Chloe Amanda Ryder

Professional Doctorate in Health Psychology

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Table of Contents

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Portfolio Abstract

Chloe Amanda Ryder

Professional Doctorate in Health Psychology, 2025

The portfolio includes all work which I have completed whilst undertaking the Professional Doctorate in Health Psychology at the University of Staffordshire between 2021-2025. The work was conducted within my three placements where I worked as Care Team Leader at a care home in the East Midlands, Associate Lecturer in Psychology at a university in the West Midlands and Lecturer in Psychology of Physical Activity and Health Promotion at a university in South-East England. I have also undertaken additional opportunities external to placement to fulfil all requirements of the Doctorate.

The portfolio is divided into six chapters:

1. Professional Skills in Health Psychology
2. Systematic Review
3. Research: From Design to Dissemination
4. Teaching and Training in Health Psychology
5. Consultancy in Health Psychology
6. Health Psychology Interventions

Within each chapter, I present the evidence of my development throughout the Professional Doctorate in the form of research manuscripts, case studies, and reflective commentaries. These evidence the work which I have completed, as well as experiences and skills which I have developed. The content of each chapter is outlined within the introduction.

Introduction

Within this portfolio, I present work which I have conducted whilst completing the Professional Doctorate in Health Psychology at University of Staffordshire (previously Staffordshire University) between 2021-2025. I had three placements during the Doctorate. In the first year and a half of the Doctorate, I was employed as Care Team Leader at a care home in the East Midlands. During this placement, I was responsible for coordinating a 12.5-hour care shift, up to four times per week to ensure safe, personalised, and efficient care for residents living in the home who were living with Dementia, other health conditions, and complex needs. Within year two of my Doctorate, I was employed as Associate Lecturer in Psychology at a university in the West Midlands. Within this role, I was responsible for supervising level six (final year) student research projects, coordinating a long-term conditions module, and delivering sessions to students ranging from first year to MSc level. In year three to halfway into the fourth year of my Doctorate, I was employed as full-time Lecturer in Psychology of Physical Activity and Health Promotion at a university in South-East England. During my role within the placement, I was responsible for re-writing and coordinating modules for level 6 and MSc, as well as supervising final year research projects, developing research ideas, and was personal academic tutor supporting students with wellbeing needs outside of their education. I am currently employed as a Research Fellow in Quantitative and Mixed-methods research at the Health Determinants Research Collaboration (HDRC), sitting within the Public Health team in a local authority setting.

I have completed six core competencies in Health Psychology across different works areas within my placements throughout the Doctorate.

Chapter 1: Professional Skills in Health Psychology

The first chapter of my portfolio focuses on the professional skills in Health Psychology. Within this chapter, I present a reflexive report of the professional competence and skills which I have developed through the Doctorate. I kept a reflexive diary throughout my Professional Doctorate, extracts of which are supporting the reflexive report.

Chapter 2: Research: From Design to Dissemination

Within chapter two, I present my quantitative research project which investigated influential factors for nutritional intake and food choice motivations for individuals living with Ehlers-Danlos Syndrome. This piece of research is also accompanied by a reflective commentary which includes my experiences of conducting this research, opportunities for dissemination, and rationale for decisions made throughout the research.

Chapter 3: Systematic review

Chapter three presents my systematic review which explored the comparison of quality of life for individuals living with Ehlers-Danlos Syndrome, and Mast Cell Activation Syndrome. A reflective commentary is also presented within this chapter which outlines my experiences of completing this systematic review.

Chapter 4: Teaching and Training in Health Psychology

Chapter four includes a case study and evaluation of five teaching sessions which I developed and delivered which had the overall theme of ‘Long-term Conditions’. These five teaching sessions consisted of two in-person large group sessions to Level 6 undergraduate students from University of Worcester, and University of Staffordshire (formerly Staffordshire University), and three remote teaching sessions to healthcare professionals including registered nurses and healthcare workers surrounding a Health Psychology perspective on Dementia. The case study includes processes surrounding assessment of training needs, teaching structure and content, resources, materials and methods, assessment of learning outcomes. The evaluation describes sources of feedback which I obtained during my teaching sessions highlighting areas of strength, areas of development, and a self-reflection.

Chapter 5: Consultancy in Health Psychology

The fifth chapter of my portfolio includes the consultancy case study, outlining a piece of work which I completed for Social-Ability. For this consultancy work, I wrote a 3000-word report, mapping the Clients technological intervention with Health Psychology theory and techniques, to help demonstrate reasons for effectiveness. The case study outlines the processes which I completed including assessing the request for consultancy, planning and negotiating the work and contract, establishing and maintaining working relationships with the Client, conducting the consultancy, and evaluating the impact. This chapter also includes the contract which I developed as part of this consultancy process.

Chapter 6: Health Psychology Interventions

The final chapter of my portfolio includes two Health Psychology interventions. The first is a one-to-one and face-to-face intervention, and the second is a group intervention which was delivered remotely via online methods. For my one-to-one intervention, I worked with a Client living with OCD to improve nutritional intake. For the group intervention, I worked with five Clients living with Ehlers-Danlos Syndrome to improve stress management. The two interventions are detailed through case studies during which assessment, formulation, delivery and evaluation are discussed. Both case studies are also complemented with a reflective commentary which includes my rationale for decisions and experience of facilitating both interventions.

Table of completion

Module	**Completion**
Professional Skills in Health Psychology	June 2025
Research from Design to Dissemination	January 2025
Systematic Review	June 2024
Teaching & Training in Health Psychology	June 2021
Consultancy in Health Psychology	January 2024
Health Psychology Interventions	June 2025

Chapter 1: Professional Skills in Health Psychology

1.1 Reflexive Report

Background

The following reflexive report summarises my personal and professional development whilst completing the Professional Doctorate in Health Psychology. The report reflects on placements which I have completed throughout the Doctorate and work submitted for competencies from September 2021 until June 2025. Section one explores my work completed for the core competencies required to become a qualified Health Psychologist. Section two discusses the required professional skills outlined by the British Psychological Society (2021) and Health and Care Professions Council (2023).

It is essential that Health Psychologists are reflective practitioners (Thompson & Thompson 2023), ensuring that all key events are reflected upon through exploring the aspects which went well, as well as elements for improvement. Throughout my Professional Doctorate, I kept a reflective diary, using Gibbs' cycle (Gibbs, 1988). Prior to starting the Doctorate I struggled with reflections, however using Gibbs' Cycle consistently throughout my training has enabled me to focus on positive and negative events and develop a clear action plan of what I need to do in future situations.

Placement Overview

Throughout the Professional Doctorate, I have completed three placements. My first placement was in a job role I was already working in prior to commencing the Doctorate; I was a Dementia Care Team Leader in a care home in the East Midlands. My role involved being in charge and responsible for co-ordinating the care shift and ensuring that residents had the best possible care. I was responsible for communicating with multiple healthcare professionals including registered nurses, paramedics and mental health rapid response team practitioners. I received medication training and on some shifts was responsible for dispensing medication to all residents. I left this placement in January 2023 after securing full-time hours as Associate Lecturer in Psychology.

I started my second placement in September 2022, as an Associate Lecturer in Psychology at a university in the West Midlands. Initially this was part-time with my Dementia Care Team Leader role, however I moved to full time in January 2023. As Associate Lecturer I had mainly teaching responsibilities, developing lectures, seminars and workshops for levels 4 to 7. I also supervised level 6 students research projects which covered a range of topics from health, forensic, and cognitive psychology. This placement was completed in July 2023 due to uncertainty in hours for associate lecturers in the next academic year.

My third placement was at a university in South-East England, where I was a full-time lecturer in Psychology of Physical Activity and Health Promotion in the School of Sport, Health and Exercise Science. Within this role I developed significantly, both personally and professionally, with confidence in my abilities and skills increasing due to being given many opportunities to grow in a very supportive environment. Within my role, I was module coordinator for a level four module and was responsible for developing and re-writing two further modules to ensure they were in line with two accrediting bodies – the British Psychological Society (BPS), and the Clinical Exercise Physiology (CEP) accreditation panel. I completed this placement in December 2024 due to being unable to relocate nearer to work and the commute long-term was not feasible.

I am currently a Research Fellow in Quantitative and Mixed-Methods in the Health Determinants Research Collaboration Team (HDRC) within the public health department in a Local Authority Setting. I am responsible for designing quantitative and mixed-methods evaluations for teams within the council, collaborating with academics from partnering universities on research bid applications, delivering training to help improve the research culture in the council, and in charge of the HDRC pillar one work which explores data management and governance. This role is currently fixed term until June 2026.

Section One: Core Competencies

Teaching and Training in Health Psychology

Prior to this competency and commencing the Professional Doctorate, I had no previous experience of delivering teaching sessions, meaning I was anxious about this competency. The overarching theme for the teaching sessions that I designed and delivered was ‘Long-term conditions’, with three sessions exploring Dementia from a Health Psychology perspective for healthcare professionals, and two sessions exploring illness management interventions and the psychophysiological link between stress and the onset of health conditions. The healthcare professional sessions were delivered within my first placement, but challenges and little support meant all sessions had to be delivered in one day, remotely. Although different to how I had originally planned, the sessions went well and delivering sessions remotely was a new experience to reflect on, compared to my large group teaching sessions which were both delivered in-person. Remote sessions allowed for me to navigate technical barriers including facilitating group discussions online and using online tools such as Mentimeter for capturing key discussions.

The two large group teaching sessions were delivered at University of Worcester and University of Staffordshire on Level 6 Health Psychology modules. Prior to the first large group session I was nervous, due to finding it challenging to speak in large group environments. Overall, I enjoyed the session and received positive student and observation feedback which helped to increase my confidence. Prior to the second large group session I was less nervous following my first session feedback. However, I found this session challenging at points due to the student group being quieter in discussions, meaning the session finished ahead of time. I reflected that my limited experience of teaching showed more in this session due to not being able to facilitate further student discussion or knowing how to extend the session post originally planned. Following this session, I had supervision and reflected on the session, devising an action plan for future sessions to prepare additional tasks for sessions which finish early to aid further group discussions.

Within my third placement I was the only member in the school with a Health Psychology background, with colleagues predominantly being from a sport and exercise science or sport and exercise psychology (SEP) background. This made me apprehensive as to how I would fit into the team and deliver the curriculum, knowing that I was not overly familiar with SEP content either. Apprehension eased as I was able to integrate general psychology knowledge, research methods skills, and health psychology through a health promotion lens within teaching content. I was given the opportunity to re-write a Level 7 MSc module to meet BPS and CEP accreditation requirements. This opportunity faced challenges and provided learning opportunities due to being unfamiliar with the CEP accreditation requirements and course content. The rewrite of the module went successfully, receiving accreditation from both boards. Following this I was assigned module coordinator; I felt proud of this opportunity to see the work of the re-write come together, produce and deliver all sessions on the module.

This allowed me to get a good rapport with students, set expectations and provide as much student support as possible.

I have enjoyed lecturing and working in academia and feel proud of the achievements which I have completed. Although currently in a research fellow role, I aim to work in academia in the future. I know when I re-enter a lectureship role, I need to consciously manage my work-life balance, as I feel this was something I struggled with, feeling the pressure to continuously prove myself as a young lecturer whilst completing my professional doctorate.

Consultancy

Prior to beginning the doctorate, I had no experience in consultancy. The opportunity for the competency came within my first placement following the Client providing a demonstration of their intervention for the residents. Within initial meetings, I explained my role as a Trainee Health Psychologist and explored the work which the Client was wanting as part of this consultancy. The Client identified a piece of qualitative research exploring carers experiences of using their technological intervention, which initially made me nervous due being inexperienced in qualitative research. Through supervision and support from doctorate peers who were more familiar with qualitative research, I approached this opportunity positively, designing the study, securing ethical approval and being in a position for participant recruitment quite quickly. This was my first experience of working with a Client for consultancy, meaning I wanted to ensure that I worked in a positive manner and developed a strong working relationship with the Client which is essential for a successful consultancy process (Earl & Bath, 2004).

The positive working relationship proved essential when it was clear that due to ethics, I was not able to recruit participants independently. After 4-months of recruitment, I was unable to recruit enough participants meaning a new deliverable had to be negotiated. Through active listening skills (Weger et al, 2014) and in-action reflection (Schön, 1983), I provided three new deliverable options, allowing the Client to choose the deliverable best suiting their needs. The new deliverable was a 3000-word report underpinning their intervention with Health Psychology theories, and techniques. The final report was sent to the Client, and they have since shared with organisations including the Alzheimer's Society, which was something I was not expecting when first writing the report, but it was amazing to see the positive impact it was having.

I received positive feedback from the Client who were happy with the working process and deliverable. For future consultancy opportunities, I know the importance of flexible working with the Client and negotiation skills for if a new deliverable needs to be decided. I will ensure that I have a positive working relationship with the Client, keeping communication transparent, open and recommend a clear deadline for future Consultancy opportunities which will help to keep the work focussed and ensure that any challenges are not continued for longer than necessary.

Systematic Reviewing

Prior to completing this competency, I had experience of completing three reviews during my undergraduate and master's degrees, and I knew that systematic reviews were something which I enjoyed completing. I completed my systematic review in my second placement with my workplace contact who was happy for me to choose the topic, lead the review, provide support and act as a second reviewer. I felt positive for this review, however found it quite challenging to initially find a topic.

I had not registered a review using PROSPERO, meaning I had to learn the requirements for this. Following choosing a topic and the review registered on PROSPERO, far more results were produced (with most being irrelevant) when searching data bases, making me question whether it was my search terms affecting results. I sought advice from my placement academic librarian who helped structure my search terms efficiently, providing a successful search. When working with my workplace contact to complete the review, we had challenges when using Mendeley with files not being accepted by my laptop. We reviewed articles independently in all stages following the PRISMA diagram, and when needing to input files into each new folder, we would have a meeting to ensure articles were identical. For reviews completed in my current job role since, I have used different software (Rayyan) which allows for a more efficient collaborative process when screening articles.

I hoped I would be able to have a first experience of completing a meta-analysis for this review, however this was not possible due to high levels of heterogeneity. Out of 16 included articles, there were 15 articles which explored Ehlers-Danlos Syndrome (EDS), and only one which explored Mast Cell Activation Syndrome which made comparisons and the results section challenging to draft. On initial draft feedback, I received constructive feedback surrounding my results section, identifying that it was not suitable, reducing my confidence in the review. Working with the competency lead, my supervisor, and my workplace contact, I was able to re-draft and ensure the results section was stronger.

Since completing the review, I have presented the findings at the BPS ‘Celebrating Psychology in the Midlands’ conference in September 2024. This was my first experience of a conference outside of the Professional Doctorate, which I was nervous for but also excited to be able to have the opportunity to share my review. I have also prepared this review for publication, which initially was challenging to find a journal which suited the topic of my review. Once I found a journal which my review was suitable for, I updated the searches and currently in the process of preparing the review for publication.

Research: From Design to Dissemination

For my quantitative empirical study, I combined my interest of EDS, nutrition and the information learnt from my systematic review about factors influencing quality of life for individuals living with EDS. The study provided development opportunities including experiencing a new ethics process at my third placement, which included a peer review, and the need to use a patient and public involvement and engagement (PPIE) panel to receive feedback on my participant information sheet and consent form. Although nervous to engage with a PPIE panel it gave me an opportunity to share my study, ensuring suitability and accessibility (Lammons et al, 2024). Since passing the competency, I have prepared my study for the British Journal of Health Psychology, seeking supervision to refine the number of hypotheses and overall results section. On reflection, I attempted to focus on too much within my study, and for the mediation and moderation hypotheses, there was not a clear rationale, weakening the overall quality. This experience has helped me know to focus on a more specific topic for future research and the positive impact this will have on quality.

Within my job as Research Fellow in Quantitative and Mixed-Methods, I am continuously developing my skills as a researcher. I have been working on three research bids to different funders including National Institute for Health and care Research (NIHR), UK Research and Innovation and the National Lottery Communities Fund. All funders have different requirements for co-applicants, and my role within each bid has varied meaning I have adapted my skills and collaborated with many academics. Once qualified as a Health Psychologist, I aim to be research active, continuing to research in the field of EDS. My work role has allowed for me to see the full importance of mixed-methods research, and the importance of qualitative research to explore individuals' experiences. Therefore, my future research will ensure representation of individuals experiences whilst offering practical implications for individuals living with EDS.

Health Psychology Interventions

This was the competency that at the beginning of my doctorate journey, that I was the most apprehensive about due to having no experience and having negative experiences of working in a care environment previously. I began with the non-face-to-face intervention and delivered a group intervention over six weeks with five individuals all living with hypermobile EDS, wanting to reduce their stress levels. This intervention went well, with most participants showing a reduction in stress from baseline to post-intervention. Although a successful intervention for participants, I felt that as a practitioner and Health Psychologist that I delivered this intervention in a 'safe' format, using psychoeducation and workshops which I was familiar with running as a lecturer. Although I reflected that this was being 'safe' in my delivery, it was what the participants needed; I received positive feedback that they enjoyed learning more about EDS and stress management techniques. I think this difference highlighted my tendency to be too self-critical and underestimate my abilities which is something which I continuously find challenging. For future intervention work, reflection and clinical supervision will be essential to ensure that I am not overly self-critical and allow for my confidence to grow.

The individual and face-to-face intervention was the competency which challenged me the most. The client was initially motivated to improve her physical activity levels; however, from the first session I found it difficult to maintain open communication with the participant despite building rapport and asking open questions. Sessions that were completed before the participant withdrew were all shorter in duration than originally planned, lasting only 30 minutes. The Client was difficult to engage with, cancelling sessions last minute or wanting sessions to be online rather than in person which was not possible for this intervention. Initially reflecting, I felt that the unsuccessful nature of the intervention was my fault due to my inexperience. However, after seeking supervision and peer support, I began to understand that although I may be inexperienced, the difficulties encountered were not entirely in my control. I knew that I wanted to try and change my mind set for this competency, so I found a new 1-1 opportunity, with a Client wanting to improve her diet quality.

This second 1-1 intervention opportunity was a lot more successful; the participant was highly motivated which helped with intervention delivery. I was nervous for this intervention and had low self-confidence from the first opportunity. However, I took reflections from the first intervention and prepared conversation prompts, additional resources and tasks which could be completed in session if the Client was difficult to engage with. This second provided opportunity to develop my skills as an intervention facilitator and learn from my first experience. For future individual interventions I will ensure to prepare resources and tasks to use if the Client is struggling with open conversation during sessions.

Professional Skills

In line with the BPS (2021) and HCPC (2023), I have developed many professional skills throughout the professional doctorate. Throughout the doctorate, I completed self-reflection using Gibbs' Reflective Cycle (Gibbs, 1988) weekly reflective diary. Initially, I found completing the reflective diary quite challenging, with being more inclined to focus on any negative events or challenges which made the reflective diary hard for me to engage with. However, throughout the doctorate, I reflected more positively and saw that my self-confidence throughout the doctorate increased. I found monthly and annual reports easier to reflect on my progress throughout the doctorate and competencies due to being more structured. Monthly and annual reports along with workplace contact forms were also a good opportunity for me to receive feedback from my supervisor and workplace contacts throughout the doctorate on my development.

Section two: General Professional Competencies

Systems for legal, ethical, and professional standards in Health Psychology

As a Trainee Health Psychologist, it is essential that I uphold both ethical and legal standards which are highlighted by the BPS (2021) and HCPC (2023). Within placement one, as a Team leader, I was required to follow legal, ethical, and professional laws and regulations including safeguarding (Care Quality Commission, 2022), the Health and Social Care Act (2008), and General Data Protection Regulation (Information Commissioners Office, 2025). It was essential that laws are upheld within the care setting to ensure safeguarding of residents. As team leader, I was responsible for medication rounds, working collaboratively with the registered nurse and was responsible for controlled medication and dispensing all daily medication for residents. This provided opportunities to learn clinical skills, medication policies including covert medication legislation, and importance of detailed care planning from registered nurses.

Within placements two and three as lecturer, it was essential to adhere to legal, ethical, and professional standards within academia to encourage reflective, evaluative and evidence-informed approaches to higher education (Advance HE, 2023). As an early-career academic and researcher, it was essential that I learnt and fostered the professional standards as presented in the Professional Standards Framework (Advance HE, 2023). I experienced the importance of General Data Protection Regulation (GDPR) in relation to completing accurate student records surrounding wellbeing concerns, student engagement, research project supervision and 1-1 student tutorials. In my second placement, I guided students through the research ethics process and had responsibility for assessing research ethics applications. I was familiar with the research ethics processes and guidelines as outlined by the BPS code of human research ethics (BPS, 2021b), meaning I felt confident with this role due to understanding ethics and requirements from my own research.

On reflection, as an associate lecturer, my recording keeping was not as concise compared to when I was full-time lecturer. In my third placement, I was personal academic tutor, module coordinator with a large team, and project supervisor which had a stricter ethics process, therefore recording keeping was crucial to be up-to-date and clear. I have maintained diligent record keeping moving into my current role as research fellow where I am currently drafting a data catalogue, which will be the place for colleagues to go for accessible data. This data catalogue emphasises the importance of differences between accessible and available data, the research governance process, and importance of ethics in research and data sharing.

Health Psychology advice and guidance to others

As part of the professional doctorate, I have also been involved in the buddy system, offering support for trainees who are in the years below. I was a buddy for two years, providing advice and support surrounding the Professional Doctorate systems, paperwork, providing reflections on what I have found useful, how I have remained organised throughout, and advice surrounding specific competency questions. I have always enjoyed providing advice and supporting individuals, especially surrounding Health Psychology. I have felt confident to give advice and provide support where needed, which will continue once qualified for anyone considering Health Psychology.

I am a committee member on the Division of Health Psychology (DHP), as Co-Trainee Lead. This voluntary role includes being responsible for running monthly sessions for all Trainee Health Psychologists completing the independent BPS, or Professional Doctorate route. These monthly sessions provide support for trainees through advice, guest speaker presentations on aspects of training, or research, and wellbeing check-in sessions to support trainees with any challenges they may be experiencing or areas of support. I have been in this post since September 2024 and am thoroughly enjoying being on the DHP committee and providing support for trainees who attend sessions.

Communication skills in different contexts

Throughout the doctorate, I had opportunities to develop my written communication skills to a lay audience through a variety of online articles including for the Institute of Optimum Nutrition (ION), British Psychological Society, and being responsible for writing the schools' PULSE magazine in my third placement. In my initial article for ION, I was unsure about the level of technical language required and needed support for ensuring that my communication style was suitable for the lay audience. However, for both BPS articles, I felt more confident in my written communication following positive feedback surrounding my first article.

