

Exploring influencing factors for physical activity participation and promotion in people with advanced head and neck cancer

Protocol of a qualitative study

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Abstract

Background: Higher physical activity levels are associated with better quality of life in people affected by head and neck cancer. Nevertheless, most individuals with these cancer types show a sedentary behaviour or very low activity levels. Insights on factors influencing physical activity from the perspective of individuals affected by an advanced head and neck cancer diagnosis is still sparse and the views of their significant others have not been explored yet. To design suitable interventions to support this group to be or become more active in the future, there needs to be more in-depth knowledge about the factors that influence their activity behaviour.

The aim of this study is to explore factors influencing capabilities, opportunities, and motivation for physical activity participation and promotion in people with an advanced head and neck squamous cell carcinoma from the perspective of people being affected and their significant others.

Methods: Semi-structured interviews will be held with people with advanced head and neck cancer and focus group interviews will be conducted with significant others of people being affected. Interviews will be transcribed verbatim and analysed by a content analysis with a deductive-inductive approach based on the domains of the behaviour change wheel.

Expected outcomes: This study will give insights on physical activity participation and promotion from the perspective of people affected by an advanced head and neck squamous cell carcinoma and their significant others. The results will build the foundation for subsequent research projects to design and test physical activity promotion programmes tailored to this group.

Keywords: qualitative research, physical activity, influencing factors, head and neck cancer, behaviour change wheel

Abbreviations: HNSCC: head and neck squamous cell carcinoma; PA: physical activity

Background and Rationale

Head and neck cancer ranks as the seventh most common cancer type worldwide of which about 90% are squamous cell carcinomas¹. These cancer types are usually diagnosed in stage three or four and need extensive medical treatment², that can leave the person with a variety

of different impairments and treatment sequelae including swallowing problems, fatigue and a reduced quality of life^{3,4}

Physical activity (PA) and exercise have positive effects on the health status and quality of life in patients with head and neck cancer⁵. Higher activity levels are associated with better quality of life⁶, physical functioning, body composition and fatigue^{7,8}, but the majority of people with these cancers show a sedentary lifestyle or very low activity levels⁹. A scoping review was conducted by the study team to compile the existing knowledge on factors influencing PA in individuals with head and neck cancer and the suggestions by health care experts and researchers in the field¹⁰. This review concluded that personal, social, environmental, and health-related factors significantly influence PA participation for patients with head and neck cancer. These factors encompass personal characteristics like age and co-morbidities, as well as factors such as attitude, interest, and motivation. Treatment side-effects and the overall health condition of individuals are also important factors. Experts suggest that further research is necessary to develop interventions that encourage patients' participation and support them to overcome potential PA barriers. They also recommend that the implementation of PA interventions into the clinical pathways should be explored in more detail.

Insights from the perspective of individuals with a head and neck cancer diagnosis on the context of PA participation is still very sparse⁹. More in-depth knowledge should be gained to enable the design of suitable interventions to support this group to change their behaviour successfully and sustainably towards a more active lifestyle. The perspectives of people being affected is crucial to tailor interventions to their needs.

Additionally, the experiences and opinions of significant others of people with head and neck cancer have not yet been explored. A 'significant other' is a person who is important to one's well-being¹¹, who is usually a partner or spouse or another close person, such as a family member or a friend. These significant others are a valuable source of information to understand the complex situation of PA participation in this group and will help to gain an important insight on how to design an adequate intervention to help individuals with head and neck cancer to change to a more active lifestyle¹².

To understand and enhance behaviour change, the behaviour change wheel by Michie et al.¹³ is a useful framework, which provides a systematic way to understand behaviour change and to design interventions. The hub of the wheel consists of the aspects of capability, opportunity, and motivation (COM-B model) of behaviour. The second layer states nine intervention functions that can be used to bring about behaviour change including education, persuasion,

incentivization, coercion, training, restriction, environmental restructuring, modelling, and enablement. The most outer layer of the wheel includes seven policy categories that can be used to implement interventions (see appendix A).

The aim of the study is to explore capabilities, opportunities, and motivation for PA participation in people with a diagnosis of an advanced head and neck squamous cell carcinoma (HNSCC). This will be examined from the perspective of people being affected by HNSCC and the perspective of their significant others.

