Decision regret and shared decision-making in patients undergoing hyperbaric oxygen therapy

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Abstract
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Introduction: Hyperbaric oxygen therapy (HBOT) is used for various medical conditions. HBOT is demanding and varies in effectiveness. This intensity combined with logistical challenges may lead to patients regretting undergoing HBOT. Therefore, shared decision-making (SDM) seems applicable when considering HBOT. The goal of this study was to assess the level of SDM as perceived by HBOT patients and relate this to post-hoc regret about choosing HBOT.
Methods: Patients referred for ≥ 10 sessions HBOT, were recruited for this prospective cohort study. Participants completed the SDM-Q-9 and SDM-K-Q questionnaires within one week of HBOT initiation. At least six weeks after HBOT completion or discontinuation participants completed the Decision Regret Scale (DRS) questionnaire. Multivariable linear regression analysis was applied to find factors influencing decision regret and SDM.
Results: Sixty-two patients (mean age 61.5 years; 36 female), primarily treated for radiation-related injuries, were included. Minor complications, including fatigue and temporary visual changes, were common. Mean SDM-Q-9 and SDM-K-Q scores were 61.9% and 72.1%, respectively. Among 54 patients completing the DRS, mean regret score was 13.4%. Lower regret correlated with symptom improvement (B = −16.56, $P = 0.036$) and more side effects (B = −6.81, $P = 0.014$). Males tended to report more regret (B = 8.26, $P = 0.081$), while age and SDM-Q-9 scores were not significant predictors. No factors significantly affected SDM-Q-9 scores.
Conclusions: HBOT patients reported limited involvement in decision-making and low levels of regret. Interestingly, minor complications were associated with less regret, suggesting complex dynamics in patient experience and treatment justification. These findings highlight the importance of individualised shared decision-making and patient education in the context of HBOT to ensure treatment choice aligns with patient values and expectations.

Introduction

Hyperbaric oxygen therapy (HBOT) is a medical treatment that has shown to be beneficial for a wide array of medical conditions, such as post-radiation injuries, sudden sensorineural hearing loss, and (ischaemic) diabetic foot ulcers.[1–7] While there is evidence regarding the effectiveness of HBOT for various (chronic) disorders, the therapy is intensive. It consists of daily treatment sessions, in which patients are confined to a pressurised chamber in which they breathe 100% for 1.5 to 2 hours. These sessions are repeated for four to eight weeks. Because HBOT-facilities are often not in the immediate proximity, there is also an additional travel burden. Given the demanding nature and logistical challenges of HBOT, as well as the sometimes poor health condition of the patient, not all have the endurance to complete the treatment. Additionally, temporary minor complications such as ear barotrauma, sinus discomfort, transient myopia, fatigue, and claustrophobia during HBOT-sessions can further hinder patients' ability or willingness to continue therapy.

Shared decision-making (SDM) is an increasingly important principle in healthcare, in which patients and healthcare providers work together to make informed decisions about treatment options in a collaborative approach. This leads

to improved treatment experience and patient-reported outcomes.[8–10] SDM may therefore be vital to manage patient expectations and to improve motivation for patients entering HBOT. Conversely, it may dissuade patients who may not be up to the challenge. While medical professionals are increasingly aware of the importance of SDM, patients may not always be aware of their right to be involved in this decision-making process or even what SDM entails.[11]

Some patients who have undergone HBOT may regret this decision afterwards, because it is a demanding treatment with possible (albeit temporary) side-effects, while its effectiveness is not guaranteed. Decision regret is a mostly negative emotional response following (healthcare) decisions. Decision regret analysis (DRA) helps identify areas where communication and decision support may need improvement, ultimately enhancing patient outcomes.[12] The theory of regret regulation proposes that regret can be experienced both retrospectively and prospectively and can arise from both actions and inactions.[13] The temporal nature of regret is particularly important, as the emotional impact of a decision may evolve over time. Initially, the regret following a choice, like the intense treatment of HBOT, may be acute. However, if positive outcomes, such as healing or recovery, become apparent over time, initial regret may diminish or transform into a sense of acceptance or even satisfaction. Therefore, DRA should be conducted only after an appropriate follow-up period and with a clear definition of the type of regret being investigated. DRA has already been applied in other medical areas,[14] confirming that collaborative and detailed discussion should take place to minimise regret when counselling patients regarding the treatment.