Writing the school's PULSE magazine in placement three provided additional learning points, as I had to ensure that my writing style was suitable for a lay audience as well as the magazine being in line with UoP marketing policies and guidelines. This experience helped me to understand different marketing policies, the importance of branding including colour schemes and specific fonts where required. I received positive feedback which I have taken forward into my current role as I am responsible for the newsletter which also requires me to adhere to branding guidelines as set out by NIHR.

I have also developed my verbal communication skills by attending conferences outside of the annual professional doctorate conference. In September 2024, I attended the BPS 'Celebrating Psychology in the Midlands' conference, presenting my systematic review. One main challenge which I struggled with was timing, as I had a lot to discuss surrounding EDS, the review including results, and practical implications. From this experience, I reflected on avoiding including every detail and presenting the most important information from the work. I also had the opportunity to experience my first podcast interview discussing EDS and my research with the organiser of a charity in America who works to support individuals living with EDS. I was very nervous for the podcast as this was something which I had not experienced before, however throughout the podcast my nerves faded quickly, and I was able to enjoy the process and experience. I hope to be able to do more podcasts in the future, developing these skills further and disseminating research to wide audience.

I was initially under-confident at the beginning of the doctorate, meaning that the thought of teaching large groups, and communicating to different audiences was overwhelming. My face-to-face communication skills have significantly developed, delivering lectures to up to 140 students, and smaller guest workshops and seminars I delivered were interactive and promoted practical student learning on topics. At the beginning of the doctorate, I was unsure of delivering large group sessions, and this was reflective in observation feedback which I received surrounding facilitating further group discussion and ensuring sessions ran to time. Throughout my development as lecturer, I now facilitate group discussions confidently and recognise the importance of developing a rapport with students to encourage this within sessions.

Team-working skills

Research highlights the importance of teamwork within Dementia care (Hartgerink et al, 2014; Lloyd et al, 2011; Nowaskie et al, 2020). As Team Leader in placement one, I was responsible for encouraging teamwork within each shift, as well as working with nurses when I was on medication rounds. Being a team leader was something which I found quite challenging. This experience was potentially hindered by being a young team leader and overseeing carers who were not receptive to a younger team leader, with the perception I was inexperienced. As a result of these challenges, I completed a Level 3 diploma in Team Leadership and Motivation, earning a distinction. Following this course, I found a positive change in my abilities especially with younger colleagues, however for older colleagues I still found the same challenges difficult to overcome.

Team working felt more natural in academia, as everyone was valued regardless of age or experience, and a peer support system provided support. Although an early career academic and researcher, in placement three, I was respected by all team members, and opinions, insights, and experiences were valued. This aided the teamworking process and ensured that we provided the best possible lectures and student experience. Working as a team provides opportunities to make new connections, collaborations and to learn from others (Driskell et al, 2018). My experiences in care initially hindered my confidence in my abilities to work as a team and to be a module coordinator leading smaller teams. Through monthly meetings in placement three with my academic mentor, speaking through my experiences and how I need to improve, I began to trust my capabilities which made me feel more comfortable in teamworking and leadership. I now feel comfortable when working in a team, which is highlighted in my current research fellow role, collaborating with the other research fellows, other colleagues within the council and university partners.

Service user and carer involvement

Public participation involvement and engagement (PPIE) is promoted within health research and is strongly encouraged within public health service development, policy development and decision-making processes (Gilchrist et al, 2022; Rahman et al, 2022). Prior to the doctorate, I did not have any experience of engaging with PPIE for my research. As part of the ethical approval process for my empirical research, I was required to recruit a PPIE panel for feedback surrounding my research and participant facing documents. This was a positive experience, as I was able to recruit nine individuals for the PPIE panel who provided constructive feedback on the information sheet and consent form surrounding terminology used, accessible language, and the research inclusion and exclusion criteria. I found PPIE challenging in relation to the required standardised wording of the templates from placement three for the information sheet and consent form for GDPR and data management purposes. Participants in the PPIE panel commented on their dislike of legal language which made it challenging to balance, as I was unable to change this language on the standardised templates. I implemented most changes following PPIE feedback and felt the research was improved following the feedback.

Within my current research fellow role in public health, we value the importance of PPIE within all aspects of our work and have our own public voices group. This ensures that work which we do is focussed on improving the health for residents whilst meeting community needs. I will ensure to use PPIE panels within my future research and work as a Health Psychologist.

Need for engagement in continuing professional development (CPD)

The HCPC (2023) highlights the requirement for Health Psychologists to regularly attend CPD. This CPD is intended to help with development, ensure practice is up to date, and that skills are continually developed. As part of the doctorate, I have regularly engaged in CPD opportunities through short courses, level 3 diplomas, and attending webinars. I enjoy engaging in CPD opportunities as it provides me with a continuous opportunity to learn, to hear about research being conducted in a variety of fields and allows for me to take an interest in other areas of interest such as nutrition. I believe that my CPD in nutrition has helped shape my knowledge which I have used within my research, helping to build my rationale and understanding of influential factors of nutritional intake, as well as work within my individual face-to-face intervention. I aim to continue the level of engagement in CPD once qualified and want to undertake CPD in topics such as neurodiversity, and psychological intervention skills such as acceptance and commitment therapy. I believe that these will help me to be better prepared with any future clinical work which I complete.

Equality, Diversity, and Inclusion (EDI)

Throughout the doctorate, working in a variety of settings and as a research fellow, I have developed a clear understanding of the importance of EDI within research and practice (Kelly et al, 2022). Whilst working as a lecturer, there were different EDI considerations and policies which I followed. In my second placement at a university in the West Midlands, this included the requirement to upload all teaching session materials 48-hours before the session to ensure that students were able to access content, download and adapt to specific requirements, and could process lecture content prior to the session. At the beginning of my role as Associate Lecturer, I did not appreciate the rationale for this and followed other lecturers' practice by uploading pre-lecture slides with some content missing, to facilitate engagement. However, following feedback from students who were neurodiverse, I understood the importance of releasing materials in advance. Without this open and transparent feedback from students, I would not have changed my practice to release full session slides, through apprehension of impacting engagement. This highlighted the importance of open communication with students in academia and incorporating student feedback into practice to ensure full accessibility.

Overall, within my role as a lecturer, I supported students to the best of my abilities, with ensuring that students who had long-term conditions were supported (and felt supported) to have adjustments in sessions, or additional individual tutorials if they missed any lectures or seminars due to their health. This included developing and implementing student support plans, ensuring students were supported with their learning and sessions which I delivered were fully inclusive. As a lecturer, I always tried to be open and approachable with students, ensuring they felt that they could communicate their needs and ask for support when required. In my current role as research fellow, I continue to follow an EDI approach in research, with having an EDI objective within my appraisal for 2025/26.

Understanding organisational and systemic issues

I have worked in various settings and environments as a Trainee Health Psychologist. In my first placement working in Dementia Care, it was challenging to integrate Health Psychology into the care environment. Initially, when I enrolled on the Doctorate, management within my first placement were very supportive, and wanted to give me opportunities to incorporate Health Psychology to help improve resident care. In reality, this became hard to implement, and there was a lot of resistance from staff and management. I believe the little understanding in Health Psychology added to the resistance, highlighted by low attendance in my healthcare professional teaching sessions which were for care staff. On reflection my low confidence meant that I was not persistent enough to encourage change and understanding of Health Psychology. If I was to experience this environment again, I believe my confidence and trust in my own abilities would help me to promote the role of Health Psychology and facilitate full integration of Health Psychology within a care environment to ensure full support for residents.

In placements two and three I found it easier to integrate Health Psychology with only minor resistance from some colleagues. In placement three at a university in South-East England, I was given the opportunity to help re-develop a level 6 module which was currently in the SEP curriculum, re-shaping the module to better align with the BPS accreditation requirements. This was a challenging experience, with the current module coordinator becoming quite defensive of his work on the module and not wanting to work collaboratively. The colleague commented that shaping the module around the lifespan of an individual linking to biopsychosocial aspects of health and health promotion made the module into health psychology, which was not wanted in the SEP team or by students. However, I had reassurance from my line manager that this was not the case, so I continued working positively with all colleagues involved to ensure the best quality module redesign for students. I think this highlights the little understanding in some settings surrounding Health Psychology, and how it can work in collaboration with a variety of fields including SEP.

I aim to continue raising awareness of Health Psychology, the roles which Health Psychologists can work in, and highlighting the importance of collaboration between healthcare professionals for overall better patient support, research collaborations, informing policy and evidence-based decision making.

Developing as a Professional Health Psychologist

At the start of the Professional Doctorate, and my journey as a Trainee Health Psychologist, I only had experience of working in a care and Dementia care environment with no experience of teaching, consultancy, or psychological intervention work. However, throughout the doctorate, I have gained significant experience in academia as a lecturer and now working in public health as a research fellow. The experiences through placements and my current job role have provided many opportunities to develop my skills in teaching and training, including module leadership, supervising students, and research.

I have developed in many areas whilst completing the Professional doctorate, including experience in assessment, formulation using models such as the COM-B (Michie et al, 2011) and delivery of interventions. This has enabled me to begin developing clinical skills and use different communication skills which I had not developed before the Doctorate or working in academia. My communication skills have significantly developed, especially my verbal communication with working as a lecturer, and my presentation skills through presenting at conferences and experiencing my first podcast interview. My research skills have also significantly developed, with having the opportunity to complete new statistical analysis within my quantitative study such as sensitivity analysis. I aim to continue developing my research skills as a Health Psychologist, specifically wanting to conduct mixed-methods research to incorporate the lived experience of individuals with EDS in my research as well as the quantitative data.

Throughout my time as a Trainee Health Psychologist, I have learnt to value the importance of self-care, work-life balance and how to manage my long-term condition whilst working and studying. This has been something which has taken me a long time to value, and I need to consciously remind myself to practice self-care. Upon qualification, I will continue to ensure that I practice this and ensure that I have a healthy work-life balance which will help with the quality of my work as a Health Psychologist.

Conclusion

Completing the professional doctorate has been instrumental to my development and has given me the experience of working as a Trainee Health Psychologist in a range of settings, especially within research and academia. I am really looking forward to seeing how my journey as a qualified Health Psychologist unfolds working in research, or academia, and continuing to work in the field of EDS through research and raising awareness.

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Chapter 2: Research: From Design to Dissemination

2.1 Quantitative Research Manuscript

Nutrition and Ehlers-Danlos Syndrome: Examination of influential factors for nutritional intake and food choice motivations.

Nutrition and Ehlers-Danlos Syndrome

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Key words: ehlers-danlos syndrome, EDS, nutrition, nutritional intake, motivation for food choice, food choice.

Data availability statement: Data can be accessed via the Open Science Framework.

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Author contributions

Chloe Ryder: conceptualisation (lead); methodology (lead) investigation (lead); formal analysis (lead); writing original draft (lead); visualisation (lead). Lisa Cowap: writing – review & editing (supporting); supervision (lead); formal analysis (supporting); validation (lead). Richard Cooke: writing – review & editing (supporting); supervision (supporting); validation (supporting); formal analysis (supporting)

Abstract

Objectives

It is unclear as to which factors influence nutritional intake and motivations for food choice for individuals living with Ehlers-Danlos Syndrome (EDS). Therefore, the aim of the current study was to explore the extent to which physical pain, pain anxiety, fatigue, nutritional knowledge and stress influence nutritional intake and motivation for food choice for individuals living with EDS.

Design

Cross-sectional; 200 participants (Mean age $_{\text{years}}$ = 38.72, *SD* = 12.25) were recruited online using purposive and opportunity sampling aimed at individuals living with EDS.

Methods

Participants completed an online survey consisting of the Perceived Stress Scale-14, Pain Anxiety Scale Short Form-20, West Haven-Yale Multidimensional Pain Inventory, Fatigue Assessment Scale, Food Choice Questionnaire and the General Nutritional Knowledge Questionnaire. Predictors of motivation for food choice and nutritional intake were assessed through linear regression, multiple regression, mediation and moderation analysis.

Results

The majority of participants had hypermobile EDS (92.5%). Participant's mean score for nutritional knowledge was 50.80 (SD = 9.29) indicating a good level of nutritional knowledge. Fatigue significantly predicted nutritional intake ($\beta = -.186$, $p = .024$) and convenience motivation for food choice ($\beta = -.309$, $p < .001$). Pain anxiety significantly

predicted familiarity motivation for food choice (β = -.247, *p* =.004). Nutritional knowledge significantly predicted health (β = .317, *p* <.001) and natural content motivation for food choice (β = .267, *p* <.001). Mediation and moderation analyses were non-significant.

Conclusions

For individuals living with EDS, it is essential that levels of fatigue and pain anxiety are reduced where possible, to ensure a healthy motivation for nutritional intake alongside recommended guidelines.

Statement of Contribution

What is already known on this subject?

- Previous research has identified that co-morbid conditions and associated symptoms such as acid reflux, restrictive food intake have an influence on nutritional intake for individuals living with Ehlers-Danlos Syndrome (EDS). Less is known about other influencing factors.
- Pain, pain anxiety, stress, fatigue, and nutritional knowledge have not yet been explored in relation to nutritional intake and food choice motivations in EDS.
- Therefore, the research question for this study was: to what extent does physical pain, pain anxiety, fatigue, nutrition knowledge and stress influence nutritional intake and motivation for food choice for individuals living with Ehlers-Danlos Syndrome?

What does this study add?

- Individuals living with EDS are influenced by symptoms of the condition, including fatigue and pain anxiety, when it comes to motivations for food choice and nutritional intake levels.

Ehlers Danlos Syndrome (EDS) is a long-term genetic condition which is usually inherited and impacts many systems within the human body (Berglund et al, 2015; Orienus et al, 2022). Ehlers Danlos Syndrome is classified as a rare/under-diagnosed long-term condition with certain subtypes such as vascular EDS, affecting 1 in 40,000 individuals across the globe (Ehlers-Danlos Society, 2023). There are 13 subtypes, with the most frequently diagnosed being Hypermobile EDS (hEDS), affecting between 1 in 5000 to 1 in 20,000 (Ehlers-Danlos Society, 2023). There are common symptoms across all subtypes such as stretchy, fragile skin which easily bruises, chronic pain, severe headaches, fatigue, reduced psychological wellbeing, and digestive/gastrointestinal (GI) complications (Castle-Clarke, 2019; Ehlers-Danlos Support, 2017; Fikree et al., 2017, NHS, 2022; Tinkle et al., 2017; Voermans et al., 2010; Zeitoun et al, 2013).

Previous research has indicated that digestive and GI disorders, food intolerances and allergies, and complications within the gut-brain interaction are common for individuals living with EDS (Baeza-Velasco et al, 2015; Inayet et al, 2018; Paiba & Harris, 2023; Topan et al, 2022; Topan et al, 2024). A systematic review highlighted GI symptoms such as irritable bowel syndrome, nausea, abdominal pain, heartburn, bloating, and early satiety are common for individuals living with hEDS, all having a negative impact on nutritional intake (Beckers et al, 2017; Nelson et al, 2015; Zeitoun et al, 2013). The review also concluded that over 90% of the prevalence of functional GI disorders were accounted for by individuals living with hEDS (Beckers et al, 2017). Due to these symptoms, many individuals living with EDS experience significant weight loss, often mis-diagnosed as a clinical eating disorder by healthcare professionals (Baeza-Velasco et al, 2016; Baeza-Velasco et al, 2021; Wright & Herbst, 2021). Thus, there is a need for further understanding of nutritional intake and motivations for food choice for individuals living with EDS, to reduce misdiagnoses and ensure implementation of appropriate support.

Research examining nutritional intake for long-term conditions which have GI symptoms highlight that pain anxiety is correlated with familiarity motivation for food choice (Elgaziari, 2024; Witaszek et al, 2023). The literature examining this correlation has only been within individuals living with Coeliac Disease and Irritable Bowel Syndrome however, signifying the need to examine this potential relationship for individuals living with EDS, due to similar associated GI complications.

Previous research has also examined the impact of anxiety disorders and generalised anxiety on nutritional intake, highlighting that anxiety reduces nutritional intake (Aucoin et al., 2021; Beaudette et al., 2017; Kim et al., 2018; Topan et al., 2024). However, this research is focused on a 'healthy' population and not within EDS. Previous research has not explored the relationship between physical pain and nutritional intake and motivation for food choice in people living with EDS. However, research suggests that individuals who have high levels of pain anxiety often have higher levels of physical pain (Fonseca-Rodrigues et al, 2022). Therefore, it is essential that pain and pain anxiety are both examined within research in relation to nutritional intake and motivation for food choice for individuals living with EDS, where both pain and pain anxiety are high (Castle-Clarke, 2019).

Fatigue is a highly prevalent symptom for individuals living with EDS (Castle-Clark, 2019) therefore it is essential to examine how fatigue impacts nutritional intake. Previous research has examined fatigue as a consequence of poor nutritional intake (Arribalzaga et al, 2021; Jones, 2015). However, there has been no research which examines fatigue as an influential factor of nutritional intake or motivation for food choice in either a ‘healthy’ population or in those living with a long-term condition. Therefore, this current study examines how fatigue may influence food choice motivation and nutritional intake for individuals living with EDS.

Food choice has been defined as a complex function (Fotopoulos et al, 2009) which is explored in depth by the Food Choice Model (Frust et al, 1996). The Food Choice Model signifies that an individual’s motivation for choosing food can be divided into three main interacting factors that influence motivation for food choice: influences, life course, and personal systems. These factors encompass cultural beliefs and actions surrounding food, intra-individual factors, physiological, economic and social norms (Eertmans *et al,* 2001; Leng *et al,* 2017; Prescott *et al,* 2002; Souza, *et al,* 2020). Contemporary research has extended the Food Choice Model to include additional impacts such as food factors (sensory factors), cognitive factors (such as knowledge and skills), and personal-state factors (such as psychological, habits, and previous experiences) as additional influences on motivation for food choice (Chen & Antonelli, 2020; Hardcastle et al, 2015; Rozin, 2015). Overall, there are numerous influences that inform individual decisions over which food to consume. Influences for motivation for food choice have mainly been explored within a population defined as healthy (not living with a long-term condition) and has not been considered within the EDS population (Gambro et al, 2013; Miller & Cassidy, 2015; Witaszek et al, 2023). Therefore, it is essential that motivation for food choice is examined for individuals living with EDS to increase understanding about this topic.

Nutritional knowledge has been shown to have a significant impact on an individuals’ nutritional intake and food choice (Gámbaro et al., 2013; Miller & Cassady, 2015; Moorman et al., 2004; Scalvedi et al., 2021). For example, Ares and colleagues (2008) examined the impact of nutritional knowledge on individuals' food choices. They found that high levels of nutritional knowledge were positively correlated with individuals choosing food from a health focus and perspective. However, nutritional knowledge was only examined in 'healthy' adults and only nutritional knowledge of participants living in Uruguay was considered. Therefore, it is essential to examine how nutritional knowledge influences nutritional intake and motivation for food choice for individuals living with EDS.

Topan and colleagues (2024) examined the influences of nutrition for individuals living with hypermobile EDS, concluding that factors such as comorbid conditions (including postural tachycardia syndrome, mast cell activation syndrome), reflux symptoms and avoidant restrictive food intake disorder were influential factors for nutritional intake. However, factors such as pain, pain anxiety, fatigue and stress were not explored, and only the subtype hypermobile EDS was focussed upon. To date, the study conducted by Topan and colleagues (2024) has been the only study to examine influences of nutrition for individuals living with EDS. The exploratory nature of the current study aims to consider factors such as pain, pain anxiety, fatigue and stress which have not currently been explored by previous research in relation to influencing nutritional intake or motivation for food choice for individuals living with EDS.

Therefore, the aim of this exploratory study was to examine factors which influence nutritional intake and motivations for food choice for individuals living with EDS, through two research questions:

RQ^1: To what extent does physical pain, pain anxiety, fatigue, nutrition knowledge and stress influence nutritional intake for individuals living with EDS?

RQ^2: To what extent does physical pain, pain anxiety, fatigue, nutrition knowledge and stress influence motivation for food choice for individuals living with EDS?

The hypotheses of the study were the following:

H^1 – Physical pain, pain anxiety, stress, fatigue, and nutritional knowledge will predict nutritional intake.

H^2 – Physical pain and pain anxiety will predict familiarity motivation for food choice.

H^3 – Physical pain and fatigue will predict convenience motivation for food choice.

H^4 – Pain anxiety, physical pain, stress, and fatigue will predict mood motivation for food choice.

H^5 – Nutritional knowledge will predict health motivation for food choice.

H^6 – Nutritional knowledge will predict natural content motivation for food choice.

H^7 – Stress will mediate the relationship between nutritional knowledge and health motivation for food choice.

H^8 - Nutritional knowledge will mediate the relationship between fatigue and mood motivation for food choice.

H^9 – Pain anxiety will moderate the relationship between pain and mood motivation for food choice.

Methods

Participants

Purposive and opportunity sampling was used to recruit participants. Recruitment was promoted on social media channels: LinkedIn, Facebook, Twitter, and Instagram. To be eligible to participate in the study individuals had to be living with EDS (any subtype), over the age of 18, and able to make their own food choices. Individuals were not able to participate if they have a current clinical eating disorder diagnosis and/or a history of an eating disorder (or disordered eating behaviour).

A total of 262 participants submitted responses to the online questionnaire. However, 62 individuals did not fully complete the study, thus withdrawal was assumed so their data was removed from the analysis. The final sample included 200 participants.

Participant Characteristics

Of the total 200 participants, 186 (93.00%) were female, 3 (1.50%) were male, 9 (4.50%) were non-binary, 1 (0.50%) was a-gender, and 1 (0.50%) was Transmale. Sample mean age was 37.82 years (SD = 12.25; range 18-71). The majority of participants (N = 185.00; 92.50%) reported a diagnosis of hEDS, while 5.50% (N = 11.00) a diagnosis of cEDS. Two participants (1.00%) reported a diagnosis of vEDS, one (0.50%) a diagnosis of mEDS and one other (0.50%) a diagnosis of aEDS.

Design

A cross-sectional design was used. There were five predictor variables: pain anxiety, physical pain, fatigue, stress, and nutritional knowledge. There were six outcome variables including nutritional intake and motivation for food choice which included five subcategories: health motivation, mood motivation, convenience motivation, familiarity motivation, and natural content motivation.

Measures

Initially, participants were asked to provide demographic information including gender, age, and Ehlers-Danlos type. Participants were also asked questions surrounding nutritional intake, including how many times a day on average does an individual eat, and how many times a day on average does an individual eat on a day when an EDS flare up is occurring.

