

Patient knowledge and experience of hyperbaric oxygen treatment

Louise MacInnes¹, Carol Baines¹, Alexandra Bishop², Karen Ford³

¹ Department of Diving and Hyperbaric Medicine, Royal Hobart Hospital, Hobart, Tasmania, Australia

² DDRC Healthcare, Hyperbaric Medical Centre, Plymouth, Devon, UK

³ Tasmanian Health Service South, Tasmania and University of Tasmania, Hobart, Tasmania, Australia

Corresponding author: Dr Carol Baines, Department of Diving and Hyperbaric Medicine, Royal Hobart Hospital, Tasmania 7000, Australia

carol.baines@ths.tas.gov.au

Key words

Communication; Panic; Patient monitoring; Questionnaire; Stress

Abstract

(MacInnes L, Baines C, Bishop A, Ford K. Patient knowledge and experience of hyperbaric oxygen treatment. *Diving and Hyperbaric Medicine*. 2021 March 31;51(1):72–77. doi: 10.28920/dhm51.1.72-77. PMID: 33761544.)

Introduction: This paper presents a quantitative and qualitative study exploring patients' knowledge and experience of hyperbaric oxygen treatment (HBOT).

Methods: Participants included 29 patients with appropriate indications who were undertaking HBOT at facilities in two different locations: Hobart, Australia, and Plymouth, United Kingdom. Participants completed surveys prior to commencing HBOT, after five sessions, and on completion of HBOT. Semi-structured one-to-one interviews were conducted with each individual on conclusion of their course. Data were analysed using descriptive statistics and interpretive description.

Results: Prior to referral, 15/29 (52%) of participants knew HBOT was used to treat divers, and of these, 9/15 (60%) were familiar with its use for non-divers. Only one third sought additional information about the process between referral for HBOT and attending their medical assessment. Anxiety was a pre-treatment concern amongst participants. However, when re-measured after five sessions and upon completion of the HBOT course, anxiety was reduced. The interview data revealed themes based around the physical, emotional and social aspects of HBOT: (1) anxiety within self; (2) naivety to normalisation; (3) enjoyment being a 'diver'; and (4) burdens of HBOT.

Conclusions: Many patients experienced anxiety prior to commencing HBOT but, with support, quickly adjusted to treatment, transitioning from a state of naivety to normalisation in their experience of the hyperbaric chamber. They enjoyed feeling like a 'diver' and considered aspects of the burdens of treatment, such as finances or logistics, a minor inconvenience. These results highlight the need for psychosocial support during treatment by identifying gaps in patient preparation for HBOT.

Introduction

Hyperbaric oxygen treatment (HBOT) is a systemic medical intervention in which the patient inhales 100% oxygen at greater than one atmosphere pressure within the confines of a purpose-built hyperbaric chamber.¹ HBOT is prescribed by specialist medical practitioners for a number of acute medical conditions, including decompression illness, and is also utilised as part of the medical management for patients with chronic conditions, such as hypoxic wounds, soft tissue radionecrosis or osteonecrosis.²

HBOT takes place in either a mono-place (single person) or multi-place chamber; the latter can seat multiple patients as well as a healthcare professional (often a registered nurse (RN) or a member of staff with specific medical skills).^{3,4} HBOT is usually administered daily, five days per week, with 30–40 consecutive treatments typically considered a full course of treatment for wound and radionecrosis indications. The multi-place chamber provides a unique situation in healthcare, with the inside attendant and the patient together sharing many components of the HBOT

experience, including being compressed to a prescribed increased ambient pressure.

Despite these shared features, understanding the patient's own experience of HBOT could inform improvements in patient-centred care and specifically patient's care needs when undergoing HBOT.⁵ A thorough exploration and understanding of the burdens, such as anxiety and ear pain, associated with HBOT as experienced by patients may help drive practice innovations.

The aims of this study were to explore individual patient knowledge of HBOT, identify the resources that improve patient knowledge, and to explore and compare patient experiences of HBOT. Also to assess how the treatment impacts the daily life of the patient. The study was conducted at two centres in two different countries.