This study aimed to explore to what extent patients knew about, and perceived SDM when HBOT was decided, and the level of post-decision regret after having undergone HBOT for various medical indications. Furthermore, we studied factors influencing decision regret and SDM and the relation between the decision-making process and the patients' eventual regret with the choice for HBOT.

Methods

This prospective cohort study was conducted among patients undergoing HBOT to evaluate their knowledge about, and perceived level of SDM before treatment and the level of decision regret at least six weeks after treatment. The study was reported along the STROBE guidelines for observational studies.[15] The study protocol was approved by the Institutional Review Board of the Amsterdam University Medical Center (number 2023.0947).

PATIENTS

Patients were considered for recruitment while in their first week of HBOT, as provided by the Department of Hyperbaric Medicine of the Amsterdam University Medical Center between November 2023 and November 2024. To be eligible, participants had to be adults (18 years or older) and referred for at least ten sessions of HBOT to treat a chronic medical condition for which HBOT has been approved.[6] Patients were excluded if they had been treated with HBOT before, were undergoing pre-operative optimisation, or were being treated for an acute indication, such as crush injury. All participants provided written informed consent prior to entering the study.

STUDY CONDUCT

After enrolment, baseline characteristics of participants were extracted from their medical files by the research team. Participants were then asked to complete two questionnaires in Dutch: the Shared Decision-Making Knowledge Questionnaire (SDM-K-Q) (reproduced at *Appendix A), assessing their understanding of SDM principles, and the Shared Decision-Making Questionnaire (SDM-Q-9) (reproduced at *Appendix B), measuring their perceived level of involvement when facing the decision to undergo HBOT.[16,17]

At least six weeks after completing the HBOT, participants were contacted by phone to assess the level of decision regret by means of the Decision Regret Scale in Dutch (DRS) (reproduced at *Appendix C).[18] This time interval was chosen to allow any temporary side effects of HBOT to subside. Patients were given the option to either digitally receive the questionnaire to fill out at their leisure, or to go through the questionnaire on the phone with one of the researchers. Patients typically also received a consultation over the phone two months after cessation of HBOT from their treating physician. This instance was used to analyse improvement of complaints, side effects and complications from HBOT, as perceived by patients or caregivers. Data confidentiality and participant anonymity were strictly maintained throughout the study.

QUESTIONNAIRES

Three validated instruments were used to assess participants' knowledge and experiences related to shared decision-making, and level of decision regret regarding the choice for HBOT.

The SDM-K-Q measures participants' factual understanding of shared decision-making principles. It consists of 24 multiple-choice items addressing core concepts such

***Footnote:** Appendix A–C are available online on our website https://www.dhmjournal.com/index.php/journals?id=397

as patient involvement, communication, and weighing treatment options. Higher scores, expressed as a percentage of the maximum score, indicate greater knowledge of shared decision-making. In a validation study among healthy citizens a mean knowledge score of 73.8% was found.[11]

The nine-item SDM-Q-9 assesses participants' perception of their involvement in the decision-making process during their consultation.[16] Each item is rated on a six-point Likert scale ranging from zero ("*completely disagree*") to five ("*completely agree*"), yielding a total score between zero and 45. The total score is then converted into a percentage of the maximum score, with higher scores indicating a stronger perception of involvement in the decision-making process. In previous studies among various outpatient groups a mean SDM-Q-9 score of 80% was found.[18]

The Decision Regret Scale (DRS) evaluates participants' level of regret regarding their decision to undergo HBOT.[19] This tool includes five items rated on a five-point Likert scale, which are then transformed into a total score, ranging from zero (no regret) to 100 (highest level of regret). It captures feelings such as whether the decision was right and whether the participant would make the same choice again. In a systematic review of studies among individuals making non-hypothetical health decisions an overall mean regret score of 16.5 was found.[20]

DATA ANALYSIS

Collected data was encoded and securely stored in a password-protected electronic database using Castor Electronic Data Capturing system, version 2025.1.0.1 (Castor EDC, Amsterdam, The Netherlands), a validated platform for clinical data management. To ensure data integrity, all entries were independently verified for accuracy and completeness by two members of the research team.