Predictor variables

Perceived Stress Scale-14

Cohen et al.'s (1983) Perceived Stress Scale 14 (PSS-14) is a 14-item scale that assesses an individual's perception of a series of situations as being stressful using a 5-point Likert scale. Within this measure, there are two subscales: positive (consisting of seven items) and negative (consisting of 7 items). Past studies have demonstrated the scale has acceptable-good internal consistency with Cronbach's alpha values ranging from 0.74-0.86 (Cohen et al., 1983; Cohen & Williamson, 1988; Hewitt et al., 1992).

Pain Anxiety Scale Short Form-20

McCracken and Dhingra's (2002) Pain Anxiety Scale Short Form 20 (PASS-20) is a 20-item scale that assesses an individual's fear and anxiety response in relation to physical pain using a 6-point Likert scale. It contains four different subscales exploring pain anxiety: cognitive, escape/avoidance, fear, and physiological anxiety (McCracken & Dhingra, 2002). Each subscale has been reported in research to have adequate-good internal consistency with all subscales having a Cronbach’s alpha ranging from 0.75-0.91 (McCracken & Dhingra, 2002). In this study, all four subscales were used.

West Haven-Yale Multidimensional Pain Inventory

Kerns et al.’s (1985) West Haven-Yale Multidimensional Pain Inventory (WHYMPI) is a 52-item scale that assesses different manners in which pain can affect an individual’s life using a 7-point Likert scale. It has three sub-scales: assessment of how pain affects the individual’s life, how a significant other responds to pain, and how pain impacts common activities. Research examining the reliability of this measure has reported Cronbach's alpha being 0.82 demonstrating good internal consistency (Kerns et al, 1985). In this study, only the assessment of how pain affects the individual’s life subscale which contains 20 items examining interference, support, pain severity, self-control, and negative mood was used.

Fatigue Assessment Scale

Michielsen et al.’s (2003) Fatigue Assessment Scale is a 10-item scale that assesses an individual's perception of their symptoms of fatigue using a 5-point Likert scale. The FAS has excellent internal consistency, having a Cronbach’s alpha of 0.90 (Michielsen et al., 2003). FAS measures both physical and psychological symptoms of fatigue which an individual may experience (Michielsen et al., 2003). In this study, both subscales of psychological and physical symptoms of fatigue were used.

Food Choice Questionnaire

Steptoe et al.’s (1995) Food Choice Questionnaire is a 36-item scale that evaluates individual’s motivations for food choice using a 4-point Likert scale. It contains nine subscales exploring key variables which affect an individual’s food choice. Previous research has identified each subscale within the measure to have good to adequate internal consistency with the Cronbach's alpha varying between 0.70 and 0.87 (Steptoe et al, 1995). In this study, only the health, mood, convenience, familiarity, and natural content subscales were used.

General Nutritional Knowledge Questionnaire

Parmenter and Wardle's (1999) General Nutritional Knowledge Questionnaire is a 41-item scale that assesses an individual's nutritional knowledge using a 3-point Likert scale. It contains four different subscales exploring different areas of nutritional knowledge: dietary recommendations, sources of nutrients, choosing everyday foods, and diet-disease relationship (Parmenter & Wardle, 1999). Each subscale has been reported in research to have adequate-excellent internal consistency with all subscales having a Cronbach's alpha ranging from 0.70-0.97 (Parmenter & Wardle, 1999). For this study, the nutritional dietary recommendations and sources of nutrients subscales were used to assess an individual's nutritional knowledge.

Only set subscales were used for the WHYMPI, Food Choice Questionnaire, and General Nutritional Knowledge Questionnaire to avoid participant burden and burnout with fatigue being a common symptom for individuals living with EDS. Research has signified that online research which is too long can also increase the likelihood of participant withdrawal and participant drop-out (McCambridge et al, 2011).

Procedure

Ethical approval was granted by [name omitted until publication]. The study was advertised on social media: LinkedIn, Facebook, Twitter, and Instagram to invite individuals to participate in the study which included a QR code and URL link to the survey.

After reading the participant information sheet and giving informed consent, participants were asked to provide demographic information. Participants were asked questions surrounding nutritional intake including how many times does an individual eat on an average day, and how many times does an individual eat on a day when a flare up is occurring. Once this initial information was provided, participants completed the psychological measures section of the survey, taking approximately 30 minutes. Following completion of the study, a debrief form was provided for participants, describing the aim of the study and signposted information if individuals needed additional support surrounding EDS, healthy eating, and overall wellbeing.

Data Screening

After data collection was completed, data screening was conducted to ensure suitability of data for analyses. As part of this process, 62 participants were removed from the dataset due to missing data. Participants which were removed due to incomplete psychological measures, particularly the General Nutritional Knowledge Questionnaire. After exclusion of these participants, skewness and kurtosis figures were calculated for the final sample; most values were within the +1/-1 range identifying that data was normally distributed with linear relationships between variables. This interpretation was supported by histograms, normal Q-Q plots, boxplots and cooks' distance values which confirmed normal distribution of data with no outliers. Scatterplots of residuals for all hypotheses also identified that homoscedasticity was not an issue within the data. Sensitivity analysis also confirmed no significant multivariate outliers within the data, after removing potential outliers and comparing R^2 values which did not show any significant differences. Therefore, no data were removed. Histograms for standardised residuals of each regression model also identified normal distribution of data. Multicollinearity was not an issue within the data, signified by the variance inflation factor (VIF) values (largest = 2.938) and tolerance values (largest = 1.000). There was independence of residuals with the Durbin-Watson statistic ranging between 1.936 and 2.108 indicated that there was independence of residuals (see table 1 for all tolerance, VIF and Durbin-Watson values). This signified that data analysis was suitable for parametric analysis could be conducted.

[Insert Table 1 here]

Analytic Strategy

Data analysis was completed using SPSS-29. For the first six hypotheses, either a correlation or multiple regression analysis was conducted. Model crossvalidation was assessed using R^2_{PRESS}. For hypothesis seven and eight, a mediation analysis was conducted using Hayes (2018) PROCESS v3.3 macro. For hypothesis nine, a moderation analysis was conducted using Hayes (2018) PROCESS v3.3 macro. These analytic strategies for all hypotheses for the current study allow for exploration of the relationship between pain, pain anxiety, fatigue, stress, nutritional knowledge, and motivation for food choice for individuals living with EDS.

Results

Descriptive Statistics

Participants' pain levels fell within the severe category (*M* = 74.21, *SD* = 17.16), with stress levels also being identified as high (*M* = 24.45, *SD* = 7.65). Participants reported eating less during an EDS flare up (M = 2.33, SD = 1.57) compared to a day where symptoms are eased and manageable (M = 3.17, SD = 1.26). See Table 2 for all descriptive statistics.

[Insert Table 2 here]

Hypothesis One

A multiple regression was conducted to explore whether pain anxiety (PA), pain, stress, fatigue and nutritional knowledge (NK) predicted nutritional intake. Overall, the model was significant F(5,199) = 2.89, $p = .015$; $R^2 = .068$), accounting for 6.8% of the variance in nutritional intake. Fatigue was the only significant predictor, negatively predicting nutritional intake ($b = -.184$, $p = .024$, 95% CI [-.077, -.005]), indicating that as fatigue levels increase, nutritional intake decreases for individuals living with EDS (see table 3).

Hypothesis Two

A multiple regression was conducted to explore whether PA and pain predicted familiarity motivation for food choice. Overall, the model was significant F(2,197) = 11.89, $p <.001$; $R^2 = .108$). The regression model accounted for 10.80% of variance in familiarity motivation for food choice. Results identified that PA was the only significant predictor, positively predicting familiarity motivation for food choice ($b = .316$, $p = .004$, 95% CI [.010, .054]). Thus, signifying that as PA levels increased, familiarity motivation for food choice also increased for individuals living with EDS (see table 3).

Hypothesis Three

A multiple regression was conducted to explore whether fatigue and pain predicted convenience motivation for food choice. Overall, the model was significant F(2,197) = 14.30, $p <.001$; $R^2 = .127$) and accounted for 12.70% of the variance in convenience motivation for food choice. Within this regression, fatigue positively predicted convenience motivation for food choice ($b = .343$, $p <.001$, 95% CI [.100, .226]). This identified that as fatigue levels increased, convenience motivation for food choice also increased for individuals living with EDS (see table 3).

Hypothesis Four

A multiple regression was conducted to explore whether stress, PA, fatigue, and pain predicted mood motivation for food choice. Overall, the model was significant F(4,195) = 3.65, $p = .007$; $R^2 = .070$) and accounted for 7% of the variance in mood motivation for food choice. However, none of the predicting variables were able to significantly predict mood motivation for food choice for individuals living with EDS.

[Insert Table 3 here]

Hypothesis Five

A regression was conducted to explore whether an individual's level of NK predicted health motivation for food choice. The model was significant F(1,198) = 22.162, $p < .001$; $R^2 = .101$) and indicated that NK explained 10.10% of variance in health motivation for food choice. Results also identified that NK was positively correlated with health motivation for food choice ($b = .317$, $p < .001$, 95% CI [.081, .197]) with higher levels of NK being correlated with higher levels of health motivation for food choice. Table 4 provides the full summary of the simple linear regression.

[Insert Table 4 here]

Hypothesis Six

A regression was conducted to explore whether an individual's level of NK predicted natural content motivation for food choice. The model overall was significant F(1,198) = 15.171, $p < .001$; $R^2 = .071$) and accounted for 7.1% variance in natural content motivation for food choice. The regression also identified that NK was positively correlated with natural content motivation for food choice (*b* = .267, *p* <.001, 95% CI [.039, .119]). Thus, identifying that higher levels of NK predicted higher levels of natural content motivation for food choice. Table 5 provides the full summary of the simple linear regression.

[Insert Table 5 here]

Hypothesis Seven

To examine whether stress was a mediating variable in the relationship between NK and health motivation for food choice, bootstrapped, bias-corrected 95% confidence levels based on 5000 samples were computed for the indirect effect to assess mediation. The mediation analysis identified that there was a non-significant indirect effect of NK for health motivation for food choice through stress, *b* = .005 BCa 95%CI [-.012, .015]. The relationship between NK and health motivation for food choice was not mediated by stress for individuals living with EDS.

Hypothesis Eight

A second mediation analysis was conducted to examine whether NK mediated the relationship between fatigue and mood motivation for food choice for individuals living with EDS. Bootstrapped, bias-corrected 95% confidence levels based on 5000 samples were computed for the indirect effect to assess mediation. The overall model was non-significant F(1,198) = 1.68, *p* = .196. The mediation analysis also identified that there was a non-significant effect of fatigue for mood motivation for food choice through NK, *b* =.007 BCa 95% CI [-.023, .007]. The relationship between fatigue and mood motivation for food choice was not mediated by NK.

Hypothesis Nine

A moderation analysis was conducted to investigate whether pain anxiety moderated the relationship between pain and mood motivation for food choice in individuals living with EDS. The model indicated that pain anxiety explained 5.6% of variance in mood motivation for food choice (R^2 = .056). Pain anxiety did not significantly predict mood motivation for food choice (*b* =.085, 95%CI [-.0353, .2980], t = 1.554, *p* = .121). The pain anxiety and pain interaction did not significantly predict any variance in mood motivation for food choice (ΔR^2 =.002, ΔF (1,96) = .563, *p* =.453. This therefore indicates that pain anxiety did not moderate the effect of pain on mood motivation for food choice for individuals living with EDS (*b* = .001, 95% CI [-.0027, .0012], t = -.750, *p* = .453).

Model Cross Validation

Following data analysis, PRESS statistic analysis was conducted for hypotheses one to six which identified that the R^2_{PRESS} statistics for all hypotheses were near to the R^2 values. This identified that results from all regression models are generalisable to the population and provides validity of results from all regression analyses.

Discussion

The overall aim of this study was to explore factors which influence nutritional intake and motivations for food choice for individuals living with EDS, specifically investigating PA, pain, stress, NK, and fatigue. Overall, fatigue significantly predicted nutritional intake, with higher levels of fatigue reducing nutritional intake levels. Fatigue also significantly predicted convenience motivation for food choice, with higher levels of fatigue increasing individuals' convenience motivation. Pain anxiety significantly predicted familiarity motivation for food choice, with higher levels of PA increasing individuals' familiarity motivation. Nutritional knowledge significantly predicted both health and natural content motivation for food choice, with higher levels of NK increasing both health and natural content motivations for food choice with individuals living with EDS.

Current results are similar to those reported in previous literature. Research examining the influence of NK on motivations for food choice within the 'healthy' population also identified that higher levels of NK were correlated to health motivations for food choice (Gambro et al, 2013; Miller & Cassidy, 2015; Moorman et al, 2004; Scalvedi et al, 2012). Given there has been no previous research examining the correlation within the EDS population, results from this study add a new understanding as to how NK influences motivation for food choice for individuals living with EDS.

For all other variables, comparing findings to previous research was limited due to this being the first study to explore these variables in relation to nutritional intake and motivation for food choice in EDS. For example, PA has not specifically been explored before in relation to either nutritional intake or motivation for food choice in either the EDS population or individuals without a long-term condition. Therefore, results from this study provide additional knowledge surrounding the relationship between PA and familiarity motivation for food choice within the EDS population. Findings from the current study surrounding pain anxiety are similar to previous research examining the influence of anxiety on nutritional intake in other long-term conditions. The influence of generalised anxiety on nutritional intake within a 'healthy' population has been previously examined, identifying that high levels of generalised anxiety are correlated with maladaptive eating behaviours, reduced nutritional intake, and comfort eating (mood motivation for food choice; Witaszek et al, 2023). Previous research examining how anxiety impacts nutritional intake for individuals living with Coeliac Disease identifies high levels of anxiety are correlated with a sub-optimal level of nutritional intake (Elgaziari, 2024). Although Coeliac Disease and EDS are different long-term conditions, both have similar gastrointestinal symptoms. Therefore, a similar finding across both studies highlights the impact of PA on motivation for food choice.

Fatigue has been explored within previous research as a symptom of a sub-optimal level of nutritional intake and poor nutritional status (Arribalzaga et al, 2021; Inglis et al, 2018; Jones, 2015) rather than as an influence for motivation for food choice and potential impacting factor for nutritional intake. Research within this field has mainly focussed upon 'healthy' adults or older adults to assess the impact of low nutritional intake. Therefore, the current study examining how fatigue impacts motivation for food choice and nutritional intake adds a new understanding, especially for the EDS population, due to fatigue being a highly prevalent symptom which runs across all EDS subtypes (De Wandele et al, 2016; Hakim et al, 2017).

Practical Implications

The results from the current study provide some practical applications which can help support individuals living with EDS, specifically ensuring support for nutritional intake and encouraging a healthy motivation for food choice.

When examining the descriptive statistics, EDS participants' pain was identified as severe. Therefore, it is essential that healthcare professionals ensure questions are asked in appointments with individuals living with EDS surrounding pain levels. This will ensure that support, such as through a pain management intervention, can be implemented if individuals are reporting high and severe levels of pain with their EDS. Although pain did not significantly predict nutritional intake or motivation for food choice within this study, PA significantly predicted familiarity motivation for food choice. This identifies that individuals living with EDS are more likely to choose food which is familiar to them due to knowing they do not increase gastrointestinal symptoms or pain, avoiding pain and reducing pain anxiety. These food choices, however, may be irrespective of the health status of food meaning that food choices may be lower in nutritional status or not beneficial for health, signifying the importance of supporting individuals living with EDS with both pain and PA levels to ensure individuals are motivated to choose a well-balanced diet rather than foods for a familiarity reason. Implications for practitioners working with individuals living with EDS include screening for levels of PA and using multidisciplinary teamwork approach to ensure the individual is supported psychologically, physically, and with their nutritional intake to encourage healthy food choices and increase levels of nutritional knowledge and awareness.

The impact of fatigue was highlighted within the current study to reduce levels of nutritional intake. Thus, signifying the need for supporting individuals living with EDS with levels of fatigue through techniques such as pacing and potentially using technology to monitor energy levels and activity throughout a day (Clark et al, 2024). This will help to ensure that fatigue levels do not increase so highly that nutritional intake levels are negatively impacted.

Limitations and Future Research

Although the current study presented some significant findings, it is not without its limitations. Firstly, within this study neurodiverse conditions were not explored such as Autism Spectrum Disorder (ASD) or ADHD. Research has highlighted a strong link between EDS and ASD and other neurodiverse conditions (Casanova et al, 2020; Csecs et al, 2022; Nisticò et al, 2022). Conditions such as Autism have been identified within research to impact food choice and significantly decrease nutritional intake due to factors such as avoidant eating behaviours, food sensitivities, and sensory overwhelm in food textures (Bourne et al, 2022; Farag et al, 2022; Sharp et al, 2013). Therefore, it would have been beneficial for this study to have included a demographic question asking participants if they have a neurodiverse condition, so this could have been explored compared to a neurotypical population, to assess if there was an impact on motivation for food choice and nutritional intake. Future research should examine neurodiversity for individuals living with EDS and assess how this impacts motivation for food choice and nutritional intake, allowing for additional conclusions to be made surrounding this topic and additional support implemented if required.

The population sample was uneven in terms of gender and EDS subtype. Females predominantly (93%) completed this study, and 92.50% of the participants were living with hEDS. The uneven sample may mean that generalising the findings from this study to other EDS subtypes and genders may be challenging. Research within the EDS field also identifies that the condition is more prevalent in the female population (Castoin, 2012). Although this study was online for all individuals to access if they chose, hEDS is the most diagnosed subtype of EDS (Ehlers-Danlos Society, 2022; Hakim, 2024). Females are also more likely to participate in research compared to males (Lefver et al, 2007), therefore, potentially providing an explanation for most individuals living with hEDS and female within the participant sample. Future research should encourage individuals living with other sub-types of EDS to participate in research to assess whether findings are similar across all subtypes. There also needs to be future research which encourages other genders to participate so that there can be an understanding as to how all individuals living with EDS are motivated for choosing foods and how the condition impacts nutritional intake.

Conclusion

Overall, this is the first study which has examined stress, pain anxiety, fatigue, pain, and nutritional knowledge in relation to motivation for food choice and nutritional intake for individuals living with EDS. The study identifies that fatigue predicted nutritional intake and convenience motivation for food choice for individuals living with EDS. Pain anxiety predicted familiarity motivation for food choice. Nutritional knowledge predicted health and natural content motivation for food choice for individuals living with EDS. There needs to be development of interventions for factors such as pain anxiety, and fatigue to encourage individuals to have a better quality of life when living with the condition which will consequently help with nutritional intake and a healthy motivation for food choice.

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Tables

Table 1. *Tolerance, VIF values and Durbin-Watson values for Hypotheses 1 to 6 for all regression analyses conducted*

Model	Variables	Tolerance	VIF	Durbin-Watson
1 (H^1)	Constant			1.977
	Perceived Stress	.624	1.602	
	Pain Anxiety	.417	2.398	
	Fatigue	.696	1.438	
	Pain	.613	1.633	
	Nutritional Knowledge	.935	1.069	
2 (H^2)	Constant			2.108
	Pain Anxiety	.619	1.615	
	Pain	.619	1.615	
3 (H^3)	Constant			1.965
	Pain	.882	1.134	
	Fatigue	.882	1.134	
4 (H^4)	Constant			1.985
	Perceived Stress	.635	1.576	
	Pain Anxiety	.431	2.318	
	Fatigue	.699	1.430	
	Pain	.613	1.632	
5 (H^5)	Constant			1.983
	Nutritional Knowledge	1.000	1.000	
6 (H^6)	Constant			1.936
	Nutritional Knowledge	1.000	1.000	

Table 2. *Participant Demographics, showing mean score (SD) for normal meals intake, flare meals intake, stress, pain anxiety, fatigue, pain, and nutritional knowledge.*

Variable	**Mean Score (SD)**
Normal Meal Intake	3.17 (1.26)
Flare Meal Intake	2.33 (1.57)
Stress	24.45 (7.65)
Pain Anxiety	38.28 (7.65)
Fatigue	32.01 (5.53)
Pain	74.21 (17.16)
Nutritional Knowledge	50.80 (9.29)

Table 3. *Coefficients Table for Hypotheses 1 to 4 for all multiple regressions conducted.*

Model	**Variables**	***B***	***SE B***	**β**	**t**	**Sig.**	**95% Confidence Lower Bound Interval**	**95% Confidence Lower Upper Bound Interval**
1 (H^1)	Constant	2.838	.809		3.510	<.001	1.244	4.433
	Perceived Stress	.017	.014	.106	1.228	.221	-.011	.045
	Pain Anxiety	-.010	.008	-.144	-1.361	.172	-.025	.005
	Fatigue	-.041	.018	-.186	-2.269	.024*	-.077	-.005
	Pain	.010	.006	.138	1.582	.115	-.003	.023
	Nutritional Knowledge	.017	.010	.127	1.802	.073	-.002	.036
2 (H^2)	Constant	4.795	.679		7.064	<.001	3.456	6.133
	Pain Anxiety	.032	.011	.247	2.891	.004*	.010	.054
	Pain	.015	.011	.112	1.307	.193	-.007	.037
3 (H^3)	Constant	8.650	1.393		6.208	<.001	5.902	11.398
	Pain	.019	.014	.100	1.415	.159	-.008	.046
	Fatigue	.183	.042	.309	4.357	<.001**	.100	.226
4 (H^4)	Constant	9.870	2.323		4.249	<.001	5.288	14.452
	Perceived Stress	.031	.054	.050	.571	.569	-.075	.137
	Pain Anxiety	.044	.029	.160	1.521	.130	-.013	.101
	Fatigue	.117	.071	.136	1.648	.101	-.023	.256
	Pain	-.015	.024	-.054	-.054	.542	-.063	.033

Note: *<.05 **<.001

Table 4. *Coefficients Table for Hypothesis 5.*

Model	**Variables**	***B***	***SE B***	**β**	**t**	**Sig.**	**95% Confidence Lower Bound Interval**	**95% Confidence Lower Upper Bound Interval**
1 (H^1)	Constant	11.098	1.526		7.272	<.001	8.088	14.107
	Nutritional Knowledge	.139	.030	.317	4.708	<.001**	.081	.197

Note: **<.001

Table 5. *Coefficients Table for Hypothesis 6.*

Model	**Variables**	***B***	***SE B***	**β**	**t**	**Sig.**	**95% Confidence Lower Bound Interval**	**95% Confidence Lower Upper Bound Interval**
1 (H^1)	Constant	4.298	1.048		4.100	<.001	2.231	6.366
	Nutritional Knowledge	.079	.020	.267	3.895	<.001**	.039	.119

Note: **<.001

2.2 Quantitative Research: Reflective Commentary

Ehlers-Danlos Syndrome (EDS) is a rare long-term condition, of which symptoms can vary significantly for an individual as the condition impacts most of the human body (Malfait et al, 2020). I conducted a systematic review prior to this research examining quality of life for individuals living with EDS and included studies highlighted that gastrointestinal symptoms negatively impacted quality of life. This finding, combined with my experience of EDS online support groups due to living with the condition, and seeing a high prevalence of struggles with diet, food, and little support or understanding surrounding nutritional intake for individuals living with EDS, led me to the current research study. Whilst scoping the literature to investigate previous research within this area, I identified that research was from a physiological perspective, exploring the impact of malnutrition in EDS, and the impact of feeding tubes (Topan et al, 2022) rather than exploring the influential factors and motivations behind individuals' food choices and nutritional intake. Therefore, my current research study examined the influential factors for nutritional intake and motivation for food choice for individuals living with EDS.