Research questions:

- What capabilities and opportunities for PA participation do people with advanced HNSCC experience?
- What motivates people with advanced HNSCC to be physically active?
- How do significant others view capabilities, opportunities, and motivation for PA participation in people with advanced HNSCC?
- What suggestions and recommendations for PA promotion do people with advanced HNSCC and their significant others have?
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Methods

Study registration:

The study project will be registered at the clinical trials registry of the U.S. National Library of Medicine¹⁴.

Ethical approval:

A clarification of responsibility was submitted to the Zurich Cantonal Ethics Committee (BASEC Nr. Req-2023-00397). They concluded that the study project does not fall within the scope of the Human Research Act.

Patient and public involvement:

The guide of the patient lab of the Swiss Cancer Centre Leman¹⁵ will be applied. A patient advisor and an individual with a HNSCC will be consulted to give feedback on specific steps of the project. This will include feedback on the development of the interview guide, during the coding process, and the analysis phase.

Methodological orientation and theory of the study:

The study will apply a descriptive qualitative approach to describe the phenomenon comprehensively with a focus on relevance for clinical practise¹⁶. This approach is used in the context of intervention development and results are presented in everyday language, rather than in a conceptual, philosophical or highly abstract framework^{17,18}.

Study Design:

Semi-structured individual interviews with people affected by HNC will take place in a face-to-face setting or virtually according to the participants preference. The individual setting is chosen to ensure that the interviewer can respond well to the needs of the interview participant. People with advanced HNSCC might need frequent breaks during the interview to be able to drink something to relieve the common side effect of having a dry mouth. Additionally, they might also have problems speaking which could lead to problems or intimidation if a group setting was chosen. Focus group interviews will be conducted with significant others of people with HNSCC. This will enable interaction between the participants and encourage discussion about the topic¹⁹. Interview guides for the individual interviews and the focus group interviews will be developed based on existing literature on influencing factors for PA participation in patients with head and neck cancer and the expertise of the study team. The behaviour change wheel¹³ will be used as a theoretical framework (see Appendix A).

Participants and sampling:

To achieve data saturation²⁰ the study population will be limited to individuals affected by a stage III or IV squamous cell carcinoma, as this subgroup constitutes the largest proportion of patients diagnosed with head and neck cancer².

Inclusion criteria for people with HNSCC:

- minimal age 18
- diagnosis of a primary head and neck squamous cell carcinoma within the last 24 months
- oral, pharyngeal, or laryngeal cancer stage III or IV
- completed surgery and/or radio(chemo)therapy in curative intent

Exclusion criteria for people with HNSCC:

- not having the physical, mental, and cognitive ability to understand, follow and hold a conversation in (Swiss-)German
- treatment in palliative intent
- recurrence of the head and neck tumour (local or distant)

Inclusion criteria for significant others of people with HNSCC:

- minimal age 18
- being a significant other (partner, spouse, close family member or friend) of an individual with a HNSCC with the above-mentioned criteria
- having the permission of the individual affected by HNSCC to talk about their experiences

Exclusion criteria for significant others of people with HNSCC:

- not having the physical, mental, and cognitive ability to understand, follow and take part in a group discussion in (Swiss-)German

Recruitment:

People affected by HNSCC, and significant others of people being affected will be recruited by direct contact with health professionals involved in their treatment and care in different regions of Switzerland. For the recruitment of significant others, the permission of the person affected by HNSCC needs to be obtained; this will be confirmed in the informed consent form.

The recruiting sites are:

- Cantonal Hospital Winterthur (KSW)
- Cantonal Hospital Lucerne
- 'ear, nose, throat and plastic surgery center' at Hirslanden Clinic, Zurich

- rehabilitation clinics 'Berner Klinik Montana' and 'Adelheid'
- if necessary, the recruitment sites could be extended to include the cantonal cancer leagues and other health institutions within the German speaking part of Switzerland

Update to recruitment sites (December 2024):

- all cantonal and regional cancer leagues were included in the recruitment process
- additional hospitals and rehabilitation clinics/centers were included to support recruitment:
 - University Hospital Bern (Inselspital)
 - University Hospital Zurich
 - University Hospital Basel
 - Cantonal Hospital St. Gallen
 - Outpatient rehabilitation Chur
 - Rehabilitation clinic Zihlschlacht

Potential interview participants will be provided with an informational brochure accompanied by a pre-stamped envelope facilitating the return of their contact details via a designated card for completion. The study coordinator (MS) will then contact the person and give further information and check if the person is eligible to participate. A minimum of 12 individuals with a HNSCC diagnosis and eight significant others will be recruited for the interviews and focus groups respectively with the goal to reach data saturation^{20,22}.