Sample size was calculated to be 58 patients to obtain a precision (i.e., the 95% confidence interval [CI]) of ± 5% around the expected mean values of the questionnaire results, based on previous literature.[11,18,20] Taking into account a possible 10% loss to follow-up, a total of 65 patients were to be recruited.

Continuous variables were summarised as means with standard deviations or medians with interquartile ranges, depending on the distribution of the data.

Possible associations between key factors and DRS or SDM-Q-9 were analysed using multivariable linear regression modelling. Key factors, based on theoretical relevance and prior literature, included age, sex, SDM-Q-9 scores, occurrence of adverse events, and perceived benefits from therapy. Similarly, a multivariable regression was performed for SDM-Q-9, using age, sex and SDM-Q-K scores as possibly influencing factors. The proportion of variance in scores explained by the model was to be reported using the coefficient of determination (R^2).

All statistical analyses were conducted using SPSS version 28 (IBM Corp., Armonk, NY, USA), and statistical significance was set at $P < 0.05$.

Results

PARTICIPANT CHARACTERISTICS

Sixty-two patients were enrolled in the study between November 2023 and November 2024. The mean age of the participants was 61.5 years (range 39–81), comprising 36 females and 26 males. The majority of patients received HBOT for radiation-related injuries. Other patient and treatment characteristics are shown in Table 1.

A total of nine (14.5%) patients did not reach their predefined number of treatment sessions. Three patients discontinued HBOT because the desired therapeutic effect was reached sooner than anticipated. Two patients stopped treatment due to logistical or personal reasons and four patients due to other

Table 1
Participants' characteristics at baseline; DRS – Decision Regret Scale; F – female; HBOT – hyperbaric oxygen therapy; M – male; SD – standard deviation

Characteristic	Total (*n* = 62)
Age; mean (range), in years	61.5 (39–81)
Sex; M/F, *n* (%)	26/36 (41.9/58.1)
Indication, *n* (%) Radiation-related Osteomyelitis Diabetic wound Impaired wound healing Other	 53 (85.5) 3 (4.8) 2 (3.2) 1 (1.6) 3 (4.8)
Number of HBOT sessions; mean (SD), range	37.3 (8.7), 14–60
Time to DRS; mean (SD), in days	74.1 (30.3)

Table 2
Side-effects reported at follow-up; HBOT – hyperbaric oxygen therapy

HBOT side-effects	*n* (%)
None	12 (19.4)
Myopia	27 (43.5)
Fatigue	45 (72.6)
Other	2 (3.2)

Table 3
Questionnaire scores: DRS – Decision Regret Scale; SDM-K-Q – Shared Decision-Making Knowledge Questionnaire; SDM-Q-9 – Shared Decision-Making Questionnaire; SD – Standard Deviation

Questionnaire	*n*	Score % (SD)	Range	Reference score
SDM-Q-9 score	58	61.9 (24.9)	5–100	80.0 [18]
SDM-K-Q knowledge score	52	72.1 (15.5)	8.3–91.7	73.8 [11]
DRS score	54	13.4 (19.0)	0–95	16.5 [20]

Table 4
Multiple regression for Decision Regret Scale (DRS) scores; statistically significant effects in bold; CI – confidence interval; HBOT – hyperbaric oxygen therapy; SDM-Q-9 – Shared Decision-Making Questionnaire

Variable	B	SE	β	*P*	95% CI
Age (years)	0.332	0.229	0.188	0.153	-0.128 to 0.792
Sex (male)	8.264	4.636	0.234	0.081	-1.073 to 17.602
SDM-Q-9 score	0.086	0.081	0.138	0.296	-0.077 to 0.249
HBOT side-effects	-6.812	2.661	-0.330	**0.014**	-12.173 to -1.452
Improvement of complaints	-16.555	7.654	-0.281	**0.036**	-31.970 to -1.139

medical issues: diagnosed malignancy (n = 2), amputation of target limb (n = 1), or hospitalisation (n = 1).