Prior to confirming my topic for this project, I also spoke with two healthcare professionals who work in the field of EDS nutrition via Microsoft Teams, and they encouraged me to complete this line of enquiry due to the absence of research in this area. This gave me the confidence and motivation to explore this topic knowing that healthcare professionals also were aware of the need for a better psychological understanding behind food choice for individuals living with EDS. Due to the exploratory nature, I proposed nine hypotheses for this study. Upon reflection, this was too many for one study, and I feel the results from this study would have been strengthened with a more specific focus. However, having the 9 hypotheses has allowed for me to identify areas for future research which I can conduct in this field in the future.

Methodology

Ethics

Prior to conducting any empirical research project, it is essential that study plans including research design, research question , hypotheses and participant population are considered in relation to ethical guidelines such as the British Psychological Society (BPS) Code of Ethics and Conduct (Aguinis & Henle, 2004; BPS, 2021; Miles & Gilbert, 2006). I completed the ethics application at my placement. The application was the most thorough I had completed compared to previous studies I had conducted, which made me nervous to begin with about all the elements I needed to complete. There were two new processes within the ethics application, which I had not completed before. For example, before submission, my study had to be peer reviewed. This was completed by my workplace contact who was very supportive and provided some insightful suggestions prior to submission to the faculty ethics panel. From this experience, for future research I would try to get a second opinion from a colleague surrounding the development of a project prior to ethics application.

Upon submission I was nervous as I knew that the panel mainly consisted of Clinical Exercise Physiologists; this made me apprehensive of their perceptions of the study and the required improvements. The feedback overall was constructive, consisting of three questions and four required recommendations prior to ethical approval, along with four advisory notes. One recommendation required the collection of feedback from a Patient and Public Involvement and Engagement (PPIE) panel surrounding the participant information sheet, specifically asking the PPIE panel to consider the amount of text and terminology. The use of a PPIE panel can help to ensure that research conducted is of a high quality, and relevant to the specific population or long-term condition being researched (Gilchrist et al, 2022; Hough et al, 2024; Patel et al, 2021). I was very nervous about collecting feedback from a PPIE panel due to this being a new experience and originally was unsure of the best approach. However, following supervision, which was helpful for suggestion of methods to collect PPIE feedback, I developed a Google Form and secured approval from support group admins on social media to collect responses from individuals living with EDS. I was surprised that I collected PPIE feedback rapidly, securing 9 individuals' feedback on the participant information sheet within 48-hours. The PPIE panel was very helpful, with some suggestions about improving accessibility to terminology used, which meant I made amendments to the participant information sheet prior to re-submission. For future research I will plan to include a PPIE panel whilst developing the research materials to ensure that my research is accessible to the target population.

I re-submitted my ethics application to the panel along with a response letter, meeting all conditions and questions except for one. Due to the ethics panel consisting of Clinical Exercise Physiologists, there was a condition I thought was not applicable (from conversations with my workplace contact and supervisor); the need for a Clinician to join the research term to confirm participant's EDS diagnosis. I responded this this recommendation commenting that it is not feasible due to the target participant number (n = 200), and the study being online. Furthermore, being a cross-sectional, psychological study, there was no need for EDS diagnosis confirmation, rather a required element of trust from participants that they were living with EDS. In all previous experiences of applying for ethics, I had met all requirements from ethics panels, which meant I was nervous about contradicting this core requirement. However, ethical approval for this study was granted on 29th April 2024, and I was very relieved and excited to begin data collection. From this experience, I have learnt that not all decisions from an ethics panel have to be agreed with and the ways in which you can debate the relevance of a recommendation to ensure the project remains suitable, and uncompromised in relation to ethics and the original aims and outcomes.

Study Design

The study design was cross-sectional due to this being the first study to examine the topic of motivation for food choice for individuals living with EDS. Limitations of cross-sectional research include only allowing for results to be captured for one timepoint (Bland, 2015; Levin, 2006). If the study was to be repeated in the future, results may be different, calling into question reliability of results within cross-sectional studies (Kesmodel, 2018). Therefore, for future research I will consider using other research designs such as longitudinal research to examine the influential factors for food choice and nutritional intake for individuals living with EDS. Due to EDS being a condition which includes flare ups of symptoms, longitudinal research may highlight the fluctuation of symptoms and provide a more in-depth understanding of this topic.

Measures

Finding suitable measures was not challenging overall, due to my previous research experiences focusing on motivation for food choice. Therefore, I knew the reliability and validity of the Food Choice Questionnaire (Steptoe et al, 1995) for assessing motivation for food choice, along with how to score participant responses, which made the main outcome scale straightforward to choose.

The most challenging scale to select was to assess nutritional knowledge, due to the study not being limited to a UK population. Therefore, I had to attempt to find a scale which was suitable for all individuals and contained questions surrounding foods or nutritional elements that all individuals would be familiar with from all countries. I chose the General Nutrition Knowledge Questionnaire (Parmenter & Wardle, 1999) for the study, as it contained questions surrounding food groups which would be familiar for all individuals. On reflection, this scale was too long for the study, which was reflected by the attrition rate, with most individuals who withdrew from the study not completing the questions for this variable. Additionally, upon calculating total scores for participants, it was challenging to determine what constituted as good or high levels of nutritional knowledge, as the scale did not include overall score boundaries. Therefore, I had to make a logical decision of what to consider a high level of nutritional knowledge for participants from a total score of 80. For future studies, if I am wanting to assess nutritional knowledge, I will need to consider a different questionnaire which is shorter to encourage completion of the study, which may help the attrition rate. For future research, I will also complete a pilot phase of the questionnaire which will help for me to identify and resolve problems prior to beginning full data collection.

Procedure

The current study was conducted using an online survey which was advertised on social media platforms: Twitter (X), LinkedIn, Facebook, and Instagram. Healthcare professionals which I had spoken with previously who work in the field of EDS also shared my study through their social media channels. Practitioners support helped significantly with participant recruitments, as practitioners are based in the UK, USA, which meant that a wide range of individuals were able to have access to the study.

Participants were not required to create a participant ID code to ensure full confidentiality and anonymity (requirement from ethics application). Not having participants create an ID code was a new experience, as in all previous studies, I have asked participants to create a unique ID code to allow them to withdraw following completion of the study or to save their progress. Chronic fatigue is a common symptom across all subtypes of EDS (Voermans et al, 2011). Therefore, on reflection, due to the length of the questionnaire, I believe that it would have been beneficial to have had a participant ID code, which would have allowed for participants to save progress and complete the study at a later point. This may have reduced participant drop-out rate and ensured that I had a more complete set of results, rather than removing 63 participants due to missing data.

Due to the study being an online survey and using Qualtrics to collect data, I was confident in the procedure of the study. Using the same platform to collect data which I had used in previous studies ensured that I was familiar with how the platform processed raw data, and to export data upon closing the study to begin data analysis.

Participants, recruitment process, and data collection

For this study, there was an inclusion and exclusion criteria due to the topic being explored. Participants were able to participate if they were over 18 years old, were living with EDS, and were able to make decisions around food and nutritional intake. The only exclusion criteria related to individuals living with a clinical diagnosis of an eating disorder or had a diagnosis in the past. This exclusion criteria was not approved by the PPIE panel upon them reading the participant information sheet. However, I remained with the initial decision, to due understanding that a diagnosis of an eating disorder can strongly influence and interfere with an individual's decisions surrounding food choice (Babicz-Zielińska, 2006; Hart et al, 2018) and did not want my results to be skewed by this factor. I was cautious about the response that this exclusion criteria would receive whilst recruiting participants, due to the debate surrounding individuals living with EDS being incorrectly diagnosed with an eating disorder due to malnutrition from gastrointestinal symptoms linked to the condition (Ishiguro et al, 2022). I was relieved to have 263 participants recruited over a 2-month recruitment period for this study. I think this reflects the need for EDS research and how much individuals living with the condition want more information and awareness of EDS.

Data screening and preparation (assumption checking)

Once the survey was closed, I exported the raw data from Qualtrics to Microsoft Excel so that I could organise the raw data, calculate total scores for each variable, and review any missing data. I identified that there were 62 participants with missing data, with most participants not completing the final two measures which assessed motivation for food choice and nutritional knowledge. Due to not wanting the missing data to skew results, I decided to remove 62 participants (Graham, 2009). However, this still left 200 participants which was identified as the target sample size from the G*Power calculations to ensure 85% confidence in results. Whilst screening data, I felt confident in this process and ensured that I remained organised throughout. All scales had scoring instructions, which meant I was able to complete this process efficiently and ensure that more time was spent on assumption checking, to ensure that parametric data analysis was suitable. To ensure that I kept organised, once I had calculated total scores, I created a new sheet on Excel and transferred final participant demographics and total scores onto a new sheet to avoid any errors when adding the final raw data into SPSS for assumption checking and data analysis.

For assumption checking, I examined boxplots, Q-Q plots, histograms, skewness and kurtosis figures, and the Shapiro-Wilk statistics. All assumption checks identified that data was normally distributed, however the boxplots and Cooks vs Leverage scatterplots identified outliers within the data set, specifically for fatigue and nutritional knowledge. Within supervision, I asked for advice for the best approach for outliers, as I was hesitant to remove more data from the data set. My supervisor suggested I conduct sensitivity analyses which I was nervous about as this was something which I had not completed before. I followed the advice of my supervisor but found it challenging to interpret the results from the sensitivity analysis, which knocked my confidence for this new skill. However, following an attempt at interpreting the sensitivity analysis graphs, and checking my interpretations with my supervisor, my confidence was increased after realising that I was on the correct path for interpretation. I enjoy learning new statistics skills and find it easier to learn new skills in a practical way, checking my understanding following an attempt. I shall continue to do this for future research and ensure that I continue to learn more about statistics and quantitative research as I continue to conduct research.

Data Analysis

Due to having 9 hypotheses, there were a combination of correlational analyses completed for this study including: regression, multiple regression, mediation, and moderation analysis. Prior to completing this research, I had conducted all these analyses in previous quantitative research projects, which meant that I felt confident in how to conduct these analyses, and how to interpret findings to produce meaningful results. Whilst completing preliminary analyses for the Professional Doctorate conference, it was quickly identified that I had worded some hypotheses incorrectly meaning that the analyses conducted were not suitable.

However, through supervision, I was able identify this issue and rectify the wording of the hypotheses to ensure suitability of the planned analyses. For future research, I will ensure that wording of hypotheses is checked thoroughly to ensure that analyses can be conducted efficiently.

Dissemination

Dissemination of research is the first essential step of knowledge translation to other healthcare professionals and professions to guide practice and ensure evidence-based decisions to be made (Edwards, 2015; Simpson, 2015; Straus et al, 2009). Whilst completing my quantitative research, I have already engaged in some opportunities for dissemination, discussing EDS and the overall research project. I have written my first article for the British Psychological Society: West Midlands branch, which examined EDS from a Health Psychology perspective. Within this article, I introduced EDS including symptoms of the condition. I discussed my research experiences of EDS as a Trainee Health Psychologist emphasising the importance of research into EDS and how healthcare professionals can use findings to inform practice and ensure support for individuals living with EDS.

An additional opportunity which I have engaged in whilst completing my quantitative research, is a Podcast with an EDS charity called AWOL Zebra, based in America. This was the first podcast which I have engaged in during my training or career, so I was extremely nervous for this opportunity. I understood its importance, as research signifies that podcasts increase dissemination opportunities for research due to reaching a wider audience of healthcare professionals and multiple populations (Ahn et al, 2016; Naff, 2020; Thoma et al, 2018). Within this podcast I was able to discuss the project, and at the time I was currently recruiting participants, so it was a good opportunity to discuss the importance of researching

EDS, the aims of the current study, and what my intentions for future research and practice are within the EDS field. Overall, I thoroughly enjoyed the experience of completing my first podcast, and this would be something which I hope to participate in, in the future.

Future Dissemination

I also have future plans for dissemination of the findings and how the results can influence practice and awareness of nutritional intake and motivational factors for food choice for individuals living with EDS. Presenting and disseminating findings of research at conferences allows for other professionals to hear about research, learn about rare conditions, and allows for research authors to explain their study in more depth (Edwards, 2015; Rowe & Ilic, 2009, 2011). I plan to attend the Division of Health Psychology Conference in June 2025 and have submitted an abstract in the hope to be accepted to give an oral presentation on this research. I also aim to get my quantitative research published in the British Journal of Health Psychology. During the write up of the article, I wrote to the specific guidelines from this journal, so I am optimistic of publication for this study, especially with the topic being unique and not explored before by previous research.

Overall Reflection

Overall, I have found completing this study extremely rewarding and it has confirmed my passion for researching EDS as well as my enjoyment of quantitative research methods. The quantitative research was an excellent opportunity for me to experience new processes, including recruiting a PPIE panel as a part of ethical approval and completing new statistical analyses such as sensitivity analyses and R^2_{PRESS} statistics. Although I was nervous to encounter these new experiences, I am now feeling more confident to complete these processes again. If I was to repeat the quantitative research, I would focus on fewer exploratory variables in one study and ensure that I included a focus on neurodiversity, as I believe that this would have contributed to the study’s findings and overall impact and reliability. I will be able to implement new skills developed from this study for future research as a Health Psychologist in the EDS field.

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Chapter 3: Systematic Review

3.1 Systematic Review Manuscript

Comparison of Quality of Life for individuals living with Ehlers-Danlos Syndrome and Mast Cell Activation Syndrome: A Systematic Review

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Key words: ehlers-danlos syndrome, EDS, mast cell activation syndrome, MCAS, QoL, QoL

Conflicts of interest: No conflicts of interest.

Abstract

The aim of this review was to examine and compare the quality of life (QoL) for individuals living with Ehlers-Danlos Syndrome (EDS) and Mast Cell Activation Syndrome (MCAS). During July 2023, the following databased were searched for published and grey literature; APA PsycINFO, Academic Search Complete, CINAHL, MEDLINE, EThOS and STORE. Sixteen studies were included within this review, and quality appraisal was completed for all included studies. Data extracted included measure used, participant characteristics, study characteristics and outcomes of each study. Results identified that QoL was negatively impacted for individuals living with EDS or MCAS compared to control groups. This review highlights the need for further research to be conducted for both conditions, and the need for interventions to be designed to help improve QoL for individuals living with these syndromes.

Research has suggested that on average it takes four years for individuals to get a full and confirmed diagnosis of a rare or under-diagnosed long-term health condition (Marwaha et al., 2022). For Ehlers-Danlos Syndrome (EDS) specifically, the diagnostic process can take up to 10 years (The Ehlers-Danlos Society, 2023b). During these four years, individuals who are living with rare long-term conditions see on average 7.3 different healthcare professionals, including general practitioners and consultants who have different specialities (Global Genes, 2014), before symptoms are fully understood and tests are conducted. On average, it takes 10 years for an individual to be diagnosed with Mast Cell Activation Syndrome (MCAS;Akin et al., 2010; Hoffman, 2017), with individuals needing to meet the stepwise diagnostic process (Molderings et al., 2011), which consists of four sets of criteria that individuals' symptoms should come under for a full MCAS diagnosis (Gianetti et al., 2021; Valent et al., 2019; Weiler 2020). The diagnostic process for individuals with suspected MCAS is a trial-and-error process (Mast Cell Action, 2023), which can provide a lot of uncertainty for individuals trying to get a diagnosis to begin treatment (Hall, 2023; Molderings et al., 2011). The length and uncertainty of the diagnostic process means that quality of life (QoL) for individuals living with MCAS is negatively impacted (Schmidt, 2022). This suggests that more research and focus needs to be spent on supporting individuals living with both suspected and confirmed MCAS to improve QoL. The definition for QoL has been debated within the literature due to the subjective nature as to what makes an individual feel that they have a good QoL (Theofilou, 2023). Only a broad definition being accepted as an evaluation which includes an individual's emotions, sense of life fulfilment, life satisfaction, work and personal relationship satisfaction (Diener et al., 1999; Clarke et al., 2000; Theofilou, 2013; Snoek, 2000).

Research into the diagnosis of rare long-term conditions has identified that 44% of participants acknowledge that a lack of understanding and delayed diagnosis negatively impacts their condition, QoL and meant that symptoms are left unmanaged (Depping et al., 2021; Global Genes, 2014; Rare Disease Day 2023). Following diagnosis, for conditions such as EDS and MCAS there is usually very little support in relation to condition management, adaptations to improve overall QoL, and where to access support (The Ehlers-Danlos Society, 2023b; The UK Mastocytosis Support Group, 2023). A study conducted by Shire (2017) identified 57% of individuals living with a rare long-term condition in the United Kingdom (UK) felt isolated from family and friends and 68% have less social interaction, highlighting that long-term conditions can have negative implications for individuals in a multitude of ways. This signifies the importance of new research into these rare long-term conditions to aid understanding for healthcare professions and in turn encourage a faster diagnostic process and increase support following diagnosis. These factors will help to support an individual to have a positive QoL.

The complicated and long diagnosis process is identified to be the first major factor which negatively impacts health-related QoL, and psychological wellbeing for individuals living with rare long-term health conditions (Bogart & Irvin, 2017; Rothrock et al., 2010). Individuals living with conditions such as EDS and MCAS may be living with both psychological symptoms, such as anxiety, stress, and depression (Bogart & Irvin, 2017; Crowe et al., 2016; Shire, 2013, Trick et al., 2016) as well as physiological symptoms such as chronic pain, fatigue, chronic headaches, and muscle pain (Bogart & Irvin, 2017; Whitehead et al., 2016). These symptoms have been identified to reduce health-related QoL for individuals living with EDS and MCAS (Bogart & Irvin, 2017). Therefore, the current systematic review aims to examine and compare the QoL for individuals living with EDS and MCAS.

Ehlers-Danlos Syndrome (EDS)

EDS is an inherited, genetic long-term chronic condition (Berglund et al, 2015; Orenius et al., 2022) and has thirteen subtypes, including hypermobile Ehlers-Danlos Syndrome (hEDS). At present there is very little research on hEDS and there are no genetic tests for diagnosis due symptoms surrounding joints and not skin fragility in comparison to other types of EDS (Castle-Clarke, 2019; Ehlers-Danlos Support, 2017; Orenius et al, 2022).

Statistics have identified that EDS affects 1 in 10,000-15,000 people (Anderson & Lane, 2021; Demmler et al., 2019; Halverson et al., 2021; Hakin et al., 2021; The Ehlers-Danlos Society, 2023a), thus signifying that EDS is a rare long-term condition. These prevalence statistics may occur due to all subtypes of EDS being difficult to diagnose and often symptoms are misunderstood by healthcare professionals meaning that individuals are mis-diagnosed with other conditions (Bell & Pearce, 2021; Castori, 2012; Castori et al., 2017; Heim et al., 1998). This suggests that the prevalence of EDS may be higher than reported statistics. Research shows that individuals may not be diagnosed with hEDS until adulthood due to little awareness of this subtype and the associated symptoms (Anderson & Lane, 2021). The Onion Model of typical EDS diagnostic journey (Groh, 2018) identifies that little awareness for both EDS and hEDS can lead to healthcare professionals considering other diagnosis possibilities such as fibromyalgia, arthritis, and mitochondrial disease before thinking of EDS (Castori et al., 2014; Groh, 2018; Tinkle et al., 2017). This contributes to the average length of diagnosis for EDS types being 10 years (The Ehlers-Danlos Society, 2023b), leading individuals to continue to self-manage symptoms such as fatigue and pain with very little support, negatively affecting QoL and increasing stress and anxiety.

Several subtypes of EDS have common physiological symptomatology including chronic pain, stretchy skin, fragile skin that bruises easily, unstable joints due to hypermobility, chronic headaches, digestive problems, and fatigue (Fikree *et al.,* 2017, NHS, 2022, The Ehlers-Danlos Society, 2023c; Tinkle *et al.,* 2017; Voermans *et al.,* 2010; Zeitoun *et al,* 2013). Chronic pain in joints and muscles and chronic fatigue are the most prevalent symptoms with 67.1% of individuals with EDS reported chronic pain, and 68.8% reported fatigue (Baeza-Velasco et al., 2018; Orenius *et* al., 2022; Rombaut *et al*., 2010; Voermans *et al*, 2010), which negatively impact individuals daily functioning including work, home, and social life (Hershenfeld *et* al., 2016; Voermans *et al*, 2010). This negative correlation between chronic pain and fatigue and daily functioning, may partially explain the high prevalence of psychological distress in individuals living with EDS (Orenius *et al*., 2022), with research identifying that anxiety, depression and panic disorder to be correlated with an EDS diagnosis (Berglund *et al*., 2015; Garcia-Campayo *et al*., 2011; Smith *et al,* 2013). Therefore, it is vital for this systematic review to synthesise current literature examining the extent of which QoL is affected by rare long-term health conditions such as EDS. Research into this topic area will allow for awareness of EDS to be improved within the healthcare professional setting, for future psychological interventions to be developed to help improve QoL, thus in turn provide more support for individuals living with the condition.

MCAS

Mast cell activation syndrome (MCAS) is a subtype of a mast cell activation disorder and is a condition which is categorised as a malfunctioning of an individual's immune system

(Genetic and Rare Diseases Information Centre, 2023). No research has been conducted surrounding the prevalence of MCAS within the UK, however, Hoffman (2017) has suggested that 14% of individuals living in the United States have been diagnosed with MCAS. The symptoms for MCAS vary significantly for each individual due to differences in trigger factors, differences in the types and levels of histamines which are overactive or over produced, and different types of MCAS such as mast cell diseases (Jennings et al., 2021; Schmidt et al., 2022). However, there are common symptoms across the levels and types of MCAS including headaches, brain fog, chest pain, joint and bone pain, fatigue, osteopenia, hypertension, and muscle pain and stiffness, along with many more (Hall, 2023; Jennings et al., 2018; Jennings et al., 2019; Jennings et al., 2021; Valent et al., 2020). This highlights the physical effects that MCAS may have for an individual, which may negatively impact QoL. However, there is currently little research around MCAS and QoL for all individuals living with the condition (Schmidt et al., 2022). Therefore, it is vital for this systematic review to synthesise research examining how QoL is affected for individuals living with MCAS.