Methods

This study was approved by the Tasmanian Human Research Ethics Committee (UTAS HREC No: H0016784) and

conducted in accordance with National Health and Medical Research Council (NHMRC) guidelines and relevant institutional governance procedures. Ethical approval was not required in the United Kingdom (UK) as the study was considered an evaluation of the service as confirmed with the Research and Development Department of the Plymouth facility.

SETTING

The Australian study setting was the Department of Diving and Hyperbaric Medicine at the Royal Hobart Hospital, a tertiary hospital in Hobart in the state of Tasmania. Data were collected from February to September 2018. HBOT was undertaken in a monoplace chamber or a cylindrical multiplace chamber.

The study setting in the UK was a private hyperbaric medical centre, the Diving Diseases Research Centre (DDRC Healthcare), Plymouth. Data were collected from February 2018 to April 2019. HBOT was delivered in a monoplace chamber or cylindrical multiplace chamber.

RESEARCH TEAM

Interviews were conducted by two RNs in Hobart and three in Plymouth, all with substantial clinical experience in the specialist field of hyperbaric and diving medicine and all of whom were involved in the direct care of the study participants. Reflexivity, through deliberate and open discussion between researchers, allowed for identification of preconceptions, and to distinguish between intuitive knowledge and new emerging knowledge from data analysis. Each research centre reviewed the data and identified codes and developing themes. The Hobart research team included an independent researcher who was not directly involved in patient care.

RECRUITMENT

Adult patients who were undertaking their first course of HBOT for either a chronic hypoxic wound, soft-tissue radiation injury or osteoradionecrosis were invited to participate. Patients who had previously received a course of HBOT and those who were due to commence HBOT > 4 weeks post-initial assessment were excluded. Similarly, patients receiving HBOT under a 'Marx Protocol' (prophylactic course of hyperbaric oxygen treatment undertaken prior and post-surgical/dental procedure) were excluded.

PROCEDURE

The same study methods, which combined quantitative and qualitative components, were employed at both the DDRC and the Royal Hobart Hospital. Data were obtained via surveys administered at three pre-set time points, and a semi-structured interview with each participant. The pre-set

time points were immediately prior to commencing their first HBOT, after the fifth HBOT and after their final HBOT.

The survey was paper/computer-based and consisted of multiple choice, Likert scale and open-ended questions, which all participants were invited to complete. The questions were designed to explore individual knowledge of HBOT, the experience of undertaking HBOT and the impact of HBOT on participant's lives. Descriptive data, including age and total number of HBOT treatments undertaken during this study, were also collated. The descriptive statistics utilised in this study were not designed to determine statistical significance but to summarise data and provide a richer context.⁶

The semi-structured, one-to-one interview (phone or face-to-face) took place at the completion of the course of HBOT. Each interview was audio-recorded, transcribed verbatim and analysed by two members of the research team.

The study was underpinned by the principles of interpretive description; a constructivist and naturalistic orientation to enquiry utilising inductive analytic approaches. This method allows researchers to illuminate the characteristics, patterns and structure of clinical phenomena in order to generate knowledge relevant for the clinical context.⁷⁻⁹ Thematic analysis was undertaken as described by Braun and Clarke.¹⁰

Each participant provided written consent, which was confirmed verbally at each interaction with the research team. Whilst no participants withdrew from the study, not all participants completed all four elements.

Results

Thirty-one patients were initially recruited, but two were excluded following consent as they did not go on to start HBOT within four weeks of assessment. Of the remaining 29 participants, 20 were based in Hobart (HBT) and nine in Plymouth (PLY). Hobart participants included 12 males

Table 1

Demographics of study participants. DW – diabetic wound; NDW – non-diabetic wound; ORN – osteoradionecrosis; RC – radiation cystitis; RP – radiation proctitis; STRN – soft tissue radiation necrosis

Characteristic	Hobart	Plymouth
Participants (<i>n</i>)	20	9
Sex (male / female)	12 / 8	6 / 3
Age range (years)	31–84	58–78
Mean HBOT sessions per participant	32	41
Reason for HBOT (<i>n</i>)	DW (12) RP (4) RC (4)	NDW (1) RP (2) ORN (5) STRN (1)

and eight females, with an age-range of 31 to 84 years. The average number of HBOT sessions per person was 32, and the predominate diagnosis was a hypoxic wound secondary to diabetes mellitus. The nine participants in Plymouth comprised six males and three females, with an age range of 58–78 years. The average number of HBOT sessions per person was 41, and the predominant diagnosis was osteoradionecrosis (Table 1).