SIDE-EFFECTS OF HBOT

At follow-up, 50 participants (80.6%) reported experiencing minor and reversible side effects from HBOT, including fatigue and temporary myopia (Table 2). During treatment, 13 patients experienced complaints unrelated to HBOT, seven of which were related to the disease for which they were referred to HBOT. Five other patients experienced flu-like symptoms, and one patient was admitted to the hospital with an unrelated infection.

SHARED DECISION-MAKING QUESTIONNAIRES

The SDM-K-Q was completed by 52 patients (84%), with a mean score of 72.1% (17.3 out of 24 answers correct; SD 15.5%; range 8.3–91.7%). The SDM-Q-K was not filled out by the initial ten participants due to logistical errors in the questionnaire availability.

The SDM-Q-9 questionnaire was completed by 61 patients (98%), yielding a mean score of 61.9% (SD 24.9%; range 5–100%). Three participants were excluded from the SDM analysis because they reported a score of zero. According to these participants, they had not discussed the therapy with their treating physician, but had requested themselves to be referred for HBOT.

DECISION REGRET SCORE

The DRS was completed by 54 patients (87%), yielding a mean regret score of 13.4 (SD 19.0). Participants completed the questionnaire after a median of 62 days (range 42–166).

REGRESSION ANALYSIS

Multivariable linear regression analysis (Table 4) showed that improvement of complaints was strongly associated with decision regret. Participants who reported improvement had, on average, a 16.6-point lower regret score (95% CI -31.97 to -1.14, P = 0.036). The presence of complications was also significantly associated with lower regret, with participants reporting 6.8 points lower regret scores per complication they experienced (B = -6.81, 95%CI -12.17 to -1.45, P = 0.014). Male participants tended to report higher regret scores than females, with an average increase of 8.26 points, although this did not reach statistical significance (95% CI -1.07 to 17.60, P = 0.081). No significant associations were observed between decision regret and age or SDM-Q-9 scores. This model explained 28% of the variance in decision regret (R^2 = 0.282).

In a separate regression model with the SDM-Q-9 score as the dependent variable, none of the factors (knowledge, age, sex) were significantly associated with perceived shared decision-making (P > 0.2 for all).

Discussion

This study investigated the role of decision regret and the level of SDM among patients with a chronic disorder for which they underwent HBOT, providing new insights into patient experiences and treatment satisfaction in this context. The majority of participants received HBOT for radiation-related conditions, mostly accompanied by temporary and minor side-effects, such as fatigue or myopia. Decision regret levels were slightly lower than reported in previous studies of similarly intensive interventions. A possible explanation for this limited level of regret may be that HBOT

is commonly considered as a last-resort treatment.[21] Patients are often referred for HBOT when other options have failed, which may cause patients to have less regret as they no longer have anything to lose and have no alternatives.

Perceived involvement in decision-making was lower than that reported in general populations, while the participants' knowledge about SDM was fairly good and similar to healthy populations.[11,18] Apparently, the participants were well aware their involvement in the decision-making process towards HBOT had been limited. Although decisional regret may hypothetically be more likely to occur when patients are less involved in the treatment decision, neither the perceived SDM nor the SDM knowledge was significantly associated with decision regret in the multivariable model. This is likely because decisional regret is a different construct than SDM and was measured sometime after completion of HBOT, while the level of SDM was gauged shortly after the start of the treatment. A measurement of decisional regret earlier during HBOT might have better reflected a relationship with the level of shared decision-making.