Current Systematic Review

This current systematic review aims to examine and compare the QoL for individuals living with EDS and MCAS. It is vital for this systematic review to identify the extent of which QoL is affected by rare long-term health conditions such as EDS and MCAS. This current systematic review is the first to synthesise research examining how QoL is impacted for individuals living with EDS and MCAS. Therefore, research into this topic area for individuals living with EDS and MCAS will allow for awareness of both conditions to be improved within the healthcare professional setting, for future psychological interventions to be developed to help improve QoL, thus in turn provide more support for individuals living with the conditions.

Therefore, the following three research questions will be explored in the current review:

Research Question ^{1}) To what extent does living with EDS affect QoL?

Research Question ^{2}) To what extent does living with MCAS affect QoL?

Research Question ^{3}) How does QoL for individuals living with EDS compare to QoL for individuals living with MCAS?

Method

This systematic review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009). Prior to the review being conducted, the review protocol was submitted and published on PROSPERO.

Search Strategy

In July 2023, four databases were searched for published literature: APA PsycINFO, Academic Search Complete, CINAHL and MEDLINE. EThOS and STORE were also searched for grey literature in this area. Additional manual hand searches were conducted in reference lists of the identified papers to identify additional literature. Search terms used for this systematic review were “quality of life” or qol AND "ehlers-danlos syndrome" OR EDS OR "mast cell activation syndrome" OR MCAS.

Study Selection and Eligibility Criteria

For the review, a start date of 1998 was chosen due to major diagnostic criteria change for Ehlers-Danlos Syndrome, especially the hypermobility type (hEDS). Research surrounding the major diagnostic criteria change has identified that diagnosis of hEDS is now more difficult, with the average length of time for diagnosis being 10-13 years (Bell & Pearce, 2021; Sobey, 2015), which may result in significant differences to self-reports of QoL. There were language restrictions of English only for this systematic review, due to the review team having no resources for translation. Due to the focus of the review, only quantitative studies examining MCAS and EDS were included, with a specific primary focus on QoL or health related QoL. Studies which focused on specific areas of QoL such as ‘oral health related QoL’ were not included due to oral health issues only being present in EDS, which would have made comparisons for QoL challenging between the two conditions.

Following searches, all articles (n=1626) were exported into Mendeley (Mendeley, 2023) and duplicates were identified and removed (n=291). Following this, titles (n = 1335) and abstracts (n = 138) of all studies were screened by the first author (CR) and second author (HM) independently. After each stage, a meeting was held between CR and HM to compare studies included and excluded at each stage with any disagreements being explored and resolved through discussion. Studies identified to be appropriate for full text screening (n = 80) using the inclusion and exclusion criteria, were then screened by both the first author and second author. Studies which did not meet the inclusion criteria were removed (n = 64) and documented within the PRISMA diagram (see figure 1), with no further analysis occurring on these studies. Studies were removed for reasons including: no direct measurement of QoL (n = 15), focussing on oral health QoL only (n = 19) and focusing upon diagnosis of MCAS (n = 5) and using case studies (n = 8) rather than examining QoL. A total of 16 studies were included for the review.

Data Collection Process and Data Extraction

Data extraction was completed by the first author (CR) with the second author (HM) checking 20% of the studies to ensure that all data was extracted thoroughly and accurately. Data that was extracted from studies included: outcome, outcome measure, participant characteristics, and characteristics of the study.

Quality Assessment

The quality of studies included within the review were assessed using the Effective Public Healthcare Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies (Thomas et al., 2004) (see table 1). The EPHPP is a quality assessment tool which places emphasis on the reviewer to decide as to whether a study is classed as 'strong', 'moderate', or 'weak' based on categories such as component ratings, study design, confounders, blinding, data collection methods, withdrawals and drop-outs, intervention integrity, and analysis (Thomas et al., 2004). The lead author (CR) assessed quality of studies during the data collection and extraction process, and second author (HM) assessed 20% of articles to ensure quality assessment was agreed for studies.

[Add Table 1 here]

Synthesis of Results

Due to the lack of heterogeneity between studies and included studies using a range of scales to measure different aspects of QoL, it was not possible to conduct a meta-analysis (Popay et al., 2006). As a result, a narrative synthesis was conducted, examining included studies in depth for scales used to measure QoL and the results to determine QoL for individuals living with EDS and MCAS. By examining studies in depth, it was possible to compare any differences in QoL reported between EDS and MCAS.

[Add figure 1 here]

Results

Description of Studies

The descriptive data extracted from studies can be found summarised in table 1.

Study Characteristics

Sample Characteristics

Sixteen studies were included within this review, with a total of 35,227 participants who were living with either EDS (n = 2548), hEDS (n = 653), or MCAS (n = 66). The remainder of participants were part of a control group (n = 31842). Ages for participants ranged from 18 to 79 across all included studies. Gender for included studies was unbalanced with there being more females (n = 3133) compared to males (n = 567). Included studies were based in a range of countries including United States (n = 3), United Kingdom (n = 2), Belgium (n = 2) Italy (n = 2), Sweden, (n = 1), Spain (n = 1), France (n = 1), Norway (n = 1), Finland, (n = 1), Australia (n = 1) and Germany (n = 1).

Design and Outcome Measures

Fourteen of the included studies were cross-sectional (Baeza-Velasco et al., 2013; Berglund et al., 2015; Bovet et al., 2016; Copetti et al., 2019; Estrella & Frazier, 2023; Inayet et al., 2018; Johanessen et al., 2016; Martinez et al., 2021; Orienus et al., 2022; Peebles et al., 2022; Rochetti et al., 2021; Rombaut et al., 2009; Schmidt et al., 2022; Verbraecken et al., 2022). Two studies were longitudinal, examining QoL pre- and post-intervention for individuals living with EDS (Hakimi et al., 2020) and hEDS (Lattimore & Harrison, 2022).

Thirteen studies used the Short Form Health Survey-36 ([SF-36] Ware & Sherbourne, 1992) to examine QoL (Baeza-Velasco et al., 2013; Berglund et al., 2015; Bovet et al., 2016; Copetti et al., 2019; Inayet et al., 2018; Johanessen et al., 2016; Martinez et al., 2021; Orienus et al., 2022; Peebles et al., 2022; Rombaut et al., 2009; Verbraecken et al., 2022). The SF-36 measures QoL on a scale of 0-100, with higher scores indicating better QoL (Bunevicius, 2017). For this review, 0-40 was classified as 'low' QoL, 41-69 was classified as 'medium' QoL, and 70+ was classified as 'high' QoL based on previous research (Bunevicius, 2017). The EORTC Core QoL questionnaire ([QLQ-C30] Kaasa et al., 1995) was also used to examine QoL for individuals living with MCAS (Schmidt et al., 2022). One study used the Patient-Reported Outcomes Measurement Information System - 29 Profile ([PROMIS-29] Hays et al., 2018) (Estrella & Frazier, 2023) and one study used the World Health Organisation QoL, short version ([WHOQOL-BREF] World Health Organisation, 2012) questionnaire (Rochetti et al., 2021).

Quality Appraisal

Quality of included studies were examined using the EPHPP. Of included studies, there were eight of moderate quality (Baeza-Valasco et al, 2023; Copetti et al, 2019; Hakimi et al, 2020; Johannessen et al, 2016; Lattimore & Harrison, 2022; Orenius et al, 2022; Peebles et al, 2022; Rocchetti et al, 2021). There were five strong quality studies (Berglund et al, 2015; Estrella & Frazier, 2023; Inayet et al, 2018; Martinez et al, 2021; Rombaut et al, 2009). Finally, there was one study which was assessed to be of a weak quality (Bovet et al, 2016).

[Add Table 2 here]

Results of Studies

Results extracted from included studies can be found summarised in table 2.

Examination and Synthesis of QoL through sub-scales.

Within this review, eight domains of QoL were identified: Physical functioning (PF), Physical role limitation (PRL), Bodily Pain (BP), General Health (GH), Emotional Wellbeing (EW), Fatigue, Pain, Overall QoL score. Studies were split into three groups based on condition: hEDS, MCAS, and EDS.

Physical Functioning

There were 13 studies which could contribute to the results related to physical functioning. Eight studies recruited hEDS samples (Baeza-Velasco et al., 2023; Bovet et al., 2016; Inayet et al., 2018; Johannessen et al., 2016; Lattimore and Harrison 2022; Martinez et al., 2021; Peebles et al., 2022; Rombaut et al., 2009), four recruited EDS samples (Berglund et al., 2015; Estrella & Frazier, 2023; Hakimi et al., 2020; Verbracken et al., 2002) and one recruited MCAS (Schmidt et al., 2022).

Eight studies within this sub-scale exploring hEDS used the SF-36 to examine QoL (Baeza-Velasco et al., 2023; Bovet et al., 2016; Inayet et al., 2018; Johannessen et al., 2016; Lattimore and Harrison 2022; Martinez et al., 2021; Peebles et al., 2022; Rombaut et al., 2009). Seven of these studies were cross-sectional and all identified statistically significant differences between hEDS and control groups ($p <.001$) showing that physical functioning was lower for individuals living with hEDS in comparison to a control group who were defined as healthy (Baeza-Velasco et al., 2023; Bovet et al., 2016; Inayet et al., 2018; Johannessen et al., 2016; Martinez et al., 2021; Peebles et al., 2022; Rombaut et al., 2009). The study conducted by Lattimore and Harrison (2022) was longitudinal, examining physical functioning for individuals living with hEDS in comparison to United Kingdom expected norms, identifying that physical functioning was lower for individuals with hEDS. However, this relationship was not statistically significant (p=.071).

Four studies within this sub-scale explored physical functioning for individuals living with EDS. Three studies used the SF-36 (Berglund et al., 2015; Hakimi et al., 2020; Verbracken et al., 2002), and one study used the PROMIS-29 profile (Estrella & Frazier, 2023). Three studies were cross-sectional (Berglund et al., 2015; Estrella & Frazier, 2023; Verbracken et al., 2002), and one study was a longitudinal intervention study (Hakimi et al., 2020). Cross-sectional studies which used the SF-36 identified that physical functioning was lower for individuals living with EDS compared to a control group defined as healthy, with both studies showing statistical significance ($p < 0.05$; Berglund et al., 2015; Verbracken et al., 2002). Estrella and Frazier (2023) identified that the mean physical functioning for individuals living with EDS was 12.75 (*SD* = 3.76), however, there was not a control group within this study, and no significance figures were provided. Therefore, it is challenging to make a comparison for physical functioning from this study.

Hakimi et al. (2020) conducted a longitudinal intervention study to examine QoL for individuals living with EDS (n = 18) before, immediately after and 6 weeks post rehabilitation intervention. For the purposes of this review, baseline scores when exploring QoL subscales which were collected using the SF-36. Results indicated that individuals living with EDS had a low physical functioning (*M* = 42.80, *SD* = 18.70). However, due to this being an intervention study, there was not a control group to compare physical functioning scores against, or a significance figure provided.

Schmidt et al. (2022) conducted a cross-sectional study to examine health-related QoL for individuals living with MCAS. The study compared QoL of participants living with MCAS to a healthy control group using the QLQ-C30. Results identified that individuals living with MCAS had a lower physical functioning compared to a control group defined as healthy (*p* <.001).

[Add Table 3 here]

Physical Role Limitation

There were 10 studies identified within this sub-scale. Six studies recruited hEDS samples (Bovet et al., 2016; Inayet et al., 2018; Lattimore & Harrison 2022; Martinez et al., 2021; Peebles et al., 2022; Rombaut et al., 2009) and four recruited EDS samples (Berglund et al., 2015; Copetti et al., 2019; Hakimi et al., 2020; Verbracken et al., 2002).

Six studies within this sub-scale explored hEDS and all used the SF-36 to examine QoL (Bovet et al., 2016; Inayet et al., 2018; Lattimore & Harrison 2022; Martinez et al., 2021; Peebles et al., 2022; Rombaut et al., 2009). Physical Role Limitation in the SF-36 is reversed scored; higher scores indicate lower presence of physical role limitation. Five of these studies were cross-sectional and all identified statistically significant differences between hEDS and control groups (p <.05) showing that physical role limitation was greater for individuals living with hEDS in comparison to a control group who were defined as healthy (Bovet et al., 2016; Inayet et al., 2018; Martinez et al., 2021; Peebles et al., 2022; Rombaut et al., 2009). Lattimore and Harrison (2022) was longitudinal, examining physical functioning for individuals living with hEDS in comparison to United Kingdom expected norms, identifying that physical role limitation was greater for individuals with hEDS (p = .007).

Four studies within this sub-scale explored physical role limitation for individuals living with EDS, with all studies using the SF-36 (Berglund et al., 2015; Copetti et al., 2019; Hakimi et al., 2020; Verbracken et al., 2002). Three studies were cross-sectional, and all identified statistically significant differences between EDS and control groups (p <.001) showing that physical role limitation was greater for individuals living with EDS in comparison to a control group who were defined as healthy (Berglund et al., 2015; Copetti et al., 2019; Verbracken et al., 2002).

Hakimi et al. (2020) conducted a longitudinal intervention study, as previously described. Results indicated that individuals living with EDS had high physical role limitation (M = 18.10, SD = 31.80).

Bodily Pain

There were seven studies identified within this sub-scale. Five studies recruited hEDS samples (Bovet et al., 2016; Johannessen et al., 2016; Martinez et al., 2021; Peebles et al., 2022; Rombaut et al., 2009) and two recruited EDS samples (Berglund et al., 2015; Verbracken et al., 2002).

Five studies within this sub-scale explored hEDS and all used the SF-36 to examine QoL (Bovet et al., 2016; Johannessen et al., 2016; Martinez et al., 2021; Peebles et al., 2022; Rombaut et al., 2009). Bodily pain in the SF-36 is reversed scored; higher scores indicate lower presence of bodily pain. All studies were cross-sectional and identified statistically significant differences between hEDS and control groups (p <.001) showing that bodily pain is greater for individuals living with hEDS in comparison to a control group who were identified to be healthy (Bovet et al., 2016; Johannessen et al., 2016; Martinez et al., 2021; Peebles et al., 2022; Rombaut et al., 2009).

Two studies within this sub-scale explored EDS and both used the SF-36 to explore bodily pain for individuals living with EDS in comparison to a control group (Berglund et al., 2015; Verbracken et al., 2002). Both studies were cross-sectional and identified statistically significant differences (p <.05) between hEDS and control groups showing that bodily pain is greater for individuals living with hEDS in comparison to a control group who were identified to be healthy (Berglund et al., 2015; Verbracken et al., 2002).

General Health

There were 11 studies identified within this sub-scale. Nine studies recruited hEDS samples (Bovet et al., 2016; Baeza-Velasco et al., 2023; Copetti et al., 2019; Inayet et al., 2018; Johannessen et al., 2016; Lattimore & Harrison 2022; Martinez et al., 2021; Peebles et al., 2022; Rombaut et al., 2009), and two recruited EDS samples (Hakimi et al., 2020; Verbracken et al., 2002).

Nine studies within this sub-scale explored hEDS and all used the SF-36 to examine QoL (Bovet et al., 2016; Baeza-Velasco et al., 2023; Copetti et al., 2019; Inayet et al., 2018; Johannessen et al., 2016; Lattimore & Harrison 2022; Martinez et al., 2021; Peebles et al., 2022; Rombaut et al., 2009). Eight studies were cross-sectional and all identified statistically significant differences between hEDS and control groups (p <.001) showing that general health was significantly lower for individuals living with hEDS in comparison to a control group defined as healthy (Bovet et al., 2016; Baeza-Velasco et al., 2023; Copetti et al., 2019; Inayet et al., 2018; Johannessen et al., 2016; Martinez et al., 2021; Peebles et al., 2022;

Rombaut et al., 2009). Lattimore and Harrison (2022) was longitudinal, examining general health for individuals living with hEDS in comparison to United Kingdom expected norms, identifying that physical role limitation was lower for individuals with hEDS (*p* = .0026).

Verbracken et al. (2002) conducted a cross-sectional study to examine QoL for individuals living with EDS (n = 19) in comparison to a control group (n = 24), using the SF-36. Results indicated that individuals with EDS had a significantly lower general health (*M* = 44.00, SD = 7.00) in comparison to a control group (*M* = 84.00, *SD* = 3.00) which was defined as healthy (*p* <.05).

The results from the study conducted by Hakimi et al. (2020) indicated that individuals living with EDS had lower general health (*M* = 29.40, *SD* = 16.60).

Emotional Wellbeing

There were five studies included within this sub-scale. Three studies recruited hEDS samples (Inayet et al., 2018; Lattimore and Harrison 2022; Peebles et al., 2022), one study recruited EDS sample (Hakimi et al., 2020) and one study recruited MCAS samples (Schmidt et al., 2022).

Three studies within this sub-scale explored hEDS and all used the SF-36 to examine QoL (Inayet et al., 2018; Lattimore and Harrison 2022; Peebles et al., 2022). Two studies were cross-sectional, and both identified statistically significant differences between hEDS and control groups (*p* <.05) showing that emotional wellbeing was significantly lower for individuals living with hEDS in comparison to a control group defined as healthy (Inayet et al., 2018; Peebles et al., 2022). Lattimore and Harrison (2022) identified that emotional wellbeing was lower for individuals with hEDS (*p* <.001).

Hakimi et al. (2020) indicated that individuals living with EDS had a low-medium level of emotional wellbeing (*M* = 47.10, *SD* = 21.70).

Schmidt et al. (2022) conducted a cross-sectional study to examine health related QoL for individuals living with MCAS. The study compared QoL of participants living with MCAS to a healthy control group using the QLQ-C30. Results identified that individuals living with MCAS had lower emotional wellbeing compared to a control group defined as healthy (*p* <.001).

Fatigue

There were five studies included within this sub-scale. Three studies recruited hEDS samples (Inayet et al., 2018; Lattimore & Harrison 2022; Peebles et al., 2022), one recruited MCAS samples (Schmidt et al., 2022), and one recruited EDS sample (Estrella & Frazier, 2023).

Three studies within this sub-scale explored hEDS and all used the SF-36 to examine QoL (Inayet et al., 2018; Lattimore & Harrison 2022; Peebles et al., 2022). Fatigue in the SF-36 scale is reverse scored; higher scores indicate lower levels of fatigue. Two studies were cross-sectional, and both identified statistically significant differences between hEDS and control groups (*p* <.05), showing that fatigue was higher for individuals living with hEDS in comparison to a control group defined as healthy (Inayet et al., 2018; Peebles et al., 2022). Lattimore and Harrison (2022) was longitudinal, examining general health for individuals living with hEDS in comparison to a United Kingdom expected norms, identifying that fatigue was lower for individuals with hEDS (*p* <.001).

Estrella and Frazier (2023) conducted a cross-sectional study examining QoL for individuals living with EDS, using the PROMIS-29 scale. Fatigue in the PROMIS-29 scale is reverse scored; higher scores indicate lower levels of fatigue. This study identified that the mean fatigue for individuals living with EDS was 16.41, however there was not a control group within this study and no significance figures were provided so it is challenging to make a comparison for fatigue from this study.

Schmidt et al. (2022) identified that individuals living with MCAS had a higher level of fatigue compared to a control group defined as healthy (*p* <.001).

Pain

There were six studies included within this sub-scale. Three studies recruited hEDS samples (Copetti et al., 2019; Inayet et al., 2018; Lattimore & Harrison 2022), two studies recruited EDS samples (Estrella & Frazier, 2023; Hakimi et al., 2020) and one recruited MCAS samples (Schmidt et al., 2022).

Three studies within this sub-scale explored hEDS and all used the SF-36 to examine QoL (Copetti et al., 2019; Inayet et al., 2018; Lattimore & Harrison 2022). Pain in the SF-36 scale is reverse scored; higher scores indicate lower levels of pain. Two studies were cross-sectional, and both identified statistically significant differences between hEDS and control groups (*p* <.05), showing that levels of pain were higher for individuals living with hEDS in comparison to a control group defined as healthy (Copetti et al., 2019; Inayet et al., 2018).

Lattimore and Harrison (2022) was longitudinal, examining general health for individuals living with hEDS in comparison to a United Kingdom expected norms, identifying that levels of pain were higher for individuals with hEDS (*p* <.001).

Estrella and Frazier (2023) identified that the mean pain for individuals living with EDS was 14.71 (*SD* = 4.09). Hakimi et al. (2020) indicated that individuals living with EDS had a high level of pain (*M* = 31.00, *SD* = 24.30).

Results from Schmidt et al. (2022) identified that individuals living with MCAS had a higher level of pain (*M* = 75.00, *SD* = 30.00) compared to a control group (*M* = 9.00, *SD* = 15.00) defined as healthy (*p* <.001).

Other Total QoL Score

This section explored studies which included total QoL scores to allow for comparison between EDS and MCAS in comparison to a control group. There were four studies identified within this theme. Two studies recruited EDS samples (Hakimi et al., 2020; Rochetti et al., 2021), one study recruited MCAS samples (Schmidt et al., 2022) and one study recruited hEDS samples (Orenius et al., 2022). All four studies were moderate quality.

Hakimi et al. (2020) indicated that individuals living with EDS had a low physical component of QoL (*M* = 30.50, *SD* = 7.00) and low mental component of QoL (*M* = 35.70, *SD* = 10.90).

Rochetti et al. (2021) conducted a cross-sectional study to explore QoL and psychological distress for individuals living with cEDS (n = 89), hEDS (n = 47), vEDS (n = 3), sEDS (n =

17). The main outcome measure for this study was the World Health Organisation QoL - Short version (WHOQOL–BREF) which explores general QoL, physical health, and psychological. All scores were statistically significant (p = .007).

Orenius et al. (2022) conducted a cross-sectional study to examine health-related QoL for individuals living with hEDS (n = 81) in comparison to a control group (n = 90). The main outcome measure for this study was the SF-36 exploring total scores for the physical and mental component. Results indicated that individuals living with EDS had a lower physical and mental component of QoL in comparison to a control group defined as healthy (*p* <.001).

Schmidt et al. (2022) indicated that individuals living with MCAS had a lower QoL (*M* = 21.00, *SD* = 17.00) compared to a control group (*M* = 85.00, *SD* = 12.00) defined as healthy (*p* <.001).

Discussion

The aim of this review was to compare the QoL for individuals living with EDS and MCAS. From 1626 studies initially identified, 16 studies were included within this review; 15 focussed on EDS and 1 focussed on MCAS. For both EDS and MCAS, all included studies illustrated that QoL was significantly and negatively impacted for individuals living with both conditions, in comparison to control groups.

