A professionally led peer-to-peer network for people with lived experience of oesophagogastric cancer

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Background

Patients who have undergone surgery for oesophageal or gastric (EG) cancer often experience complex and long-term rehabilitation needs. In 2024, 143 patients underwent surgery for EG cancer at Copenhagen University Hospital, Rigshospitalet. That same year, a professionally led peer-to-peer network was piloted as a collaboration between Rigshospitalet, the Danish Cancer Society, and the Copenhagen Centre for Cancer and Health (CCCH).

Aim and methods

The aim was to assess the reach, recruitment, and perceived relevance of the network for patients and relatives.

Participation was evaluated through attendance data.
Perceived benefits were evaluated through two online questionnaires midway (May 2024) and at the end (December 2024).

Organizational framework

The network met monthly for two hours in the afternoon, nine times in total. It included thematic sessions led by health professionals, a social worker, or a psychologist with opportunities for peer exchange. Themes included surgery and post-operative effects, meals and nutrition, unpredictability and psychological reactions. Participants could join on a rolling basis and participate as many times as they wished.

The EG Patient Network – An Intersectoral Collaboration

RIGSHOSPITALET

- Contact and information to patients from Region Zealand and the Capital Region of Denmark.
- Clinical presentations at network sessions.
- Presence of nurse(s) at network sessions.

THE DANISH CANCER SOCIETY

- Administration of the network, including participant registration.
- Promotion of the network via the website and local cancer counselling centres.
- Psychology-focused presentations and facilitation at network sessions.

THE CCCH

- Coordinating role, including responsibility for the programme, information materials, monitoring, and evaluation.
- Clinical and psychosocial presentations and facilitation at network sessions.
- Overall facilitation of network sessions.

Results

Participation

- 44 individuals participated: 33 patients and 11 relatives.
- Among patients, 67% (n=22) were men; among relatives, 73% (n=8) were female partners.
- 30-50% reported coming from outside of the municipality of Copenhagen.

Perceived benefits

Response rates of questionnaires were 88% (n=21) and 77% (n=20), respectively.

Proportion responding high/very high degree:

The network makes me feel less alone with challenges (n=14)
The network has provided me with more knowledge (n=15)

It was important to learn that I'm not alone and that others face similar issues.

Having become better at managing the long-term effects and other challenges following the surgery.

It wasn't until I joined [the network] that I realised I had dumping syndrome. I've become more informed overall.

I've found a forum where I can talk about difficult things without needing to explain or apologise.

Conclusion

- A professionally led peer-to-peer network can address unmet rehabilitation needs following EG cancer surgery.
- Intersectoral collaboration enabled a broad regional reach and a comprehensive programme.

Next steps

- After the pilot phase, the network became fully operational in January 2025.
- As the network continues, focus will be on exploring relatives' involvement, monitoring potential emotional strain in group settings, and assessing preferences for online formats.

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