Data collection:

All participants will receive a short questionnaire prior to the interview to collect their personal characteristics (e.g., age, education level, personal estimation of PA levels, their or their significant others' type of HNSCC diagnosis and treatment). The individual semi-structured interviews will be conducted at a place to the persons preference, either in their home, at the hospital/rehabilitation clinic, or if not possible otherwise virtually via an online video call. Focus group interviews will take place either at one of the involved clinics or at a cantonal cancer league. Prior to the start of the interview, informed consent will be signed, and remaining questions about the interview conduct will be answered. The individual interviews will last 30 to 60 minutes. Two to three focus groups with the significant others will be held and will last 60 to 90 minutes. To reach data saturation, a redundancy of themes should be achieved²³. Interviews and focus group interviews will be audio-recorded with approval of participants as stated in the informed consent form^{24,25}. Notes will be taken by the interviewer to help remember special occurrences during the interviews. A test interview will be held to test the interview guide and make necessary adjustment.

Data analysis:

Interviews will be transcribed verbatim²⁴ by first using the automated transcription tool 'noScribe'²⁶. This is followed by manually checking and correcting of the transcripts. The parts which could reveal the participants identity will be anonymized at this point. The transcripts will be checked and validation by the person who has conducted the interview. For coding and analysing the data, the software MAXQDA²⁷ will be used. A structuring qualitative content analysis will be used as described by Kuckartz²⁸ with a deductive-inductive approach. This method entails seven phases as shown in Table 1. It starts with the initial work with the text by reading the transcripts, writing memos, and summarizing cases. This will be done individually by the two researchers who will code the interview. The main categories are defined based on items of the behaviour change wheel and results of our scoping review on influencing factors for PA in head and neck cancer¹⁰. The first four interviews will be used to test the applicability of the main- and subcategory system, if necessary, adaptations will be made. The first coding cycle includes coding with the main categories by MS and by a second coder RE, MB or a research assistant in a consensual coding process²⁸. Diverging codes will be discussed between the two coders until consensus is reached, if necessary, a third person will be involved in the decision. This step is followed by inductively developing sub-categories and then coding the data with the sub-category system. When this second coding cycle is finished, simple and complex analyses follow. This will include a category-based analysis of the main and subcategories but will also explore relationships between categories and state frequencies of categories and subcategories. In regular intervals results of the coding and analysis will be discussed with senior researchers in the field of HNC and qualitative research (ME & CS) and a patient advisor. In the last phase of the research process the results to the research questions will be written and complemented with quotes from the transcript. The process of the analysis will be documented by describing the steps of the analysis and how categories were constructed and how they are based on the data.

Table 1.
The seven phases of structuring qualitative content analysis
according to Kuckartz²⁸

- 1) Reading transcripts, writing memos, summarizing cases
- 2) Developing main categories
- 3) Coding with main categories (first coding cycle)
- 4) Developing sub-categories inductively
- 5) Coding with sub-categories (2nd coding cycle)
- 6) Simple and complex analyses
- 7) Writing results and documenting process

Data protection and management:

Information about interview participants, informed consent forms and audio recordings of the interviews will be stored in a protected folder on a computer of the Cantonal Hospital Winterthur which can only be accessed by the study coordinator (MS) and an assistant who will aid in transcribing the interview. The automated transcription tool 'noScribe' allows to use audio-files which are stored locally on a protected device.

Reporting:

The consolidated criteria for reporting qualitative studies (COREQ)²⁹ will be used to guide the reporting process. Quotes that represent the theme and subthemes will be extracted from the interview transcripts.