Whilst examining the impact which EDS has on an individual's level of QoL, it was identified that individuals living with the condition had a lower QoL in comparison to a 'healthy' control group. This reduced QoL was identified across all examined domains. Across studies which used the SF-36 to measure QoL, it was identified that social functioning, physical health, pain, and pain anxiety were the highest impacted areas for an individual's QoL whilst living with EDS (Berglund et al., 2015; Peebles et al., 2022). This was evidenced by low mean scores reported (for social functioning and physical health) or high scores reported (for pain and pain anxiety) in comparison to other domains of QoL and in comparison, to control groups. For studies which did not use the SF-36 and focussed on specific aspects of mental health, fatigue, and sleep disturbance, it was identified that levels of fatigue, sleep disturbance, and anxiety were significantly higher for individuals living with EDS in comparison to control groups (Lattimore & Harrison, 2022).

Within studies which compared levels of severity of EDS, it was identified that more severe levels of EDS have poorer quality of life across all domains, with domains such as general health and physical pain having 50% lower mean scores for individuals in the severe category in comparison to milder category (Copetti et al., 2019). However, caution must be taken whilst interpreting these results due to it being unclear as to how researchers categorised mild and severe levels of EDS. For studies which compared EDS type and QoL, individuals living with Spondylodysplastic EDS (sEDS) reported the lowest levels of physical and psychological health in comparison to other types of EDS examined. Individuals living with Vascular EDS (vEDS) demonstrated the lowest levels of health satisfaction and general QoL in comparison to other types of EDS examined (Rocchetti et al.,2021). This demonstrates that the type of EDS and severity can have an impact on an individuals' level of QoL.

Whilst examining QoL for individuals living with MCAS, it was highlighted that in comparison to a 'healthy' control group, individuals living with the condition had a lower QoL across all domains (Schmidt et al., 2022). The most impacted domain of QoL for individuals living with MCAS was social functioning. For the comparison of QoL between

MCAS and EDS, it can be concluded that different domains of QoL are impacted more for EDS and MCAS. Physical role limitation and general health are impacted more for individuals living with EDS in comparison to MCAS. Whereas emotion and social functioning are impacted more for individuals living with MCAS in comparison to EDS. However, due to only one included study focussing upon MCAS and the scale used to measure QoL being specialised for cancer and not similar means that comparisons should be tentatively concluded.

Strengths and Limitations of studies included.

There were limitations of the studies included within this review. Studies included within the review used different measures to explore QoL including the SF-36, QLQ-C30, PROMIS-29 and WHOQOL-BREF (Estrella & Frazier, 2023; Hakimi et al., 2020; Peebles et al., 2022; Schmidt et al., 2022). Within each measure, scores for QoL were calculated differently, meaning that it was more complex to compare QoL for individuals living with EDS or MCAS. The different measures explored QoL through different subscales, with the studies using the SF-36 examining each subscale in turn, and only two studies providing a total score (Hakimi et al., 2020; Orenius et al., 2022). Measures such as the QLQ-C30, PROMIS-29 and WHOQOL-BREF examined QoL through different questions and subscales, meaning overall QoL could only be assessed and compared if subscales used similar terms as the SF-36. Therefore, more research needs to be conducted surrounding this topic area using the same measures to allow for further direct comparisons.

Furthermore, the measure used within the included MCAS study (Schmidt et al,. 2022) was designed for studies examining QoL in individuals living with cancer (Kassa et al., 1995). Although the measure has been identified to have high internal reliability and validity

(Schmidt et al,. 2022), the concept of it being designed for individuals living with cancer calls into question the reliability of the measure when examining QoL for individuals living with MCAS. This is due to the conditions presenting different psychological, physical, and social challenges, thus potentially meaning scores from this measure for individuals living with MCAS may be questionable in terms of reliability. Consequently, future research needs to examine QoL and MCAS using either specific measures designed for MCAS, or a more commonly used measure for QoL such as the SF-36.

Studies frequently used control groups to assess QoL, labelling the group as a ‘healthy control group’ (Inayet et al., 2018; Lattimore & Harrison, 2022; Peebles et al., 2022; Schmidt et al., 2022). However, it needs to be questioned whether this control group was healthy, living without the presence of any other physical health condition, or whether participants were purely considered to be ‘healthy’ if they were not living with either EDS or MCAS. The uncertainty as to how studies categorised the control groups as healthy may have impacted the QoL results, subsequently questioning the reliability of the comparisons made within the review. Subsequently, further research needs to examine the accuracy of reporting individuals as ‘healthy’ and ensure that any health conditions are self-reported in demographic information to ensure reliability of comparisons.

Strengths and limitations of this review

A strength of this review is that it is the first within this field to be conducted, examining both EDS and MCAS in relation to QoL. Within this review, a wide search was conducted to examine QoL for both EDS and MCAS. It has identified that QoL is negatively impacted by both conditions, highlighting the need for further research and interventions to help support individuals living with either condition.

A limitation of this systematic review is that it has not fully met the initial questions which it aimed to explore, due to MCAS being significantly under researched which resulted in only one MCAS paper included within this review. It was noted that papers which were excluded at final screening explored mastocytosis, a condition where abnormal mast cells are increased in multiple organs within an individual's body (American Academy of Allergy, Asthma, and Immunology, 2023). However, this is a different condition to MCAS (although the two are correlated), meaning the studies could not be included within the review for exploration of QoL. The little MCAS research meant only small comparisons of QoL compared to EDS could be made.

Implications for Practice and Future Research

The results from this systematic review can help to inform interventions which aim to improve QoL for individuals living with EDS and MCAS. Based upon findings, it is important for healthcare professionals to support individuals living with EDS with fatigue, pain, pain anxiety to help improve QoL. This may include multidisciplinary team work to design and develop interventions to help individuals manage levels of fatigue such as pacing (Casson et al., 2023), pain and pain anxiety such as cognitive behavioural therapy for pain (Wilson, 2017). For individuals living with MCAS, healthcare professionals should help to support individuals with social functioning, and emotional wellbeing to help support a higher level of QoL. Raising awareness and providing information to healthcare professionals, clinicians and the general public about both conditions will help to provide further support for individuals living with the conditions. The awareness will enable further conversations and ensure that individuals with the conditions do not feel isolated or unsupported in accessing healthcare or controlling symptoms, subsequently helping to improve QoL.

Future research needs to examine the impact of MCAS on individuals' QoL to ensure that support is implemented and provided for those with the condition. Furthermore, future research surrounding this topic area should prioritise clearly defining the control group which is used to compare QoL and the scale which is being used to measure QoL. This will ensure that results produced are reliable and representative of both the condition and control group.

Conclusion

Although there was a very limited number of studies within this research area, it has been identified that EDS and MCAS both negatively impact an individual's QoL across all domains examined. Further research needs to be conducted to examine QoL in relation to both conditions using similar measures to allow for direct comparison to occur, allowing more precise intervention support to be designed, developed, and implemented. There needs to be further research specifically exploring MCAS as a condition to help support individuals living with this condition.

Contribution of Authors

Chloe Ryder: Conceptualisation, Methodology, Formal Analysis, Investigation, Writing – Original Draft.

Helen McEwan: Methodology, Formal Analysis, Investigation, Writing – Original Draft.

Richard Cooke: Methodology, Formal Analysis, Investigation, Writing – Review and Editing.

Rachel Povey: Methodology, Formal Analysis, Investigation, Writing – Review and Editing, Supervision.

Lisa Cowap: Review and Editing, Supervision.

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Please note: References marked with an asterisk (*) were the included studies within the review.

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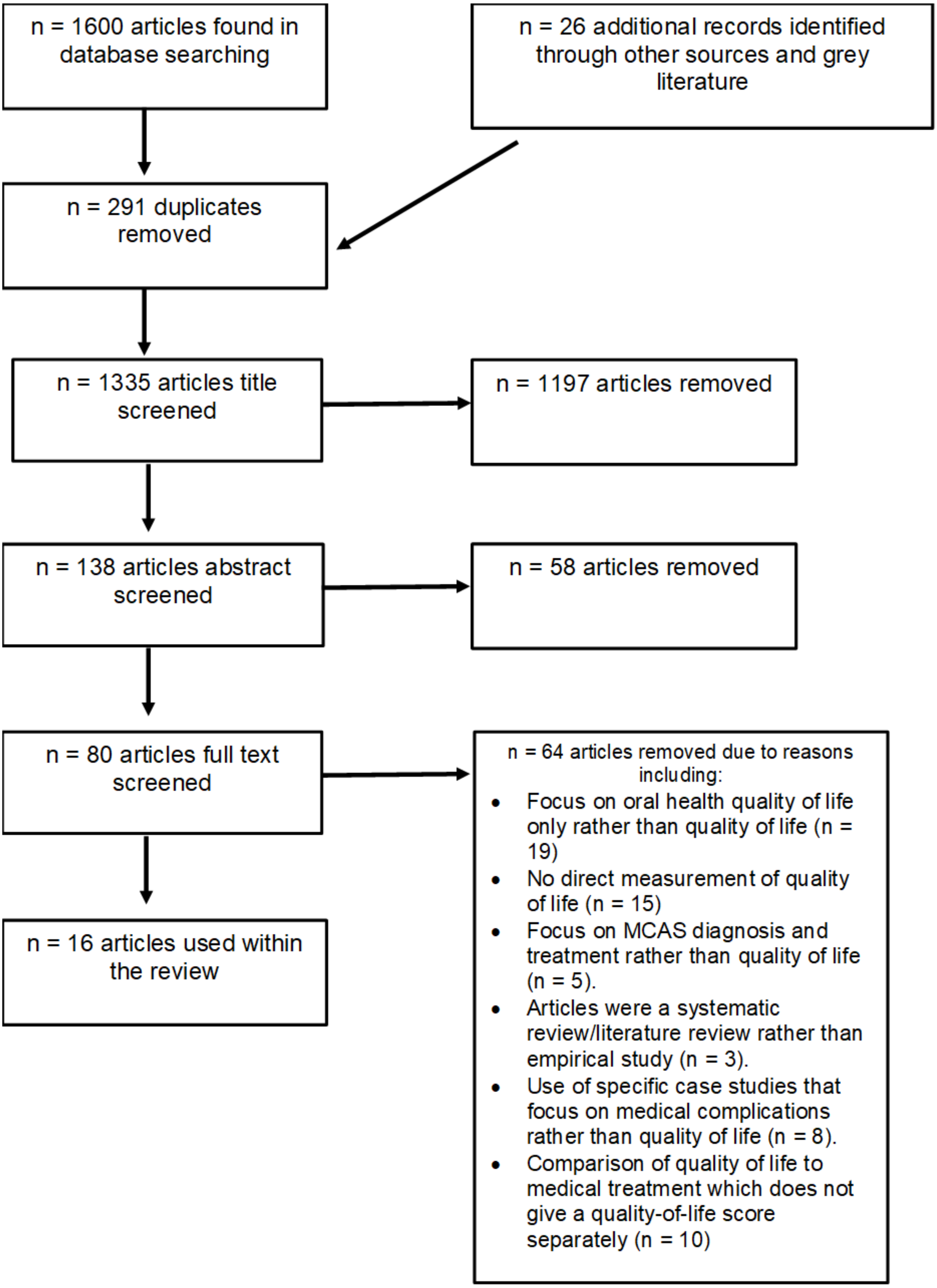
Table 1. Quality Assessment Table of included articles using the EPHPP

Article Authors and Publication Year	Selection bias	Study Design	Confounders	Blinding	Data Collection	Withdrawals/ Dropouts	Overall Rating
Baeza-Velasco, C., Rodriguez, N., Parra, L., & Gutiérrez-Rosado, T. (2023).	Moderate	Strong	Moderate	Weak	Strong	Strong	Moderate
Berglund, B., Pettersson, C., Pigg, M., & Kristiansson, P. (2015).	Strong	Strong	Moderate	Weak	Strong	Moderate	Strong
Bovet, C., Carlson, M., & Taylor, M. (2016)	Weak	Weak	Weak	Moderate	Strong	Weak	Weak
Copetti, M., Morlino, S., Colombi, M., Grammatico, P., Fontana, A., & Castori, M. (2019)	Moderate	Strong	Moderate	Weak	Strong	Strong	Moderate
Estrella, E., & Frazier, P. A. (2023)	Moderate	Strong	Moderate	Weak	Strong	Weak	Strong
Hakimi, A., Bergoin, C., & Mucci, P. (2020)	Strong	Strong	Moderate	Weak	Strong	Moderate	Moderate
Inayet, N., Hayat, J. O., Kaul, A., Tome, M., Child, A., & Poullis, A. (2018)	Strong	Strong	Moderate	Weak	Strong	Strong	Strong
Johannessen, E. C., Reiten, H. S., Lovass, H., Maeland, S., & Juul-Kristensen, B. (2016)	Moderate	Moderate	Moderate	Weak	Strong	Weak	Moderate

Lattimore, P., & Harrison, F. (2022)	Strong	Strong	Weak	Weak	Strong	Moderate	Moderate
Martinez, K. L., Mauss, C., Andrews, J., Saboda, K., Huynh, J. M., Sanoja, A. J., Jesudas, R., Byers, P. H., & Laukaitis, C. M. (2021)	Strong	Strong	Moderate	Weak	Strong	Strong	Strong
Orenius, T., Kautiainen, H., Louhi, M., Montin, L., Bulbena, A., & Lindgren, K. A. (2022)	Moderate	Strong	Moderate	Weak	Strong	Moderate	Moderate
Peebles, K. C., Tan, I., Butlin, M., Collins, F., Tofts, L., Avolio, A., & Pacey, V. (2022)	Moderate	Moderate	Moderate	Weak	Strong	Weak	Moderate
Rocchetti, M., Bassotti, A., Corradi, J., Damiani, S., Pasta, G., Annunziata, S., Guerrieri, V., Mosconi, M., Gentilini, D., & Brondino, N. (2021).	Moderate	Strong	Moderate	Weak	Strong	Weak	Moderate
Rombaut, L., Malfait, F., Cools, A., De Paepe, A., & Calders, P. (2009)	Strong	Strong	Strong	Weak	Strong	Strong	Strong

Schmidt, T, J., Sellin, J., Molderings, G. J., Conrad, R., & Mücke, M. (2022)	Moderate	Moderate	Weak	Weak	Weak	Strong	Moderate
Verbraecken, J., Declerck, A., Van de Heyning, P., De Backer, W., & Wouters, E. F. M. (2002)	Moderate	Moderate	Moderate	Weak	Strong	Strong	Moderate

Figure 1: *PRISMA Diagram demonstrating search and study selection process.*



n = 64 articles removed due to reasons including:

- Focus on oral health quality of life only rather than quality of life (n = 19)
- No direct measurement of quality of life (n = 15)
- Focus on MCAS diagnosis and treatment rather than quality of life (n = 5).
- Articles were a systematic review/literature review rather than empirical study (n = 3).
- Use of specific case studies that focus on medical complications rather than quality of life (n = 8).
- Comparison of quality of life to medical treatment which does not give a quality-of-life score separately (n = 10)

Table 2. Table including descriptive information for studies.

Article Authors, Publication Year, and country of study	**Aim**	**Design**	**Sample and Sample Size**	**Outcome & Outcome Measure**
Baeza-Velasco et al., (2023). Spain	To explore the psychosocial adjustment and QoL for individuals living with vEDS in comparison to individuals living with hEDS and a healthy control group.	Cross-sectional and mixed methods study	n=16 participants with a diagnosis of vEDS (n = 9) and LDS (n=7) – make up the HDCTv group for comparison n=16 participants with a diagnosis of hEDS	Multiple outcomes to the study including: Adjustment to illness QoL Anxiety and Depression Outcome measure: 36 items Short Form Health Survey (SF-36) Three areas of QoL including: Physical functioning, general health, and vitality.
Berglund et al., (2015). Sweden	To explore QoL, anxiety and depression levels in individuals living with EDS compared to a healthy control group.	Cross-sectional Quantitative Study	N = 250 Mean age = 46.15 (12) Age range = 18-84 N=233 females (89%) and n= 27 males (11%) Control group (n = 8903)	QoL (main outcome) Secondary outcomes included: Anxiety and Depression Outcome measure: 36 items Short Form Health Survey (SF-36)

				Subscales were individually analysed (no overall score provided)
Bovet et al., (2016) United States	To examine the health-related QoL for individuals living with EDS/JHS	Cross-sectional Mixed methods study	N=28 participants with a diagnosis of EDS/JHS Control group (n = 22462)	Health-related QoL Outcome measure: 36 items Short Form Health Survey (SF-36)
Copetti et al., (2019) Italy	To explore the discrete severity classes within hEDS by examining QoL scores.	Cross-sectional Quantitative study	N = 105 participants N= 9 males (8.6%) and n=96 females (91.4%) Mean age = 36.9 (12.1) Participants into 2 groups: Severe: n=63 Milder n = 42	QoL Outcome measure: 36 items Short Form Health Survey (SF-36)
Estrella & Frazier (2023) United States	To explore patient satisfaction with healthcare, health-related QoL and symptom management for individuals living with EDS.	Cross-sectional Mixed methods study	N = 2125 Ages ranged from 18 – 79 (*m* = 37.27, SD = 12.34) More females (83.4%) in comparison to males (16.5%)	Health-related QoL Outcome measure: PROMIS-29 Profile
Hakimi, et al., (2020) France	To examine QoL for individuals living with EDS before, immediately after and 6 weeks post rehabilitation intervention	Longitudinal Quantitative study	N=29 participants recruited in total However, only n=18 participated in the study	QoL Outcome measure: 36 items Short Form Health Survey (SF-36)
Inayet, et al., (2018) United Kingdom	To explore gastrointestinal symptoms and QoL for individuals living with hEDS and marfan syndrome.	Cross-sectional Quantitative study	N = 90 participants, n = 45 living with marfan syndrome and n= 45 living with hEDS	QoL

			N = 90 participants (control group) hEDS participant group: n = 39 females, and n= 6 males. Age range = 18.32 (m = 24)	Outcome Measure: 36 items Short Form Health Survey (SF-36)
Johannessen et al., (2016) Norway	To investigate shoulder pain, pain, and health related QoL for individuals living with hEDS.	Cross-sectional Quantitative study	N = 110 participants living with hEDS from two different hospitals N = 140 participants without the condition (control group) ***Important to note:*** Only n= 52 participants fully completed in the hEDS group Only n=29 participants fully completed in the control group	Health Related QoL Outcome measure: 36 items Short Form Health Survey (SF-36)
Lattimore & Harrison (2022) United Kingdom	To examine the impacts of an intervention on QoL for individuals living with hEDS.	Longitudinal Mixed methods study	N = 81 however only n= 76 completed the full study Participant figures were compared to UK norms within the study for pre-intervention (baseline) figures.	QoL Outcome measure: 36 items Short Form Health Survey (SF-36)
Martinez et al., (2021) United States	To examine the factors influencing health related QoL for individuals living with hEDS and HSD.	Cross-sectional Quantitative Study	3 groups of participants Control group: N = 23 HSD group: n = 27 hEDS group: n = 98	Health related QoL Outcome measure: 36 items Short Form Health Survey (SF-36)

Orenius et al., (2022) Finland	To examine health related QoL for individuals living with hEDS.	Cross-sectional Quantitative Study	2 groups hEDS group: n = 81 females n = 78 (96%) Mean age = 31(11) Control group N = 90 Females n = 82 (91%) Mean age = 38 (9)	Health related QoL Outcome measure: 36 items Short Form Health Survey (SF-36)
Peebles et al., (2022) Australia	To compare symptoms of OI in individuals living with hEDS vs. a control group. To examine QoL.	Cross-sectional Quantitative study	N = 45 participants into three groups hEDS n = 15 G-HSD N = 15 Control N = 15 However not all participants completed the study: Control: N = 12 G-HSD N = 12 hEDS n = 6	QoL Outcome measure: 36 items Short Form Health Survey (SF-36)
Rocchetti et al., (2021).	To explore QoL and psychological distress for individual living with EDS in northern Italy.	Cross-sectional study	N = 515 participants total	QoL

Italy		Observational Quantitative Study	High dropout rate – n = 156 participants completed the study N = 132 females (78%) Mean age = 40 (11.65) 4 groups of participants (different types of EDS) N = 89 had cEDS N = 47 had hEDS N = 3 had vEDS N = 17 had sEDS	Outcome measure: World Health Organisation QoL, short version (WHOQOL-BREF) questionnaire
Rombaut et al., (2009) Belguim	To examine the musculoskeletal complaints, physical activity, and health-related QoL in individuals living with hEDS.	Cross-sectional Quantitative study	N = 54 participants 2 groups: hEDS group n = 27 age range = 26-67 Control group N = 27 Age range = 24-66	Health related QoL Outcome measure: 36 items Short Form Health Survey (SF-36)
Schmidt et al., (2022) Germany	To examine health related QoL for individuals living with MCAS and mastocytosis.	Cross-sectional Quantitative Study	3 groups of participants MCAS N = 66 Females n = 55 (83%) Age m = 44.18	Health related QoL Outcome measure: QLQ-C30

			SM N = 32 Females n = 25 (78%) Age m = 53.12 Control group N = 52 Female = 67% Age m = 48	
Verbraecken et al., (2002) Belgium	To examine fatigue levels and health related QoL for individuals living with Marfan’s syndrome and EDS in comparison to a control group.	Cross-sectional Quantitative Study	3 groups of participants Marfans syndrome: N = 15 N = 9 females Age m = 33 EDS N = 19 N = 6 females Age m = 34 Control group N = 24 N = 16 females Age m = 33	Health related QoL Outcome measure: 36 items Short Form Health Survey (SF-36)

Table 3. Results of the sixteen included studies.