SURVEY DATA

The survey questionnaires and interview results were combined in order to interpret responses as a whole. Duration of the interviews was between 4–21 minutes across both sites. Prior to referral for treatment, some participants (15/29, 52%) had some knowledge or awareness of HBOT. Of these, all knew it was used to treat divers, but some (9/15, 60%) were also aware that HBOT was used to treat other conditions such as wounds and radiation injury. Only two Hobart participants knew what either a multiplace or monoplace chamber looked like and none knew what a treatment course involved. A minority of participants (9/29, 31%) sought additional information about the process between referral and attending their medical assessment with eight (HBT = 3, PLY = 5) utilising the internet and eight (HBT = 4, PLY = 4) speaking to a health professional.

Participants had little difficulty dealing with the physical aspects of HBOT, with 18/29 (62%) finding it easy to equalise pressure in their ears. These findings remained consistent across five treatments and at completion of HBOT, across both sites. There were reports of tiredness/fatigue from five Hobart participants after completing five treatments of HBOT, and this increased to 10 participants at the completion of HBOT. Fatigue was not in Plymouth.

Of the Hobart participants, 12 indicated they had experienced changes in their vision, five had no concerns about their vision, and two expressed difficulty in dealing with these changes. Four participants from Plymouth reported visual changes that were ‘manageable’.

Data from both sites indicated the majority ($n = 20$) of participants considered that HBOT did not take up too much of their time or impair their ability to work or undertake social activities. Participants did not find it financially

difficult to attend HBOT as treatment was offered at no cost to patients at both sites and some support was available to assist with transport and accommodation through non-government organisations. Participants from both sites reported logistical considerations, such as travel and car parking which was arranged by participants, to be a self manageable burden.

IDENTIFICATION OF THEMES

Four key themes, outlined below, were identified. These were: anxiety within self; moving from naivety to normalisation; enjoying being a ‘diver’; and burdens of HBOT are a ‘minor inconvenience’.

Anxiety within self

Anxiety within the participant group was measured at three separate time-points using a five-point Likert scale. The same question was asked at the conclusion of HBOT, and results showed a reduction in participant anxiety after five treatments and throughout HBOT (Table 2).

Moving from naivety to normalisation

Participants had little overall knowledge of HBOT prior to treatment. However, they quickly moved from a naïve emotional response to a sense of normalisation and acclimatisation to the (previously) unfamiliar environment of HBOT.

Participants at both sites expressed initial anxiety. One had “*visions of tubes in the mouth*” (participant 16, Hobart) and another said, “*I thought they [the mono-place chambers] looked like coffins*” (participant 1, Plymouth). One participant explained: “*You’re closed in, you go into a pressurised environment. The first day I found it strange ... but after that, I didn’t find any impost on my body at all*” (participant 20, Hobart).

Some participants reported a quick reduction in anxiety after the initial treatment, with one explaining, “*I think at the beginning I was maybe a bit anxious, a bit worried, not knowing what to expect to happen. But then it went very smoothly... It felt like it was secure and safe ...so I was just anxious because it is new...you have to experience it to feel*

Table 2

Participant response to “*I feel anxious about going into the hyperbaric chamber*”. Data are number of patients responding per category.

* incomplete

Survey time	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Pre-treatment	7	3	10	5	4
Post five treatments	18	4	2	1	1
On completion*	19	5	0	1	2

Table 3

HBOT delivery method. Data are number of patients

Chamber type	Hobart	Plymouth
Monoplace only	3	0
Multiplace only wearing Amron Hood™	2	4
Treatment in both chambers	15	5
Total number of participants	20	9

better about it, I think" (participant 14, Hobart) and another reported, "As soon as I had done it once, [I found it] *quite relaxing*" (participant 16, Hobart).