Unexpectedly, patients who experienced side-effects during HBOT reported less decision regret. One explanation may be that side-effects provide tangible evidence that 'something happened', reinforcing the perception that treatment was active. This paradox has been noted in surgical literature as well: regret is not consistently higher in patients who experience complications, particularly when outcomes are still satisfactory.[22] In this way, mild complications may act almost like a confirmation, reassuring patients of treatment activity and strengthening decision confidence.

The men participating in this study trended toward higher regret scores. Besides, participants who experienced relief of their complaints during the course of HBOT reported lower regret. These findings suggest that various personal and contextual factors play a role in shaping patient satisfaction in the HBOT setting.

STUDY LIMITATIONS

Potential limitations of this study include in the first place its single-centre design, in which the HBOT facility is accommodated within the hospital. This may limit the generalisability of the findings to broader patient populations or other HBOT settings. Multicentre studies often capture a more diverse range of clinical practices and patient demographics, potentially yielding results that are more widely applicable.

Second, the study relied heavily on self-reported measures, such as patient questionnaires assessing SDM knowledge, perceived involvement, and decision regret. Self-report data are inherently subject to response biases, including social desirability bias, recall bias, and differences in individual interpretation of questionnaire items, which may affect the accuracy and reliability of the findings.

Third, the response rate for the DRS and SDM-K-Q questionnaires was approximately 85%. The 15% who did not complete the questionnaires may have introduced attrition bias.

Fourth, if decisional regret had been recorded in more instances, changes could have been detected in regret during HBOT and possible correlations with other factors might have been found. Also the severity of disease of the participants was hardly taken into account, while only patients were included who were sufficiently able to comply. This could have influenced the level of regret, given the burden of HBOT, which would especially have affected those with a poor condition.

STUDY STRENGTHS

Despite these limitations, this study contributes valuable insights by systematically evaluating SDM and decision regret in patients undergoing HBOT. Understanding the patient experience in this context is crucial, as HBOT is a demanding treatment, both physically and mentally, often requiring daily commitment over several weeks. However, even this taxing treatment may be perceived differently, as the indications for HBOT cover a wide spectrum of patients, from relatively healthy, working-age individuals receiving HBOT after radiation therapy for oncology, to older patients with multiple comorbidities undergoing treatment for chronic wounds. By highlighting patient perspectives, the study identifies critical areas where patient-centred care can be improved through SDM, including enhancing communication, setting realistic expectations, and providing structured decision support. SDM is widely recommended as a method of care in modern healthcare.[23] However, this method is not practiced ubiquitously, neither in the clinical nor in the primary healthcare setting.[24] This is particularly true in the realm of hyperbaric medicine, where evidence remains scarce.[25]

Although our results did not show a direct association between perceived shared decision-making or SDM knowledge and decision regret, patient involvement remains an essential component of care. In HBOT, which often requires a long-term commitment, engaging patients in treatment decisions can help ensure that therapy aligns with their goals, preferences, and expectations. Structured decision-making tools and clearer communication strategies may still enhance patients' sense of support, potentially reducing regret and improving overall satisfaction and clinical outcomes.

Future research should focus on developing and evaluating targeted interventions, such as decision aids or structured

counselling protocols, to enhance SDM in the hyperbaric medicine setting. A different line of research that would be valuable to pursue would be evaluating and promoting SDM among the referring specialties to get a better sense of patients who decide to undergo HBOT versus those who do not, and to what extent SDM influences this decision.

Conclusions

This study found relatively low levels of decision regret among patients undergoing HBOT, while patients perceived moderate involvement in decision-making and showed to have generally adequate SDM knowledge. Neither SDM perception nor knowledge was directly associated with regret, whereas patient characteristics and complications appeared to play a more influential role. These findings highlight the complexity of patient experiences in HBOT and underscore the importance of tailored, patient-centred approaches, particularly given the heterogeneity of this population. Structured communication and decision support may help to further reduce regret and enhance satisfaction. Further research may be performed with larger, multi-centre cohorts to explore other potential determinants of decision regret in HBOT patients, as well as further research into the temporal alterations in decision regret during and after HBOT.

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