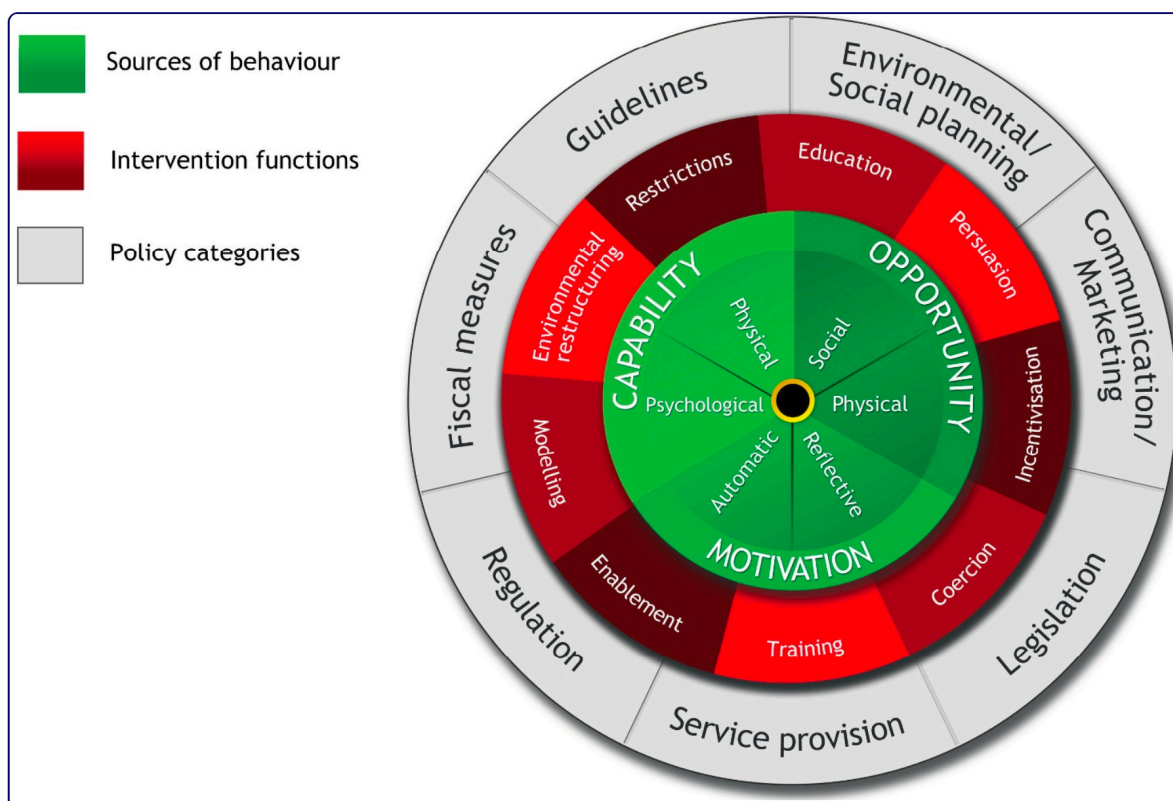
Expected results

The results of this qualitative study will provide in-depth knowledge on PA participation from the perspective of individuals affected by an advanced HNSCC. Additionally, views of significant others of people affected by HNSCC are included which will provide valuable information from a different point of view. The more sedentary individuals with HNSCC might be difficult to recruit because they might not want to talk about this topic, likewise individuals with speech impairments due to a laryngeal cancer might not be able to participate in the interviews but their significant others can share their experiences. The combined results from individuals directly affected and significant others will have the potential to give a more comprehensive overview on the topic. This will build a foundation for the future development of tailored PA promotion programmes for this patient group (see Appendix B).