Article Authors and Publication Year	Statistical Analysis	Results	Effect Size	Significance (*p*)	95% Confidence Intervals
Baeza-Velasco et al., (2023).	Binary logistic regression	**PF:**: HDCTv participants m = 68.7 (24.3) hEDS participants m = 39.0 (24.4) **Vitality**: HDCTv participants m = 50.9 (13.5) hEDS participants m = 27.1 (11.8) **GH:** HDCTv participants m = 41.0 (13.2) hEDS participants m = 21.3 (10.7)	No effect sizes were provided	**PF**: 0.013 **Vitality**: 0.005 **GH**: 0.013	**PF** (None Reported) **Vitality** 1.01-1.14 **GH** 1.01-1.71
Berglund et al., (2015).	Independent T-test was used to compare differences between groups. Linear regression was also used.	**PF:** EDS group: 48.3 Control group: 87.9 **PRL**: EDS group: 23.8 Control group:	No effect sizes were provided	All subscales analysed had a p value of .000	**Physical Component** 25.80-28.60 **Mental Component** 40.60-43.60

		83.2 **BP:** EDS group = 31.6 Control group = 74.8 **GH:** EDS group = 34.2 Control group = 75.8 **Vitality:** EDS group = 30.2 Control group = 68.8 **SF:** EDS group = 53.7 Control group = 88.6 **ERL:** EDS group = 58.3 Control group = 85.7 **MH:** EDS group = 65.5 Control group = 80.9			
Bovet et al., (2016)	Independent T-test was used to compare differences between groups	No precise figures provided for the control group. **PF** *m* = 30.0 **PRL** *m* = 10.2	No effect sizes were provided	**PF** .001 **PRL** .001	None Reported

		ERL *m* = 59.2 **Vitality** *m* = 26.3 **MH** *m* = 59.9 **SF** *m* = 32.2 **BP** *m* = 21.9 **GH** *m* = 26.8		**ERL** <0.05 **Vitality** .001 **MH** .001 **SF** .001 **BP** .001 **GH** .001	
Copetti et al., (2019)	Hierarchical Regression	**ERL** Milder group: *m* = 59.33 (40.03) Severe group: *m* = 32.65 (38.94) **GH** Milder group: *m* = 36.57 (17.74) Severe group: *m* = 18.11 (11.94) **MH** Milder group: *m* = 63.14 (17.14) Severe group:	No effect sizes were provided	**ERL** 0.001 **GH** <0.001 **MH** 0.002 **PA** <0.001 **PH** <0.001 **PP** <0.001	None Reported

	m = 50.73 (20.93) **PA** Milder group: *m* = 68.33 (16.74) Severe group: *m* = 38.33 (21.98) **PH** Milder group: *m* = 146.93 (57.76) Severe group: *m* = 66.97 (39.81) **PP** Milder group: *m* = 44.67 (20.27) Severe group: *m* = 21.49 (13.52) **PRL** Milder group: *m* = 33.93 (33.96) Severe group: *m* = 7.14 (15.83) **PEH** Milder group: *m* = 181.48 (60.01) Severe group: *m* = 118.10 (65.51) **SA** Milder group: *m* = 59.00 (21.40)	**PRL** <0.001 **PEH** <0.001 **SA** <0.001 **Vitality** <0.001

		Severe group: *m* = 34.71 (22.58) **Vitality** Milder group: *m* = 42.50 (18.12) Severe group: *m* = 22.86 (15.21)			
Estrella & Frazier (2023)	Pearson's Correlation	**Physical function** *m* = 12.75 (3.76) **Anxiety** *m* = 11.05 (4.39) **Depression** *m* = 10.02 (4.07) **Fatigue** *m* = 16.41 (3.19) **Sleep disturbance** *m* = 14.40 (3.42) **Social role participation** *m* = 9.52 (3.46) **Pain interference** *m* = 14.71 (4.09) **Pain intensity** *m* = 5.64 (1.76)	**Physical function** *m* = 12.75 **Anxiety** *m* = 11.05 **Depression** *m* = 10.02 **Fatigue** *m* = 16.41 **Sleep disturbance** *m* = 14.40 **Social role participation** *m* = 9.52 **Pain interference** *m* = 14.71 **Pain intensity** *m* = 5.64	No significance values were provided	**Physical function** 33.09-42.11 **Anxiety** 56.40-66.60 **Depression** 54.39-63.41 **Fatigue** 60.80-70.20 **Sleep disturbance** 52.23-65.17 **Social role participation** 35.29-44.11 **Pain interference** 61.27-68.33 **Pain intensity** (not reported)

Hakimi et al., (2020)	One way ANOVA	**PF:** 42.8 ± 18.7 **PRL:** 18.1 ± 31.8 **ERL:** 33.3 ± 41.2 **Vitality:** 21.6 ± 13.8 **Emotional Well-being**: 47.1 ± 21.7 **SF**: 45.1 ± 29.7 **Pain**: 31.0 ± 24.3 **GH**: 29.4 ± 16.6 **Health change**: 45.8 ± 35.6 **Physical composite score**: 30.5 ± 7.0 **Mental Composite score**: 35.7 ± 10.9	No effect sizes provided	Only NS provided as significance values	None Reported
Inayet et al., (2018)	Chi-squared test Independent sample t-test	**PF:** Control m = 100.0 hEDS m = 60.0	No effect sizes provided	**PF:** <0.001	None Reported

		PRL: Control m = 100.0 hEDS m = 50.0 **ERL**: Control m = 100.0 hEDS m = 50.0 **Fatigue**: Control m = 95.0 hEDS m = 30.0 **Emotional wellbeing:** Control m = 100.0 hEDS m = 50.0 **SF**: Control m = 87.5 hEDS m = 50.0 **Pain**: Control m = 77.5 hEDS m = 50.0 **GH:** Control m = 100.0 hEDS m = 45.0		**PRL:** <0.001 **ERL**: <0.001 **Fatigue**: <0.001 **Emotional wellbeing:** <0.001 **SF:** <0.001 **Pain:** <0.05 **GH:** <0.001	
Johannessen et al., (2016)	Mann-Whitney U-test	**PF**: hEDS group *m* = 55.7 (24.9) control group *m* = 87.8 (17.5) **PR** hEDS group *m* = 11.9 (25.6)	No effect sizes were provided for the results of this study	**PF** <0.001 **PR**: <0.001 **BP**	None Reported

		control group m = 67.2 (40.7) **BP:** hEDS group m = 31.2 (15.4) control group m = 62.7 (31.3) **GH:** hEDS group m = 37.8 (17.1) control group m = 69.7 (23.0) **Vitality** hEDS group m = 32.7 (16.7) control group m = 50.3 (24.1) **SF** hEDS group m = 56.0 (31.5) control group m = 79.3 (24.6) **Emotional role** hEDS group m = 69.9 (41.4) control group m = 86.2 (31.5) **MH** hEDS group m = 69.9 (16.1) control group m = 73.1 (20.0)		<0.001 **GH** <0.001 **Vitality** 0.001 **SF** 0.001 **Emotional role** 0.040 **MH** 0.196	
Lattimore & Harrison (2022)	Wilcoxon	**PF** hEDS group m = 31.3 (20.3) control group m = 89.8 **PRL** hEDS group m = 9.7 (19.7) control group m = 85.3 **ERL** hEDS group m = 30.0 (16.1)	**PF** r^2 = -.04 **PRL** r^2 = -.31 **ERL** r^2 = -.36 **Fatigue** r^2 = -.45 **Emotional Wellbeing** r^2 = -.43	**PF** 0.7149 **PRL** 0.0077 **ERL** 0.0018 **Fatigue**	None Reported

		control group m = 83.8 **Fatigue** hEDS group m = 18.0 (15.5) control group m = 60.5 **Emotional wellbeing** hEDS group m = 51.5 (18.7) control group m = 73.1 **SF** hEDS group m = 38.8 (24.7) control group m = 88.6 **Pain** hEDS group m = 38.4 (16.5) control group m = 80.5 **GH** hEDS group m = 22.9 (16.4) control group m = 74.1	**SF** r^2 = - .45 **Pain** r^2 =-.35 **GH** r^2 = -.13	0.0001 **Emotional Wellbeing** 0.0002 **SF** 0.0063 **Pain** 0.0001 **GH** 0.0026	
Martinez et al., (2021)	ANOVA	**PF** hEDS group m = 45.7 (27.2) control group m = 70.9 (29.8) **PRL** hEDS group m = 20.2 (34.0) control group m = 58.7 (43.0) **BP** hEDS group m = 35.1 (23.4) control group m = 62.8 (25.4) **GH**	No effect sizes were provided.	**PF** <0.001 **PRL** <0.001 **BP** <0.001 **GH** <0.001 **SF** <0.001	None Reported

		hEDS group *m* = 28.5 (20.1) control group *m* = 57.6 (24.4) **SF** hEDS group *m* = 47.7 (27.3) control group *m* = 78.8 (24.6) **ERL** hEDS group *m* = 49.0 (41.2) control group *m* = 85.5 (28.1) **Vitality** hEDS group *m* = 22.6 (21.3) control group *m* = 53.1 (22.2) **MH** hEDS group *m* = 60.0 (21.1) control group *m* = 79.3 (13.8)		**ERL** <0.001 **Vitality** <0.001 **MH** <0.001	
Orenius et al., (2022)	Independent t-test Pearson’s correlation	HRQoL–physical component = hEDS group (M = 34.69, SD = 20.32) HC group (M = 95.83, SD = 7.32); HRQoL– mental component = hEDS group (M = 61.63, SD= 23.05) HC group (M = 80.58, SD = 17.73);	hEDS r= -.38 HC group r = =.73	**Physical Component** <.001. **Mental Component** < .001	-0.55 to -0.18
Peebles et al., (2022)	ANOVA Chi-squared	**PF** Control: 96 ± 10 hEDS: 33 ± 18	No Effect sizes were provided	All significance figures were <0.05	None Reported

PRL
Control
92 ± 29
hEDS:
8 ± 20

BP
Control
83 ± 27
hEDS
28 ± 15

GH
Control
67 ± 20
hEDS
20 ± 14

Fatigue
Control
60 ± 14
hEDS
8 ± 8

SF
Control
90 ± 29
hEDS
38 ± 26

ERL
Control
92 ± 29

		hEDS 33 ± 42 **Emotional Wellbeing** Control 78 ± 10 hEDS 44 ± 15			
Rocchetti et al., (2021).	ANOVA	**Health satisfaction** sEDS m = 2.12 (0.78) cEDS m = 2.57 (1.00) hEDS m = 2.38 (1.05) vEDS m = 2.00 (1.00) **General QoL** sEDS m = 2.35 (0.79) cEDS m = 3.16 (0.95) hEDS m = 2.98 (0.92) vEDS m = 2.33 (0.58) **Physical health** sEDS m = 36.55 (22.75) cEDS m = 49.88 (22.11) hEDS m = 39.21 (20.06)	**Health Satisfaction** f = 1.39 **General QoL** f = 4.18 **Physical Health** f = 4.56 **Psychological** f = 5.42 **Social Relationship** f = 3.74 **Environment** f = 1.69	**Health satisfaction** 0.258 **General QoL** 0.007 **Physical health** 0.004 **Psychological** 0.001 **Social relationship** 0.013 **Environment** 0.171	**Health Satisfaction** None Reported **General QoL** -1.46 to -0.15 **Physical Health** -.022 to -21.12 **Psychological** -32.98 to -6.50 **Social Relationship** -35.60 to -2.17 **Environment** None Reported

		vEDS m = 67.86 (28.57) **Psychological** sEDS m = 38.97 (19.98) cEDS m = 58.71 (17.70) hEDS m = 53.72 (20.01) vEDS m = 58.33 (20.83) **Social relationship** sEDS m = 38.24 (21.66) cEDS m = 57.12 (23.69) hEDS m = 50.71 (24.62) vEDS m = 69.44 (4.81) **Environment** sEDS m = 47.24 (17.85) cEDS m = 56.74 (17.18) hEDS m = 52.73 (17.20) vEDS m = 53.13 (5.41)			
Rombaut et al., (2009)	Mann-Whitney U Test	**PF** hEDS	No effect sizes were provided for this study.	**PF** <0.001	None Reported

	median = 35 Control group Median = 95 **SF** hEDS median = 50 Control group Median = 100 **PRL** hEDS median = 0 Control group Median = 100 **ERL** hEDS median = 67 Control group Median = 100 **MH** hEDS median = 68 Control group Median = 84 **Vitality** hEDS median = 40 Control group Median = 75 **BP** hEDS	**SF** <0.001 **PRL** <0.001 **ERL** <0.001 **MH** <0.001 **Vitality** <0.001 **General Health** <0.001 **Health Change** 0.049

		median = 35 Control group Median = 100 **General Health** hEDS median = 33 Control group Median = 73 **Health change** hEDS median = 50 Control group Median = 50			
Schmidt et al., (2022)	ANOVA Linear Regression	**Global health status** MCAS: M = 21 (17) Control: M = 85 (12) **Physical function** MCAS: M = 47 (24) Control: M = 97 (6) **Role function** MCAS: M = 12 (20) Control: M = 94 (14) **Emotional function**	**Global health status** = 3.89 **Physical function** = 2.26 **Role function** = 3.15 **Emotional function** = 2.83 **Cognitive function** = 2.21 **Social function** = 3.31	All p values were <0.001	None Reported

		MCAS: M = 21 (24) Control: M = 84 (18) **Cognitive function** MCAS: M = 33 (30) Control: M = 90 (16) **Social function** MCAS: M = 18 (22) Control: M = 94 (17)			
Verbraeckenet al., (2002)	ANOVA Mann-Whitney U Test	**PF** Control 97±1 EDS 59±5 **SF** Control 92±3 EDS 68±8 **PRL** Control 96±4 EDS 25±14 **ERL**	No effect sizes provided	**PF** <0.05 **SF** <0.05 **PRL** <0.05 **ERL** N.S **MH** <0.05 **Vitality** <0.05	None Reported

	Control 94±4 EDS 74±15 **MH** Control 84±2 EDS 64±7 **Vitality** Control 75±2 EDS 54±5 **BP** Control 92±3 EDS 45±7 **General Health** Control 84±3 EDS 44±7 **Health Changes** Control 59±1 EDS 68±8	**BP** <0.05 **General Health** <0.05 **Health change** <0.05

3.2 Systematic Review: Reflective Commentary

Systematic reviews are defined by the inclusion of certain characteristics including a detailed plan, clear and comprehensive search strategy, and the synthesis of all relevant studies on a chosen topic area (Uman, 2011). Research has examined the strengths of conducting systematic reviews within research, with it being identified that systematic reviews are a very thorough and transparent method of research (Mallett et al., 2012) which allow for reliable conclusions and summaries to be made on a particular topic area (Knaap et al., 2008; Mallett et al., 2012).

I conducted the review at my placement in collaboration with my workplace contact (HM). HM was happy for me to take the lead on the review, choosing a topic area which I had interest in and agreed to help me conduct the review. One of my research interests includes underdiagnosed/rare long-term conditions, so I chose to conduct a review on exploring quality of life (QoL) for individuals living with Ehlers-Danlos Syndrome (EDS) and Mast Cell Activation Syndrome (MCAS). Research has identified that MCAS and EDS are linked, and along with Postural Tachycardia Syndrome (PoTS) make the 'trifecta' of conditions (Kucharik & Chang, 2020). Both EDS and MCAS are very under-researched conditions and have significant impacts on an individuals life; therefore, essential to research how symptoms of both conditions impact an individuals QoL.

I had experience of completing systematic reviews prior to conducting this review, one at undergraduate level and one at MSc level. From prior experience, I knew I enjoyed conducting systematic reviews due to being able to follow a logical, clear, and structured process, which meant I was looking forward to conducting this review. I was also able to reflect on prior completed reviews to know what I should do differently for this review, such as being clear and precise with search terms, and what I would do the same such as using Mendeley as the software of choice to complete the screening process.

Designing the Systematic Review

Scoping Searches

I initially wanted to explore the effectiveness of interventions to improve QoL for individuals living with EDS and MCAS, however during scoping searches, I was only able to identify minimal intervention studies (both EDS), so it meant that this topic was not feasible. PROSPERO searches also identified previously conducted or in progress reviews examining interventions for specific topics. During an initial scoping search, I identified a gap in the literature for examining QoL for individuals living with EDS and MCAS. This identified gap in the literature during the scoping search, meant that I revised the topic area, to examine QoL for individuals living with EDS and MCAS, with the aim of making comparisons between the conditions. Following a revision of the topic area and approval from HM and my supervisor, I searched PROSPERO to see whether there were any reviews on this topic area. I identified that QoL in EDS had been explored within three systematic reviews, however these focussed upon specific areas including health-related QoL (Foster et al., 2022; Umar et al., 2022), and whether psychosocial interventions improve QoL with EDS or Joint Hypermobility syndrome (Bohling & Kahn-Lodhi, 2023) and MCAS had not been explored.

Writing the Protocol

The key component of all methods of research including systematic reviews is having a clear research question (Fandino, 2019). Therefore, when writing up the protocol it was vital that I had clear research questions for my review. The review had three research questions to allow as much depth as possible and comparison of QoL for EDS and MCAS. The protocol for the systematic review was written during a 2-month time period. The first draft was given feedback, and it was identified that I had not included the right information for a PROSPERO protocol. This was my first attempt at writing up a full protocol for PROSPERO and for a systematic review, meaning that some key components such as the inclusion and exclusion criteria were correct to include. However, information such as strategy for data synthesis was missing from my first attempt at the protocol. Therefore, using the feedback provided, and looking at PROSPERO guidelines specifically, I re-wrote the protocol for the review, ensuring that I included all specific information and learnt from my first attempt. The second attempt of the protocol was approved and then submitted to PROSPERO, where it was accepted and placed onto the PROSPERO website. I found writing the protocol quite challenging; it was hard to write an inclusion and exclusion criteria for this review, knowing what the right factors were to include or not. Working in collaboration with HM helped with this process as I was provided with reassurance of creating an appropriate inclusion/exclusion criteria.

On reflection I would have chosen to also include mastocytosis (a sub-condition linked to MCAS) in the review, as this would have provided more studies to include, to allow for comparisons of QoL for the condition and sub condition. Due to MCAS being a very under researched condition in the United Kingdom, and researched biologically in the United States, I think that this topic was potentially too narrow to complete a review on at this present time. This was reflected with the inclusion of only one MCAS study within the review.

Defining Search Terms

I had to approach this quite differently to how I had approached previous systematic reviews due to not focussing on interventions and focussing on QoL. This was a process which had to be completed multiple times, due to complications when originally identifying the search terms which were going to be used for the review. When completing the initial search terms, I did not input them correctly into the database, so the terms brought back a lot of initial results which we were not expecting due to EDS and MCAS being both rare/underdiagnosed long-term conditions. The high number of results was surprising to both HM and I when beginning to look at the papers which may be included within the review. From identifying higher than anticipated number of papers from search terms, I sought assistance from my placements academic librarian who helped me organise the search terms into the databases to allow for results provided to focus on the topic. Organising search terms more efficiently into the databases included the use of brackets and apostrophes to ensure that phrases only were being included (such as ‘Ehlers-Danlos Syndrome’), ensuring that only relevant papers were being provided in the search process. Organising search terms in the correct way brought results down to 1626 (including grey literature) which was in line with what I originally expected. For future systematic reviews, I will ensure that I organise search terms effectively to ensure results produced are focussing upon the chosen topic and following the inclusion and exclusion criteria.

Conducting the review

Screening

Due to both HM and I had used Mendeley before and having success using the software on previous systematic reviews, the decision was chosen to use Mendeley to help organise the screening process. This was essential whilst working in collaboration to ensure that no mistakes were made, or duplication of a process occurred. Hayden (2022) identified that working in collaboration with other researchers to complete a systematic review can lead to duplication of studies, errors, and potential for miscommunication. Therefore, it was essential that we used Mendeley in the same way, such as setting up the same folders for each stage of the data collection and extraction process. The use of Mendeley, and regular communication either via email or online meetings using Microsoft Teams, ensured that there was clear communication, no duplication and helped to minimise the risk of any human error during the data collection and extraction process.

However, there were initial technological issues when setting up and using Mendeley. This was due to my laptop being of a certain brand, it would not import the results from the databases into Mendeley due to not recognising the data file type when extracting studies from databases. This meant that HM and I needed to problem solve to overcome the issue, so it still enabled the use of Mendeley. HM was able to import results into her Mendeley and therefore was able to import the results into my Mendeley account also. This allowed for us both to have access to the screening process and organise Mendeley in the same way to allow for full consistency and accuracy during the process. We ensured that after every stage of the screening process, that our Mendeley accounts and folders were synced to ensure no mistakes were made (such as studies being missed or duplicated). HM as second author completed the same screening processes as I did, to ensure full accuracy and ensure all appropriate studies were included in the review.

Quality Appraisal

I used The Effective Public Health Practice Project (EPHPP) quality assessment tool for quality appraisal of the 16 studies included within the review. It was my first time using the

EPHPP, as in previous reviews I had used the Critical Appraisal Skills Programme (CASP) checklist. Whilst working in collaboration with HM for this review, it was a good opportunity to use a different quality appraisal tool due all included studies being quantitative as it allowed me to appraise studies in a different way and learn new skills whilst being supported by a mentor. To begin with, I was quite unsure in my ability to accurately appraise the included studies using the EPHPP. Using a new quality appraisal tool meant that I felt unsure of whether I was assessing articles in the correct way, and if I was using the appraisal tool correctly. I know from previous learning of new skills or using new methods for research, I always question my own abilities and have a lower level of self-confidence. However, as second author, HM checked 20% of the studies quality too, and there were no discrepancies in the quality identified. Any studies which I was potentially unsure of in terms of quality, I spoke through these with HM which provided support and guidance of what to look for in future reviews if I am unsure of quality of studies again. Using the EPHPP for the first time whilst working collaboratively and receiving supervision helped to build my self-confidence for using this quality appraisal tool again in future reviews.

Data Extraction

For the data extraction process, I followed the Cochrane template for how to extract data of the included studies and created a table. Due to this systematic review looking purely at QoL and no focus on interventions (or effectiveness of interventions), the data extraction table looked different to how I had completed the tables in previous systematic reviews. This left me feeling uncertain of what information was needed for a full and clear data extraction of the included studies in the review. Therefore, both HM and I decided what specific information to extract from the included studies, whilst following the template which included: study aim, participant information, any use of control group, study design, outcome, outcome measure, statistical analysis used, results, significance and effect size (where applicable). To avoid confusion or duplication of work, I completed data extraction for all 16 included studies and collated information into the data extraction table. HM's role as second author included checking data extract of 20% of studies, and any additional studies which I needed assistance with due to unclear presentation of statistics and results. From the included studies, there were two studies which I required further assistance with due to figures being presented differently to how I would usually expect within a quantitative research paper. Therefore, I asked for HM's input as she has more research experience, thus used to data being presented in different ways and how to report that data. Having HM check 20% of data extraction of the included studies ensured that data was extracted correctly of the included studies to allow for the analysis to be as reliable and accurate as possible.