Most participants experienced HBOT in both mono- and multiplace chambers (Table 3). A number of participants attributed their familiarisation with this new HBOT environment to interactions with the staff member inside the multiplace chamber on their first dive: "Having the first dive with somebody else – it gave me the ability to ask questions, have questions answered, not be at all concerned about, you know, ears popping and so on and so forth, it was great...she made me feel really comfortable" (participant 18, Hobart) and "having company in there made it okay" (participant 7, Plymouth).

For some, receiving treatment in a hyperbaric chamber of their choice was important. All but one ("I sort of enjoyed the interaction with the chamber assistants" (participant 11, Hobart)) of the participants who experienced both chamber types preferred the monoplace chambers. Lying in the monoplace chamber was described as "more comfortable" (participant 12, Hobart) and "far more civilised" (participant 5, Hobart). The movies in the monoplace were "a good distraction" and "made the time pass faster" (participant 9, Hobart). In Plymouth, patients could watch a film in the multiplace as well as the monoplace chambers, so this factor did not influence hyperbaric chamber choice. The Amron™ hoods (Amron, California, USA), which are the usual method used to administer oxygen in the multiplace chamber, were described as "annoying and uncomfortable" by several participants (participants 5, 7, 12, 14, 19, Hobart; participant 5, Plymouth).

Being in the "right mindset" was seen to be important (participant 6, Hobart). As explained by participant 8, Hobart: "You just had to tell yourself that it was alright", and, "I had to go in there and I knew I had to, so I just trusted myself and that's all there is" (participant 3, Hobart). This view was similarly expressed by others: "It's just a matter of convincing myself that it is doing me good" (participant 18, Hobart), and, "by reading a book the time seemed to pass more quickly" (participant 9, Plymouth).

By the completion of their course, 13/29 (45%) of participants described the experience of having HBOT as "normal" and many were dismissive of any specific physical or psychological experience associated with being in the hyperbaric chamber: "Whilst I'm inside the chamber itself, it feels normal" (participant 18, Hobart).

Enjoying being a 'diver'

The machinations of the hyperbaric chamber and unique social experience quickly led to participants assuming the identity of a 'diver'. This was evidenced by the participant's use of language and diving-specific jargon, both within the hyperbaric facilities and in the community with family and friends. Several participants spoke enthusiastically about sharing their experience with others: "They are all interested ... [and] seem to be very keen on knowing what it is all about" (participant 19, Hobart). "I talk to everyone about it...It's been a joke all along...in the sense: 'where are you going today?', 'You know where I'm going – diving!'" (participant 4, Hobart) "[They] think you are really diving, but you are not diving ...now I have a picture of me in it so I can actually show them what it is!" (participant 17, Hobart).

The delight in having photographs both of the hyperbaric chambers and participants themselves receiving treatment was a way of sharing "something you have never experienced in everyday life" (participant 17, Hobart) and involving family and friends in care. Recording the experience with photographs seemed more in keeping with an adventure or recreational activity than a medical procedure, which in turn contributed to the experience of hyperbaric oxygen treatment as enjoyable.

Interactions with healthcare professionals alleviated potential difficulties associated with HBOT. "It was pleasant... I come in every day, watch a movie, talk to [the technician] and everybody else, it's all good fun" (participant 6, Hobart) and "Support from all the staff, absolutely brilliant" (participant 5, Plymouth). The technicians (who operate the hyperbaric chambers) were particularly identified as creating a positive atmosphere: "They tease, particularly one... it makes the day" (participant 1, Hobart).

Burdens of HBOT are a 'minor inconvenience'

Participants described the logistical considerations and impact of attending a course of HBOT as burdensome. However, these difficulties were largely accepted in light of their positive outcomes: "I just considered it a minor inconvenience for the benefit" (participant 18, Hobart), and, "If it's going to prove successful I think that it is worth doing" (participant 3, Plymouth).

