Call: HORIZON-HLTH-2022-STAYHLTH-02

Topic: HORIZON-HLTH-2022-STAYHLTH-02-01

Funding Scheme: HORIZON Research and Innovation Actions (RIA)

miGut-Health

Personalised blueprint of intestinal health

Deliverable No. 6.3

Predictive lifestyle factors

Grant Agreement no.: 101095470

Project Title: **miGut-Health**: Personalised blueprint of intestinal health

Contractual Submission Date: 31/12/2023

Actual Submission Date: 29/02/2024

Responsible partner: University Medical Centre Groningen (P4 - UMCG)

Funded by the European Union

Project funded by

Schweizerische Eidgenossenschaft
Confédération suisse
Confederazione Svizzera
Confederaziun svizra

Swiss Confederation

Federal Department of Economic Affairs, Education and Research EAER
State Secretariat for Education, Research and Innovation SERI

Grant agreement no.	101095470
Project full title	**miGut-Health:** Personalised blueprint of intestinal health

Deliverable number	**D6.3**
Deliverable title	**Predictive lifestyle factors**
Type[1]	R
Dissemination level[2]	PU
Work package number	6
Author(s)	G. Dijkstra, M.J.E. Campmans-Kuijpers, R.K. Weersma (all UMCG)
miGut-Health reviewers	Jurgita Skieceviciene (LSMU)
Keywords	e-health, IBD, health care, fatigue

Funded by the European Union and from the Swiss State Secretariat for Education, Research and Innovation (SERI) under contract No 22.00445. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Health and Digital Executive Agency (HaDEA).

Neither the European Union nor the granting authority can be held responsible for them.

[1] **Type**: Use one of the following codes (in consistence with the Description of the Action):
- R: Document, report (excluding the periodic and final reports)
- DEM: Demonstrator, pilot, prototype, plan designs
- DEC: Websites, patents filing, press & media actions, videos, etc.

[2] **Dissemination level**: Use one of the following codes (in consistence with the Description of the Action)
- PU: Public, fully open, e.g. web
- SEN: Sensitive, limited under conditions of the Grant Agreement

Table of Contents

Summary 3
1 Introduction 4
2 Description of Activities 4
3 Results & Discussion 4
4 Conclusion 5

Summary

E-health telemonitoring systems such as MyIBDCoach can be used to identify (modifiable) lifestyle and psychological factors as well as fatigue in inflammatory bowel diseases. This offers the opportunity for taking a holistic and patient-centred approach to treat IBD and IBD-related fatigue, targeting a broad range of physical- and psychological factors yielding a better understanding of factors that hinder or facilitate care seeking in IBD patients.

1 Introduction

Lifestyle and psychosocial factors impact mucosal inflammation and subjective well-being in Inflammatory Bowel Disease (IBD) patients. However, systematic lifestyle interventions do not fall under standard care. This study aimed to estimate the prevalence and to gather patient perspectives on lifestyle, psychosocial factors and fatigue in individuals with IBD supported by the e-Health system MyIBDCoach.

2 Description of Activities

A multicentre study was conducted, enrolling IBD patients who use the telemedicine platform MyIBDCoach to report on disease activity, lifestyle and psychosocial factors. In addition, a nationwide online survey, distributed via the Dutch patient organisation, gauged patient perspectives on these factors. In the UMCG cohort, we performed latent class growth analyses to identify distinct trajectories for fatigue in IBD patients. Finally, we conducted a qualitative study, taking a phenomenological methodological approach. Sixteen adult IBD patients recruited from the UMCG with disease in remission and severe fatigue (i.e., Checklist Individual Strength – subjective fatigue ≥ 35) were invited for semi-structured interviews. Data of this qualitative study were analyzed using template analyses.

3 Results & Discussion

Within the telemedicine MyIBD cohort (*n*=460), the results showed the following:

- 16.3% followed a specific diet,
- 67.4% did not meet the exercise norm,
- 9.3% actively smoked, and
- 7.6% consumed excessive amounts of alcohol.

About one-third experienced poor sleep at least regularly, emotional distress at least occasionally, and high perceived stress.

The nationwide survey (*n*=1126) revealed that most respondents (58-91%) believed that stress, unhealthy diet, poor sleep, physical inactivity, and anxiety or depression could cause intestinal symptoms. Around 70% were making changes or were motivated to change their diet, stress management, and physical activity. Only 6-19% of patients received hospital support and the majority were satisfied with it. Approximately 20% of patients desired, but lacked support concerning stress, physical activity, diet, and sleep.

In the UMCG cohort we found five trajectories for fatigue, showing individual variation in level and course over time, with a significant group (33%) characterized by chronic high levels of fatigue. Additionally, distinct trajectories were identified for physical activity, sleep problems and stress. The subgroup with chronic high fatigue levels was more likely to report patterns of persistent high levels of sleep problems and stress, and low levels of physical activity.

In the qualitative study we identified six main reasons to (not) seek care for fatigue:

1) cognitions about fatigue and coping,
2) perceptions of fatigue-related care and previous care experiences,
3) knowledge and behaviour of the healthcare provider,
4) somatic factors,

5) social factors and
6) practical factors.

Furthermore, we identified needs regarding how to offer care, i.e., taking a holistic approach, active and person-centered offer of care, with practical needs taken into account, as well as what kind of care to offer, i.e., information provision on fatigue management, eliminating physical causes for fatigue, discussing medication options, lifestyle support, psychological support, peer support and practical support.

4 Conclusion

There is considerable scope for improving lifestyle and psychosocial factors in IBD patients, emphasizing the necessity to systematically integrate these factors into everyday care. Patients widely recognize the impact of these factors, with most expressing openness to initiate changes across various aspects. These insights emphasize the potential for targeted interventions, particularly in areas where additional support is desired.

Furthermore, we show the existence of distinct paths of fatigue and lifestyle factors in IBD patients over time and the substantial role of chronic low levels of physical activity and high levels of sleep problems and stress in experiencing persistent high levels of fatigue. Targeting lifestyle factors may thus be important in the treatment of IBD-related fatigue.

Finally, our qualitative study indicates that IBD patients' perceptions, coping and knowledge, as well as healthcare professionals' behaviors play a major role in seeking fatigue-related care. Findings emphasize the importance of discussing IBD-related fatigue actively and taking a holistic and patient-centred approach to treat IBD-related fatigue, targeting a broad range of physical- and psychological factors. These findings yield a better understanding of factors that hinder and facilitate care seeking in fatigued IBD patients and hereby provide ways to optimize the uptake of care.

Concept papers of all three studies have been written and will be prepared for publication.