determined themes are indicated with dashed lines and the deductively determined themes are indicated with full lines.

> "Well, I would say that I am more open to it than I was when I came. Because when I came, I thought, 'What on earth is this about? What should they know about anything? That's strange!' But okay. Use your imagination a little, and you can find a purpose for it, depending on how it's done." (FGI-2, K4, l. 1193-1196)

The analysis revealed several shortcomings in the existing management of LEC. Initially, attitudes varied towards including pharmacies in the management of LEC as several participants did not view community pharmacies as part of the healthcare system and hence not as a natural place to receive healthcare advice. During the interviews, both groups eventually recognized pharmacy's potential contribution in relation to LEC.

"Well, it's also important that they know their limits, I think. Because we're almost leaning towards the GP and the psychologist and the oncologist. They need to know how far they can go." (FGI-2, K2, l. 807-809)

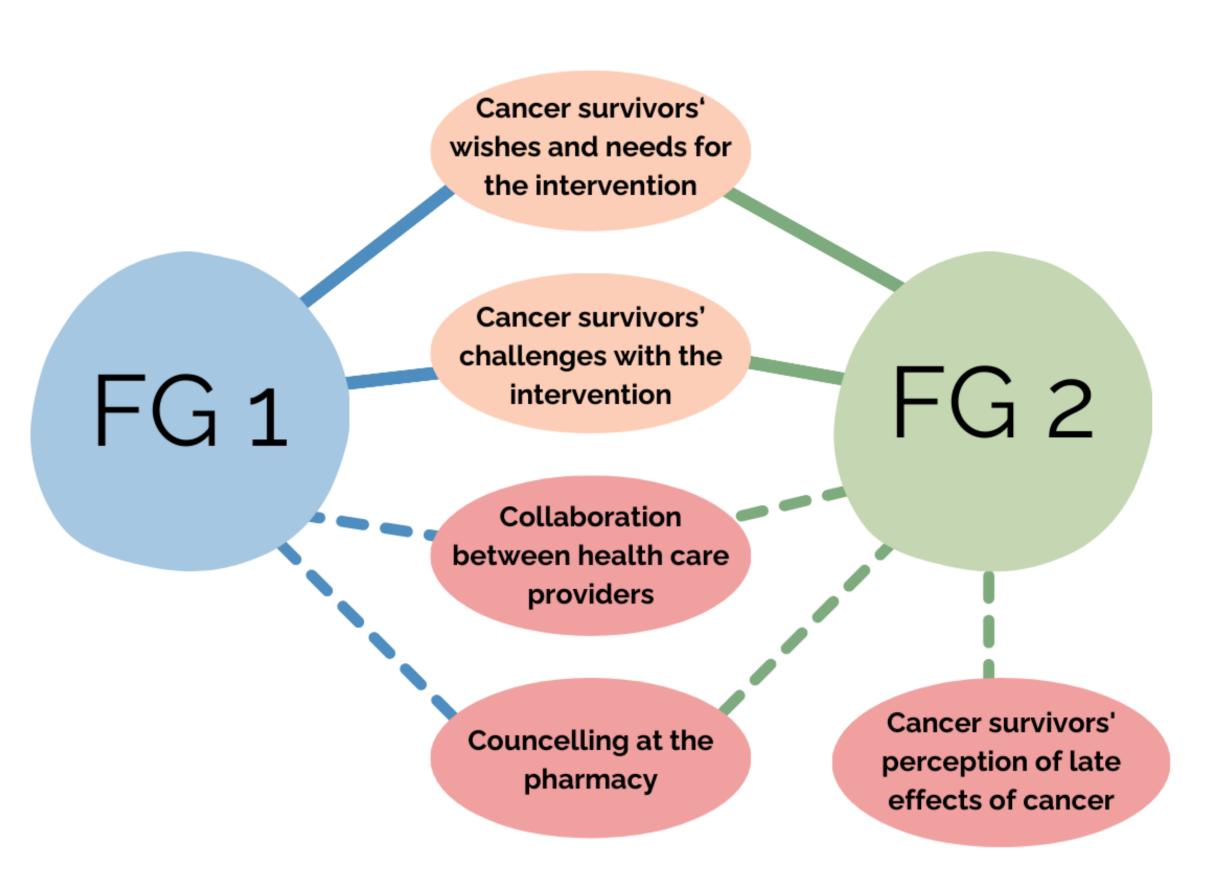


Figure 1: Themes for both focus group interviews (FGIs). Solid lines show deductively identified themes, dashed lines the inductively identified themes.

The participants agreed on key aspects of a community pharmacy-based intervention design for managing LEC:

- Discretion
- Staff training for sensitive conversations and awareness of cancer-related issues
- Clear boundaries for pharmacy advice and referrals to healthcare professionals
- Emphasis on advice relevance over sales
- Focus on the survivor's needs, including active listening and expectation polling.

Conclusion:

Cancer survivors were open towards pharmacy playing a role in relation to LEC, despite many of them initially not perceiving the pharmacy as a place for health counselling. Cancer survivors need a central place to receive information, and the pharmacy can be an ideal focal point for information on offers for LEC in the local area. The cancer survivors have several suggestions for the content and running of a community pharmacy-based intervention for cancer survivors with LEC, see figure 2.

Key recommendations for the intervention

Counselling

The dialogue should be tailored to the individual cancer survivor's needs, and the focus should be on counselling rather than

Written materials

Cancer survivors expressed a need for written informational material about late effects of cancer. A specific suggestion was a brochure similar to the existing ones freely available at pharmacies.

Facilitating support groups

Participants miss support groups where they can talk to other cancer survivors experiencing the same late effects. Cancer survivors are interested in the pharmacy facilitating these meetings.

Cooperation within the healthcare sector a need is expressed for clear guidelines for handling late effects after cancer, making it

easier for cancer survivors to navigate the available offers.

Discretion

A focus on discretion at Danish pharmacies is needed.. Lack of discretion will deter some cancer survivors from participating in the counseling.

Appointment Scheduling

The intervention should include the option for scheduling appointments, allowing both the cancer survivors and pharmacy staff to prepare.

Pharmacy perception

Cancer survivors currently do not view pharmacies as places for health counseling. Awareness of competencies and a change of perceived role needed.

Pharmacy staff competencies

Pharmacy staff must possess the necessary competencies to engage in a dialogue and know when to refer cancer survivors to other offers within the healthcare system.

Figure 2: Key recommendations for the intervention based on the agreements of the cancer survivors in the two focus group interviews