Others felt they were an encumbrance: "I did feel guilty that I had to rely on other people... I felt I was a bit of a burden and an imposition" (participant 7, Hobart). The strain on

relationships with family increased over time and was most evident in those who needed to relocate for the duration of HBOT away from their relational networks “[The] *only problem for me was that I’ve been away from home for eight weeks*” (participant 8, Plymouth).

Fatigue was another burden of a long treatment course. Responses to fatigue varied, however, with some participants finding it frustrating and others relishing the opportunity for additional naps or to improve their sleep pattern. Some acknowledged that fatigue was not just related to the treatment itself or the length of the course, but the cumulative effect of a long medical treatment journey, one component of which was HBOT.

Participants in Plymouth raised boredom as a factor that they needed to overcome and recommended to others to address this issue by “*bringing a book to read*” (participants 3 and 9). This was not noted by participants in Hobart.

Oxygen-induced myopia was a troubling medical side effect of their treatment. This impacted on participants’ everyday lives: “*The vision thing has been quite difficult to get used to [but it’s a] small price to pay*” (participant 18, Hobart). Another stated “*I hate it, I really hate it but what can you do? You have just got to put up with it*” (participant 19, Hobart). Two participants in Plymouth reported improvement in vision, “*So that’s a plus*” (participant 9).

Despite burdens, participants all wished to continue with treatment, “*There are the downsides and everything, but I mean, if it’s making me better, I’ve got no problems with it. I’ve just got to live with the other parts of it*” (participant 17, Hobart). Burdens were described as a “*small price to pay... benefits far outweigh the negatives*” (participant 18, Hobart). Advice for other patients attending for treatment included, “*Don’t worry about it, go for it*” (participant 5, Plymouth).

Although some participants were pleased to finish their course of treatment, levels of engagement remained high throughout their HBOT course, some expressing sentiments of loss upon completion, and many were willing to revisit HBOT in the future. The general feeling was: “*I’m glad I’ve done it and I wouldn’t hesitate to do it again if I had to*” (participant 8, Hobart).

Discussion

The range of feelings and emotions presented by participants across both study sites are similar to findings by Chalmers et al, who reported that “*treatment uncertainty can subsequently provoke feelings of anticipatory apprehension and anxiety based on fear of the unknown*”.¹¹ This phenomenon is recognised in interventions such as magnetic resonance imaging (MRI), but there is limited commentary concerning anxiety experienced by patients undertaking HBOT.^{12,13} Studies have shown that anxiety typically abates

following initial HBOT as treatment becomes familiar and is perceived as unproblematic.^{14,15} Our research showed that the experience of anxiety prior to initial HBOT was considerable. The unfamiliarity of the new treatment, having to trust a new and highly technical environment and a fear of the unknown could be impediments to commencing or continuing treatment. These issues must be sensitively but proactively addressed by clinicians, particularly at the beginning of the patient journey.

The sense of belonging created by technical and other staff appears to be instrumental in the development of the patient identity as a ‘diver’. Perhaps uniquely within healthcare, HBOT offers the opportunity to reframe identity given the culturally appealing connotations of diving and staff who may themselves be divers, and a willingness to confer membership of this social group to patients. Consistent with social identity theory and self-categorisation theory, this self-identification appears to move patients out of the traditional sick role and provides an alternative self-concept, with associated pride and self-esteem derived through belonging to and identifying with a social group utilising jargon and slang to cement membership, denote status and provide social capital.^{16,17}

Despite these positive connotations, HBOT remains a medical treatment requiring participation and adherence to regulations by patients. Studies indicate that patients with chronic conditions experience burden not only from their chronic disease but also from the impact and workload of treatment regimens, which in turn affects patients’ experience and links to their self-management strategies.^{18–23} This study shows that perceived burdens were not an impediment to participants initially engaging with treatment. Whilst the experience of burden somewhat changed over the duration of the HBOT, participants and their relational networks had sufficient capacity and resilience to enable them to maintain attendance.