- 281 1. Sung, H. *et al.* Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality
282 Worldwide for 36 Cancers in 185 Countries. *CA. Cancer J. Clin.* **71**, 209–249 (2021).
- 283 2. Gormley, M., Creaney, G., Schache, A., Ingarfield, K. & Conway, D. I. Reviewing the epidemiology of
284 head and neck cancer: definitions, trends and risk factors. *Br. Dent. J.* **233**, 780–786 (2022).
- 285 3. Vermaire, J. *et al.* The course of swallowing problems in the first 2 years after diagnosis of head and
286 neck cancer. *Support. Care Cancer* (2022) doi:10.1007/s00520-022-07322-w.
- 287 4. Hammermüller, C. *et al.* Depression, anxiety, fatigue, and quality of life in a large sample of patients
288 suffering from head and neck cancer in comparison with the general population. *BMC Cancer* **21**, 94
289 (2021).
- 290 5. Samuel, S. R. *et al.* Effectiveness of exercise-based rehabilitation on functional capacity and quality of
291 life in head and neck cancer patients receiving chemo-radiotherapy. *Support. Care Cancer Off. J.*
292 *Multinatl. Assoc. Support. Care Cancer* **27**, 3913–3920 (2019).
- 293 6. Rogers, S. N., Travers, A., Lowe, D., Levy, A. R. & Midgely, A. W. Importance of activity and recreation
294 for the quality of life of patients treated for cancer of the head and neck. *Br. J. Oral Maxillofac. Surg.* **57**,
295 125–134 (2019).
- 296 7. Lynch, P. T. *et al.* Effectiveness of physical activity interventions in improving objective and patient-
297 reported outcomes in head and neck cancer survivors: A systematic review. *Oral Oncol.* **117**, 105253
298 (2021).
- 299 8. Capozzi, L. C., Nishimura, K. C., McNeely, M. L., Lau, H. & Culos-Reed, S. N. The impact of physical
300 activity on health-related fitness and quality of life for patients with head and neck cancer: a systematic
301 review. *Br. J. Sports Med.* **50**, 325–338 (2016).
- 302 9. Rogers, S. N., Lowe, D. & Midgley, A. W. Patients' views of physical activity whilst living with and beyond
303 head and neck cancer. *Int. J. Oral Maxillofac. Surg.* **51**, 323–331 (2022).
- 304 10. Schmocker, M., Engst, R., Wirz, M. & Bana, M. Factors influencing physical activity in individuals with
305 head and neck cancer - a scoping review. *Submitt. Publ. BMJ Open* (2023).
- 306 11. Merriam Webster Dictionary. Definition of SIGNIFICANT OTHER. [https://www.merriam-](https://www.merriam-webster.com/dictionary/significant+other)
307 [webster.com/dictionary/significant+other](https://www.merriam-webster.com/dictionary/significant+other) (2024).
- 308 12. Gil, N. *et al.* The role of partner support for health behaviours in people living with and beyond cancer: A
309 QUALITATIVE STUDY. *Psychooncology.* **31**, (2022).
- 310 13. Michie, S., van Stralen, M. M. & West, R. The behaviour change wheel: a new method for characterising
311 and designing behaviour change interventions. *Implement. Sci.* **6**, 42 (2011).
- 312 14. ClinicalTrials.gov. <https://classic.clinicaltrials.gov/ct2/home>.
- 313 15. Colomer-Lahiguera, S. *et al.* A guide to patient and public involvement in cancer research. (2021).
- 314 16. Sandelowski, M. Whatever happened to qualitative description? *Res. Nurs. Health* **23**, 334–340 (2000).
- 315 17. Neergaard, M. A., Olesen, F., Andersen, R. S. & Sondergaard, J. Qualitative description - the poor
316 cousin of health research? *BMC Med. Res. Methodol.* **9**, 52 (2009).
- 317 18. Bradshaw, C., Atkinson, S. & Doody, O. Employing a Qualitative Description Approach in Health Care
318 Research. *Glob. Qual. Nurs. Res.* **4**, 2333393617742282 (2017).
- 319 19. Kitzinger, J. Focus group research: using group dynamics to explore perceptions, experiences and
320 understandings. (2005).
- 321 20. Guest, G., Bunce, A. & Johnson, L. How Many Interviews Are Enough?: An Experiment with Data
322 Saturation and Variability. *Field Methods* **18**, 59–82 (2006).
- 323 21. Duffy, S. A. *et al.* Health behaviors of head and neck cancer patients the first year after diagnosis. *Head*
324 *Neck* **30**, 93–102 (2008).
- 325 22. Guest, G., Namey, E. & McKenna, K. How Many Focus Groups Are Enough? Building an Evidence Base
326 for Nonprobability Sample Sizes. *Field Methods* **29**, 3–22 (2017).
- 327 23. Hennink, M. M., Kaiser, B. N. & Marconi, V. C. Code Saturation Versus Meaning Saturation: How Many
328 Interviews Are Enough? *Qual. Health Res.* **27**, 591–608 (2017).
- 329 24. Flick, U. *An Introduction to Qualitative Research*. (SAGE, 2018).
- 330 25. Denzin, N. K. & Lincoln, Y. S. *The SAGE Handbook of Qualitative Research*. (SAGE Publications, 2017).
- 331 26. Dröge, K. noScribe; <https://github.com/kaixxx/noScribe>. (2024).
- 332 27. MAXQDA - Die Software für Qualitative & Mixed-Methods-Forschung. *MAXQDA*
333 <https://www.maxqda.com/de/>.
- 334 28. Kuckartz, U. & Rädiker, S. *Qualitative content analysis: methods, practice and software*. (SAGE
335 Publications, 2023).
- 336 29. Tong, A., Sainsbury, P. & Craig, J. Consolidated criteria for reporting qualitative research (COREQ): a 3
337 2-item checklist for interviews and focus groups. *Int. J. Qual. Health Care J. Int. Soc. Qual. Health Care*
338 **19**, 349–357 (2007).

Appendix A:

The Behaviour Change Wheel by Michie et al.¹³



Appendix B:

Overview of the overall research project

