

Understanding the impact of early onset colorectal cancer on quality of life: a qualitative analysis of online forum data

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Background:

Incidence of early onset colorectal cancer (EOCRC) occurring in patients <50 is rising [1]. By virtue of diagnosis at a different life stage, younger patients may experience differing health-related quality of life (HRQOL) impacts. Understanding these impacts is vital to develop supportive interventions. Online forums offer researchers an unfiltered insight into patient experience, providing a rich source of qualitative data. This study utilises qualitative analysis of online forum messages to understand the pertinent HRQOL impacts of EOCRC.

Methods:

An online forum specifically for EOCRC was identified. A phenomenological approach, with inductive coding (with 10% dual coding) and thematic analysis of extracted messages, was used to describe diagnostic experience and effect on HRQOL.

Conclusion

Qualitative analysis of online forum messages is an effective and efficient methodology for identifying HRQOL impacts, reflecting those highlighted through systematic review and offering additional insights, particularly into the impact of isolation. This novel methodology could be adapted for use by qualitative researchers across the NHS offering a window into patient lived experience. Understanding the unique HRQOL of EOCRC provides a basis for further research into how NHS colorectal cancer services must adapt to the meet the needs of an expanding younger cohort.

Results:

Data extraction and analysis were conducted over one month. Eight main themes emerged from 463 forum messages posted over a five-year period. The themes identified using this time and cost-efficient methodology overlapped with those identified through systematic review^[2,3] and additionally offered deeper insight into the considerable impact of isolation amongst younger individuals, who do not represent the typical colorectal cancer patient.

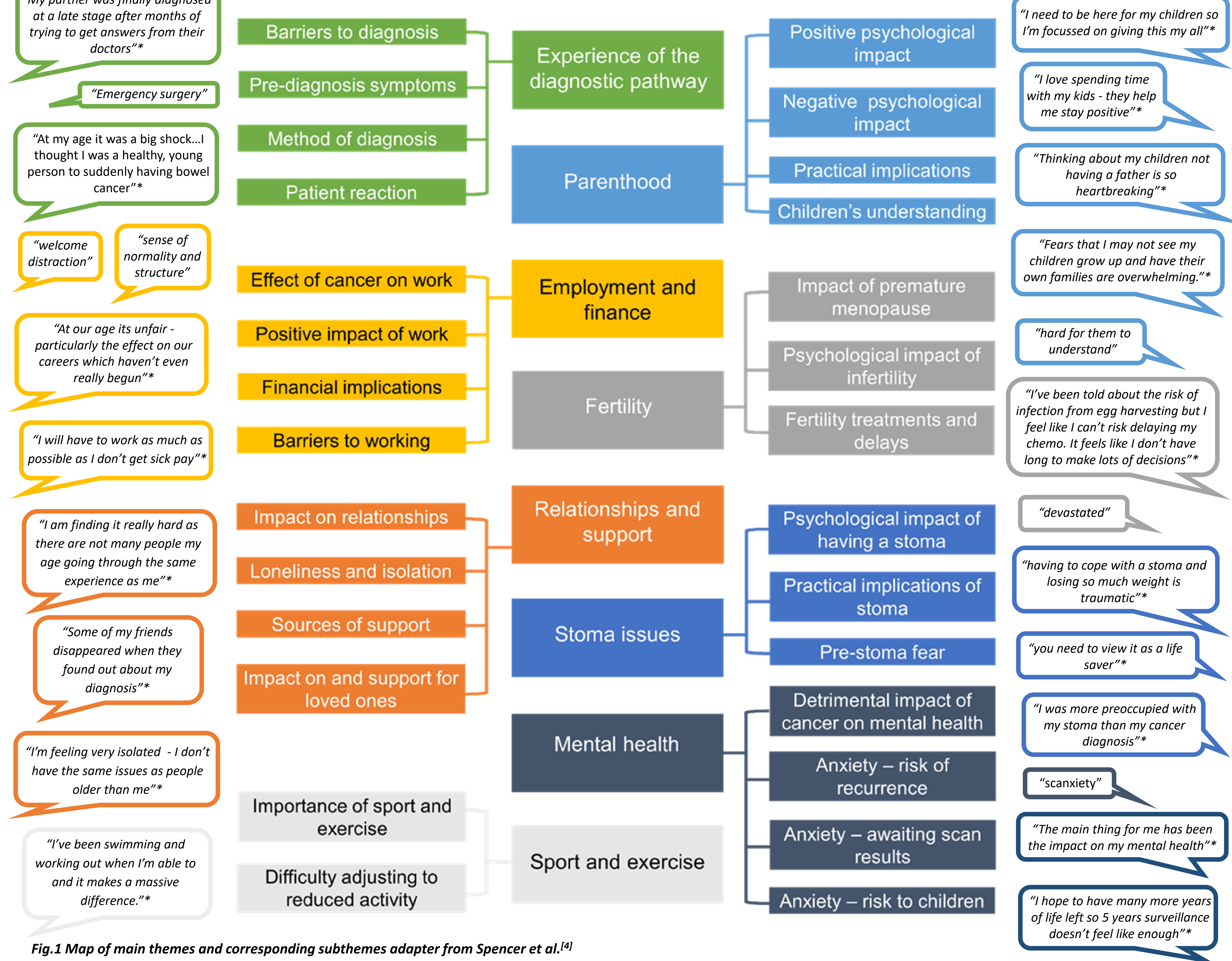


Fig.1 Map of main themes and corresponding subthemes adapter from Spencer et al.^[4]

*Denotes quotes paraphrased to protect anonymity of posting users. All paraphrased quotes checked by co-researchers to ensure retention of true meaning.

References

1. Siegel, R. L., Wagle, N. S., Cercek, A., et al. (2023). Colorectal cancer statistics, 2023. CA: A Cancer Journal for Clinicians, 73, 233–254
2. Sodergren, S. C., Husson, O., Robinson, J., et al. (2017). Systematic review of the health-related quality of life issues facing adolescents and young adults with cancer. Quality of Life Research, 26, 1659–1672.
3. Waddell, O., McLauchlan, J., McCombie, A., et al. (2023). Quality of life in early-onset colorectal cancer patients: systematic review. BJS Open, 7(3).
4. Spencer, A., Bedding, C., Nicklin, E., et al. (2024). Understanding the impact of early onset colorectal cancer on quality of life: a qualitative analysis of online forum data. Quality of Life Research, 34(4), 1003–1013.