Conclusions

This study has identified key components of the patient experience of HBOT. Whilst there has previously been little research to guide practitioners, this study suggests that opportunities for improved practice could focus on addressing the initial anxiety felt by participants, supporting them to transition from a state of naivety to normalisation within the hyperbaric chamber, celebrating the experience of being a HBOT ‘diver’ and acknowledging the willingness of patients to accept burdens as a minor inconvenience whilst supporting them to minimise any impact. This has the potential to improve the lived experience of patients undertaking this unique health care treatment.

Findings from two sites in different countries have highlighted many common experiences for patients. It is recommended that the patient experience of HBOT be further

explored at multiple geographical sites with varied chamber styles and include a wide range of patient cohorts.

References

- 1 Bennett M. An introduction to diving and hyperbaric medicine – how does it work and how do we do it? In: Riley R, editor. Australian anaesthesia 2007. Melbourne: Australian and New Zealand College of Anaesthetists; 2007 p. 41–53.
- 2 Moon RE, editor. Undersea and Hyperbaric Medical Society hyperbaric oxygen therapy indications (14th ed). North Palm Beach (FL): Best Publishing; 2019. [cited 2020 Jul 23]. Available from: <https://www.uhms.org/images/UHMS-Reference-Material.pdf>.
- 3 Jain KK. Textbook of Hyperbaric Medicine (eBook). Springer International Publishing; 2017. [cited 2020 Jan 17]. Available from: <http://doi.org/10.1007/978-3-319-47140-2>.
- 4 Baines C, Sykes P. Professional capability within the Australian hyperbaric nursing workforce. Aust J Adv Nurs. 2014;32:6–13.
- 5 Schmidt AL. Patients' perceptions of nursing care in the hospital setting. J Adv Nurs. 2003;44:393–9. doi: [10.1046/j.0309-2402.2003.02818.x](https://doi.org/10.1046/j.0309-2402.2003.02818.x). PMID: 14651711.
- 6 Given LM, editor. The Sage encyclopedia of qualitative research methods, Vol 2. Los Angeles (CA): Sage; 2008. [cited 2020 Jun 01]. Available from: <https://us.sagepub.com/en-us/nam/the-sage-encyclopedia-of-qualitative-research-methods/book229805>.
- 7 Hunt MR. Strengths and challenges in the use of interpretive description: Reflections arising from a study of the moral experience of health professionals in humanitarian work. Qual Health Res. 2009;19:1284–92. doi: [10.1177/1049732309344612](https://doi.org/10.1177/1049732309344612). PMID: 19690208.
- 8 Thorne S, Kirkham SR, O'Flynn-Magee K. The analytic challenge in interpretive description. Int J Qual Methods. 2004;3:1–11. doi: [10.1177/160940690400300101](https://doi.org/10.1177/160940690400300101).
- 9 Barbour RS. Checklists for improving rigour in qualitative research: A case of the tail wagging the dog? BMJ. 2001;322:1115–7. doi: [10.1136/bmj.322.7294.1115](https://doi.org/10.1136/bmj.322.7294.1115). PMID: 11337448. PMCID: PMC1120242.
- 10 Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psych. 2006;3:77–101. doi: [10.1191/1478088706qp063oa](https://doi.org/10.1191/1478088706qp063oa).
- 11 Chalmers A, Mitchell C, Rosenthal M, Elliott D. An exploration of patients' memories and experiences of hyperbaric oxygen therapy in a multiplace chamber. J Clin Nurs. 2007;16:1454–9. doi: [10.1111/j.1365-2702.2006.01700.x](https://doi.org/10.1111/j.1365-2702.2006.01700.x). PMID: 17655533.
- 12 Chapman HA, Bernier D, Rusak B. MRI-related anxiety levels change within and between repeated scanning sessions. Psychiatry Res Neuroimaging. 2010;182:160–4. doi: [10.1016/j.psychres.2010.01.005](https://doi.org/10.1016/j.psychres.2010.01.005). PMID: 20409694.
- 13 Clark C, Rock D, Tackett K. Assessment of the magnitude of the anxiety of adults undergoing treatment in a hyperbaric chamber. Mil Med. 1994;159:412–15. doi: [10.1093/milmed/159.5.412](https://doi.org/10.1093/milmed/159.5.412). PMID: 14620414.
- 14 Hjeltn K, Löndahl M, Katzman P, Apelqvist J. Diabetic persons with foot ulcers and their perceptions of hyperbaric oxygen chamber therapy. J Clin Nurs. 2009;18:1975–85. doi: [10.1111/j.1365-2702.2008.02769.x](https://doi.org/10.1111/j.1365-2702.2008.02769.x). PMID: 19638057.
- 15 Lee A, Former L, Jansen EC. Patient's perspective on hyperbaric oxygen treat of osteoradionecrosis. Int J Technol Assess Health Care. 2014;30:188–93. doi: [10.1017/S0266462314000038](https://doi.org/10.1017/S0266462314000038). PMID: 24805932.
- 16 Hornsby M. Social identity theory and self categorization theory: A historical review. Soc Personal Psychol. 2008;2:204–22. doi: [10.1111/j.1751-9004.2007.00066.x](https://doi.org/10.1111/j.1751-9004.2007.00066.x).
- 17 Portes A, Landolt P. Social capital: Promise and pitfalls of its role in development. J Lat Am Stud. 2000;32:529–47. doi: [10.1017/S0022216x00005836](https://doi.org/10.1017/S0022216x00005836).
- 18 Haynes RB, McDonald HP, Garg AX. Helping patients follow prescribed treatment: Clinical applications. JAMA. 2002;288:2880–83. doi: [10.1001/jama.288.22.2880](https://doi.org/10.1001/jama.288.22.2880). PMID: 12472330.
- 19 Demain S, Goncalves A-C, Areia C, Oliveira R, Marcos J, Marques A, et al. Living with, managing and minimising treatment burden in long term conditions: A systematic review of qualitative research. PLoS One. 2015;10:e0125457. doi: [10.1371/journal.pone.0125457](https://doi.org/10.1371/journal.pone.0125457). PMID: 26024379. PMCID: PMC4449201.
- 20 Eton DT, de Oliveira DR, Egginton JS, Ridgeway JL, Odell L, May CR, et al. Building a measurement framework of burden of treatment in complex patients with chronic conditions: A qualitative study. Patient Relat Outcome Meas. 2012;3:39–49. doi: [10.2147/PROM.S34681](https://doi.org/10.2147/PROM.S34681). PMID: 23185121. PMCID: PMC3506008.
- 21 May C, Sibley A, Hunt K. The nursing work of hospital-based clinical practice guideline implementation: An explanatory systematic review using normalisation process theory. Int J Nurs Stud. 2014;51:289–99. doi: [10.1016/j.ijnurstu.2013.06.019](https://doi.org/10.1016/j.ijnurstu.2013.06.019). PMID: 23910398.
- 22 Shippee ND, Shah ND, May CR, Mair FS, Montori VM. Cumulative complexity: A functional, patient-centred model of patient complexity can improve research and practice. J Clin Epidemiol. 2012;65:1041–51. doi: [10.1016/j.jclinepi.2012.05.005](https://doi.org/10.1016/j.jclinepi.2012.05.005). PMID: 22910536.
- 23 Gallacher K, May CR, Montori VM, Mair FS. Understanding patients' experiences of treatment burden in chronic heart failure using normalization process theory. Ann Fam Med. 2011;9:235–43. doi: [10.1370/afm.1249](https://doi.org/10.1370/afm.1249). PMID: 21555751. PMCID: PMC3090432.

Acknowledgements

Thanks to Marguerite St Ledger-Dowse who worked closely with the research team to test and refine the questionnaire.

Conflicts of interest and funding: nil

Submitted: 12 June 2020

Accepted after revision: 15 January 2021

Copyright: This article is the copyright of the authors who grant *Diving and Hyperbaric Medicine* a non-exclusive licence to publish the article in electronic and other forms.