Writing up the systematic review

Introduction, Methodology, and Discussion

The introduction and methodology sections were the clearest for me to write for this review. Due to writing reviews in previous education, I knew what was required within the introduction section; to write and develop a clear rationale as to why the review is required. It was also essential that within the introduction that I gave a clear definition and overview of both EDS and MCAS due to potential readers possibly not hearing of these long-term conditions. When writing the methodology section, I followed the structure of previous reviews that I had completed and the PRISMA guidelines. These PRISMA guidelines were designed to ensure that individuals conducting a systematic review were able to clearly report the rationale for the review, the stages of the review and the results (Page et al., 2021). Having a template to follow allowed me to ensure that I was including all required information within this section, including the inclusion and exclusion criteria, clear reporting of the search terms and databases used, and the PRISMA diagram to report the data extraction and appraisal process.

Narrative Synthesis and Writing the Results Section

During supervision and through conversations with HM, it was clear that a meta-analysis could not be conducted as there was not enough homogeneity across studies to conduct a meta-analysis. Therefore, a narrative synthesis seemed suitable to conduct for this systematic review.

Overall, this was the most challenging part of the review due to different outcome measures and presentations of the results for QoL (including different subscales being used) across studies. From the narrative synthesis and analysis of results, there were many themes identified with many studies overlapping across multiple themes. This made it challenging to write the results section, to ensure transparency of the findings. Originally, HM and I worked collaboratively to draft the results section, to try to overcome the challenges presented by the more complicated themes identified within the narrative synthesis.

Within the 16 included studies for the review, there was only one MCAS study included which meant that it was not fully possible to make direct comparisons. This meant that RQ 3 was not fully answered within the review. Although QoL for individuals living with MCAS is a key area to explore, I think that due to it being an under-diagnosed and under-researched condition, this hindered the strength of the conclusions which I could make within the results of this review.

Upon handing the review in for draft feedback, it was identified that the results section was not suitable for a narrative synthesis/systematic review. The results section originally only mentioned studies in full depth on first mention within each sub-element of QoL. The additional times mentioned, the findings and statistics were summarised in results tables. The initial thought process surrounding this was that it provided the reader a clear comparison of QoL for EDS and a control group, MCAS and a control group or MCAS and EDS direct comparisons. This was disappointing feedback to receive due to trying to overcome challenges and provide the best possible results section that HM and I could produce together. However, after receiving guidance and further in-depth feedback from my supervisor and the systematic review competency lead, I was able to re-write the results section to ensure that it was suitable for a narrative synthesis. I had feedback on the re-drafted results section, which confirmed that the rewrite was much improved and now in line with a narrative synthesis, meaning that themes were reported clearly and QoL for individuals living with EDS and MCAS could be highlighted. Although disappointing to receive feedback which highlighted that results were not suitable, it was a valuable learning experience, as for future reviews which have more complicated results, I now understand the most effective and appropriate ways to report results.

Dissemination

The dissemination is an important part of any research to ensure that research is used for helping to increase awareness, understanding and knowledge (Marín-González et al., 2017). This is particularly important as both EDS and MCAS are underdiagnosed/rare long-term conditions which are also researched less in comparison to other conditions. Therefore, whilst disseminating the findings, practical applications of the results of this review have been highlighted. This includes exploring QoL interventions for individuals living with either EDS or MCAS to ensure that they are supported both physically and psychologically.

My aim is to get the systematic review published and whilst writing the review, I complied with the Journal of Health Psychology publishing and formatting guidelines. For the review, the Journal of Health Psychology was the chosen article for potential publication due to its aims being “help shape research in health psychology around the world” (Sage Journals, 2024). Due to the review topic focussing upon two very under-researched conditions, myself and HM decided it would be an appropriate journal to submit to, to help raise awareness surrounding the two conditions. The findings and completion of this review has also enabled me to find and think about avenues of further research for my own Professional Doctorate empirical research. The review helped to identify gaps within the research literature for EDS specifically, which I am currently exploring within my own empirical research project for the Professional Doctorate.

Overall reflection

Overall, due to the complexity and little research on these two conditions, the review has been challenging but rewarding to complete. Collaboration was something which I had not completed before on a piece of research or a review, due to completing other reviews for assessments during my undergraduate degree and Masters. It was a good opportunity to learn the process of collaboration in research, thinking about roles, responsibilities, and the importance of communication. If I was to repeat the review, I would ensure that I was more inclusive to MCAS subtypes (such as mast cell activation disease, and mastocytosis) and not restrictive to only studies looking at MCAS directly. This would allow for conclusions to be made about the impact of MCAS on QoL more reliably and would allow for any comparisons of QoL between EDS and MCAS. I will be able to implement the skills learnt and developed from completing this review in future reviews which I will be wanting to complete as a Health Psychologist.

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Chapter 4: Teaching and Training in Health Psychology

4.1 Teaching and Training in Health Psychology Case Study

Background

This case study outlines the assessment of needs, planning, design, and delivery of five teaching sessions. Table 1 provides a summary of the teaching sessions. Teaching sessions were completed at the University of Worcester, Staffordshire University and in my first placement. The students ranged from BSc psychology students to healthcare professionals, including registered nurses and healthcare workers such as care assistants and senior carers. Two of the five sessions were delivered to a large group, and three of the five sessions were delivered to a small group. All five sessions ranged between one hour and two hours in length.

Table 1. *A Summary of the Five Teaching Sessions.*

Teaching Session	Title	Students	Duration	Number of Students Attending	Location
1	Illness Management Interventions: long-term conditions, self-management, and adherence	BSc Psychology Students, Level 6. Health Psychology Module.	2 hours	33	University of Worcester
2	The Psychophysiological Link between Stress and the Onset of Health Conditions	BSc Psychology Students, Level 6. Health Psychology Module	2 hours	20	Staffordshire University
3	Dementia from a Health Psychology Perspective	Healthcare Professionals: Registered Nurses and Healthcare workers.	1 hour 30 minutes	4	Live Online Sessions via Microsoft Teams
4	Health Psychology and Dementia: Implications for Nutrition and Hydration	Healthcare Professionals: Registered Nurses and Healthcare workers.	2 hours 30 minutes	4	Live Online Sessions via Microsoft Teams
5	Health Psychology and Dementia: The Whole Home Approach for better Wellbeing for Residents in Care Home Settings	Healthcare Professionals: Registered Nurses and Healthcare workers.	1 hour	4	Live Online Sessions via Microsoft Teams

Assessment of Training Needs

Whilst creating materials for educational sessions, it is vital that a needs assessment is conducted. A needs assessment is defined in research to be an approach which explores the knowledge and interests of a student group about a particular topic (McCawley, 2009). Thus, indicating that needs assessments allow for educators to identify a gap in knowledge alongside what students are motivated to learn about a particular topic. Needs assessments allow for educators to identify student goals for each teaching session, thus building training sessions which are student-centered, engaging, and encourage students to be motivated to learn (Biggs & Moore, 1993; Winefield, 2004). The result of completing a thorough needs assessment should be to promote student's deep learning, which is identified as a high priority aim of teaching (Biggs & Moore, 1993).

For both large group teaching sessions, I used the Biggs (1987) 3P model of learning which views learning as a constructive process influenced by contextual factors and characteristics of the learner. During completion of the needs assessment for teaching session one and two, I asked the Health Psychology module lead questions via email surrounding student factors, usual learning activities and the desired learning outcomes for the session. Due to being familiar with the University of Worcester, I was already knowledgeable surrounding lecture times, the layout of the allocated lecture room, and the structure of lectures including timings of comfort breaks for students. This enabled me to focus more on questions surrounding student characteristics and preferences of students for activities within the session, thus enabling a student-centered focused to the needs assessment the lecture content. However, due to hesitancy of the module lead about disclosing any educational needs of students, such as dyslexia, I was unable to prepare additional materials for the session to make all content inclusive (for example, using a pastel yellow background for pre-lecture content) to meet all student's needs.

The completion of the needs assessment for healthcare professionals was a collaborative approach between myself, my manager and the healthcare professionals who were going to be attending the three teaching sessions. Research has identified the importance of healthcare professional students to be active learners; choosing the topics they learn and the method in which they learn (Fox & Bennett, 1998; Norman *et al,* 2004). Therefore, for the completion of my healthcare professionals needs assessment, I asked healthcare professionals questions during conversations at the workplace surrounding topics preferred for teaching sessions and ensured that I listened to all healthcare professionals who wanted to attend the sessions, alongside the preferences of the manager of what she wanted people to learn more about.

During the completion of a needs assessment, I took into consideration the following factors: motivation to learn, learning styles and methods, and explored teaching healthcare professionals in more depth to ensure all teaching sessions were suited to all students.

Motivation to Learn

Research has identified that motivation to learn is explored as the level of energy and drive to learn for the student, influencing their ability to work effectively and achieve potential (Edgar *et al,* 2019; Martin, 2004). Key psychological theories explore the motivation to learn, taking into consideration intrinsic factors such as behavioural influences and personality, alongside extrinsic factors such as environmental factors which can influence a student's motivation (Cook & Artino, 2016). Fry *et al* (2009) explore a strategic approach to learning, where students use both surface and deep learning depending upon their motivation. For example, students may use a surface approach to learning if they consider the information is required to be retained for short periods of time (i.e., examinations or coursework). Whereas students will implement a deep approach if they are intrinsically motivated to learn about the topic and want to use knowledge learnt in practice (Fry *et al,* 2009). Therefore, deep learning is the aim for teaching sessions, to encourage students to be intrinsically motivated by the topic rather than viewing it as something which is only useful for short-term actions (Entwistle & Ramsden, 1983; Fry *et al,* 2009; Prosser & Trigwell, 1999).

Motivation to learn was a factor which I took into consideration within each needs assessment, particularly for the healthcare professional small group teaching sessions. Bligh and Browne (2015) explore education to healthcare professionals as key within clinical practice, allowing for improvement within patient care. The five moments of need framework (Gottfredson & Mosher, 2012) indicate that healthcare professionals need to be able to; learn something new, learn something more, apply learnt knowledge, problem solve from knowledge learnt and be able to change practices based on new learnt knowledge (Daniel & Wolbrink, 2019). Using this framework was beneficial whilst conducting the needs assessment for healthcare professionals, as I was able to consider what new topics healthcare professionals wanted to learn more about. Healthcare professionals were also able to implement knowledge learnt in sessions to action positive changes within their practice.

Learning Styles and Methods

Learning styles are defined as the favoured way of exploring new information which is beneficial for effective learning process (Hatami, 2013; Huston & Huston, 1995). Thus, referring to cognitive, psychosocial and personality behaviours which may influence how students learn and interact with their learning environment (Curry, 1981; Dantas & Cunha, 2020; Mangold *et al,* 2018; Romanelli et al, 2009).

Curry's (1983) model uses an onion metaphor to explore the learning processes and the behaviours which individuals use within an educational environment. This was the model which I used to explore learning styles whilst conducting the needs assessment. The model includes instructional preferences, social interaction, information processing style, and cognitive personality style (Curry 1983). The elements of social interaction and instructional preferences explore an individual's preferences in relation to the learning environment, and how much social interaction an individual likes during learning (Cassidy, 2004; Curry, 1983; Dantas & Cunha, 2020). These two elements of the model were ones I took into consideration whilst conducting the needs assessment for both large group teaching sessions with undergraduate students, as it was important for me to assess the routine learning environment of students (for example, lecture theatres or seminar rooms), alongside social interaction levels during sessions. The learning environment was important to consider, as a traditional lecture theatre does not allow for group discussions in comparison to seminar rooms. This information from the needs assessment enabled me to incorporate different activities such as online activities, group discussions, and question and answer quizzes suitable for each student group, to encourage an effective learning process for all students.

For the healthcare professional small group teaching sessions, I took into consideration the information processing style and cognitive personality style of Curry's (1983) model. The information processing style explores an individual's approach to processing information during the learning environment (Cassidy, 2004; Curry 1983). This element for healthcare professionals I took into consideration the most whilst conducting the needs assessment, I needed to ensure that I facilitated a learning environment which was correlating with students approaches to processing new information within teaching sessions. Cognitive personality style explores an individual's behaviour and personality which is only apparent within the learning environment (Cassidy, 2004; Curry, 1983). Due to running the small group teaching sessions online (live via Microsoft Teams), this was harder to take into consideration. However, I ensured that healthcare students were still able to complete their individual habits whilst learning, including group discussions, scenario activities based on a current scenario which they would experience at work, and small questions for them to consider. I chose to use these elements of Curry's (1983) model for healthcare professional sessions due to research indicating that healthcare professionals learning styles are underpinned by active participation with content using real-life scenarios, encouraging discussion of problem-solving techniques (Mangold *et al,* 2018; Stander *et al,* 2019). This enabled healthcare professional students to use a range of learning styles and methods to promote efficient learning.

Teaching Structure and Content

For teaching sessions, I used two different theories to help structure teaching sessions depending on student audience level. Andragogy explores that learning is based upon the transaction of knowledge from the educator to the students and has five key principles including: self-concept, learning experience, readiness to learn, orientation to learning and motivation to learning (Chan, 2010; Knowles, 1970). I used this theory for undergraduate large group teaching sessions, with the aim to transfer the knowledge I had on the topic areas to students who were completing their health psychology modules. This was the theory which I took into consideration for undergraduate teaching sessions, due to research indicating that undergraduate students need the transaction of knowledge from the educator in combination with activities to encourage the active learning process (Lewis & Bryan, 2021).

Heutagogy is defined as self-determined learning and has a focus on what and how the students want to learn rather on the content which is being taught by the educator (Hase & Kenyon, 2013). In comparison to andragogy, heutagogy has a refined focus on the learner, and ensures that all teaching sessions are learner-centered rather than educator-centered (Hase & Kenyon, 2013). This was the theory that I took into consideration for small group healthcare professional teaching sessions, due to research indicating that healthcare professionals need to be active within the learning process (Shin *et al,* 2015). Therefore, I had to ensure that all sessions were learner-centered to ensure an effective learning process with all students remaining engaged throughout the three sessions.

Whilst exploring teaching structure and content, I ensured that I took into consideration: learning outcomes, method of delivery, group activities.

Learning Outcomes

Learning outcomes are defined within research as the knowledge and skills base which learners will be able to establish once the learning process is completed (Allan, 1996). Bloom's Taxonomy (Bloom *et al,* 1956) is a framework which explores the classification of learning objectives which educators intend for students to achieve in a teaching session (Krathwohl, 2002). Bloom's taxonomy includes six categories: knowledge, comprehension, application, analysis, synthesis, and evaluation; knowledge and comprehension are classed as low-level thinking skills, with the remaining four as higher-level (Bloom *et al,* 1956; Krathwohl, 2002). I used this taxonomy to structure learning objectives for all sessions, ensuring that each session had a range of low and high-level thinking skills to encourage the active learning process for students.

Each group had their own separate topic and teaching needs; therefore, it was essential that I set new learning objectives for each, to encourage effective learning process. To ensure that healthcare professionals gained the appropriate level of knowledge from all teaching sessions, I used a more complex set of learning objectives in comparison to undergraduate students throughout the three sessions. This meant that all sessions encouraged healthcare professionals to understand the topic in more depth, apply knowledge learnt to scenarios, and encourage an active learning process.

Method of Delivery

For teaching session one and two, I completed the sessions in person to undergraduate students. The sessions were taught in lecture and seminar rooms, which promoted a formal learning environment, where students were receptive to the learning process. This is supported in research which identifies that lecture hall settings for education encourage engagement within the learning process, correlating with better assignment grades (Perkins & Wieman, 2005). However, due to the outbreak of COVID-19 in my work placement, I completed the three small group teaching sessions to healthcare professionals live, yet remotely, via Microsoft Teams. Therefore, I had to ensure that all sessions delivered online remained engaging, promoted group discussion, and ensured that healthcare professionals learning was not hindered through the change of delivery. This was due to previous research identifying that online learning can hinder student engagement due to reasons including technological difficulties, understanding of technology and the need for students to be highly motivated and organised (Sharma, 2020).

Group Discussions and Interactive Activities

Biggs (1996) constructive alignment theory explores how students construct their own learning and absorb knowledge learnt within teaching sessions through learning activities

(Biggs & Tang, 2007). The theory also places the responsibility on the educator to ensure that they provide learning activities to achieve complete construction of knowledge. This highlights the importance of activities within teaching sessions to ensure that students can put their learnt knowledge into practice, encouraging deep learning. Throughout all teaching sessions I used the constructive alignment theory, incorporating different activities within sessions to help learners construct knowledge including, group discussions, online activities, and scenario tasks depending upon group size and level of student audience. For large group teaching sessions, I used more online activities such as online word clouds to encourage smaller group discussions. Research has identified that online activities help to encourage student participation and allow individuals who are not confident enough to discuss in person to answer online questions (Lai, 2012; Teaching and Learning Centre, 2012). Therefore, by including the use of online activities, it allows for students who do not feel comfortable speaking in large group settings, to be able to contribute to the session, construct their knowledge, and gain feedback.

The 'Ripples on a Pond' model (Race & Brown, 2007) explores factors which influence successful learning for students. The model explores the process of learning, with students needing feedback to continue the successful learning process (Race & Brown, 2007). Whilst considering the importance of feedback, it is necessary to also take into consideration the manners in which feedback is delivered. Race (2001) explores that feedback should be timely, empowering, individual, and manageable, encouraging students to continue the learning process. This is the model which I used whilst completing all teaching sessions. Following each activity, I gave opportunity for a whole group discussion on answers, giving encouraging and constructive feedback on answers provided to aid further learning.

Resources, Materials, and Methods

Lesson Plans

Lesson plans were completed prior to every teaching session whilst also producing the PowerPoint slides for each session. Lesson plans enabled me to be prepared fully for each session, allowing consideration for timings and appropriate amount of learning material and activities planned for each session, ensuring that I did not put too much content in for the time frame, or too little.

Provision of Teaching Session Slides

Teaching session slides were developed using Microsoft PowerPoint, combining text, graphs, diagrams, and links to online activities. It was important to ensure that large amounts of text were avoided within session slides to prevent student disengagement (Hashemi *et al,* 2012). PowerPoint slides were developed to be prompts of key information to support topics discussed throughout each teaching session. The choice to have slides including key points, diagrams, and graphs from research studies was due to research identifying that precise slides encourage student engagement, participation, and interaction with the session content (Bolkman, 2019).

For both large group teaching sessions, I provided the module leader with lecture slides for the session to be uploaded for students to access 48 hours prior to the session. At the University of Worcester, I gave the module leader pre-lecture slides to upload 48 hours prior to the session, meaning that some lecture content was hidden as well as answers to activities within the session. Research indicates that pre-lecture slides increases learner engagement within the session (Kinsella *et al,* 2017), with the need to focus on the content being taught and to engage in activities to help construct knowledge. However, student feedback indicated that pre-lecture slides were not helpful as students felt that they were missing the additional information I was discussing, due to trying to write notes from lecture slides. Therefore, for teaching session two at Staffordshire University, I provided the module lead with full lecture slides 48 hours before the session. These included lecture notes at the bottom of each slide due to the topic being more complex and having a mixture of biological and psychological terminology and theory to explore how stress affects an individual's physical health.

Assessment of Learning Outcomes

The purpose of assessment within education is to explore whether learning has taken place for all students (Quality Assurance Agency, 2018). Assessment of learning outcomes were completed throughout all teaching sessions through a range of activities within sessions including group discussions, opportunity for feedback, and online activities such as word clouds (concept maps). Formative assessments were only used to assess learning outcomes due to not being involved with the assessment for large group undergraduate teaching; therefore, it was appropriate to assess learning outcomes within the session. Biggs and Tang (2011) indicate that concept maps enable educators to assess whether students have a good or poor knowledge base. Therefore, I used Mentimeter word clouds within all teaching sessions to assess knowledge pre- and post-session, allowing for assessment of student learning within teaching sessions.

Evaluation and Conclusion

Overall, I have found the experience of planning, designing, and delivering teaching sessions to be a positive, although not without challenges, especially in relation to organising healthcare professional sessions. Prior to completing this competency, I expected not to enjoy the teaching experience due to little confidence, however, I found teaching a rewarding experience, helping to increase my confidence levels. I have a new job role as Associate Lecturer in Psychology at the University of Worcester due to begin September 2022. For this experience, I am very grateful to help me to continue to build my skills in teaching for all levels of undergraduate.

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4.2 Teaching and Training in Health Psychology Evaluation

Background

This following report will outline an evaluation of five teaching sessions which I have planned, designed, and delivered to a range of students including undergraduate students and healthcare professionals for the Teaching in Health Psychology competency (see table 1 for an outline of teaching sessions). Evaluation is defined as an assessment surrounding the quality of teaching (Wilkes & Bligh, 1999). The core purpose of evaluation is to ensure that teaching content remains student-centered and meets all students needs within the learning environment (Morrison, 2003). Evaluation also allows for the identification of areas of improvement for teaching, as well as providing feedback and encouragement for teaching staff (Morrison, 2003).

Table 1. *A Summary of the Five Teaching Sessions.*

Teaching Session (TS)	Title	Students	Duration	Number of Students Attending	Location
1	Illness Management Interventions: long-term conditions, self-management, and adherence	BSc Psychology Students, Level 6. Health Psychology Module.	2 hours	33	University of Worcester
2	The Psychophysiological Link between Stress and the Onset of Health Conditions	BSc Psychology Students, Level 6. Health Psychology Module	2 hours	20	Staffordshire University
3	Dementia from a Health Psychology Perspective	Healthcare Professionals: Registered Nurses and Healthcare workers.	1 hour 30 minutes	4	Live Online Sessions via Microsoft Teams
4	Health Psychology and Dementia: Implications for Nutrition and Hydration	Healthcare Professionals: Registered Nurses and Healthcare workers.	2 hours 30 minutes	4	Live Online Sessions via Microsoft Teams
5	Health Psychology and Dementia: The Whole Home Approach for better Wellbeing for Residents in Care Home Settings.	Healthcare Professionals: Registered Nurses and Healthcare workers.	1 hour	4	Live Online Sessions via Microsoft Teams

Sources of Feedback

For this evaluation, I will be using a combination of self-reflection, feedback from students and observation forms received during teaching sessions. This combination of feedback correlates with Fry and colleagues (2008) model, exploring the four main sources of feedback which include: self-generated feedback, feedback from colleagues, incidental feedback, and feedback from students. Incidental feedback (Fry *et al,* 2008), was explored during large group sessions, due to observing levels of student retention following comfort breaks during the middle of the sessions. Healthcare professional teaching sessions incidental feedback was easier to collect by observing any student drop-out between the three sessions.

Peer Observation

Peer observation of teaching is defined as the process which an individual with a teaching position observes another teacher or lecturer (Swinglehurst *et al,* 2007). Research has identified that peer direct observation is beneficial due to providing a source of informative, valuable, and constructive feedback (Morrison, 2003; Swinglehurst *et al,* 2007). Peer observation was completed during sessions one and two by the Health Psychology module lead at the University of Worcester and my Professional Doctorate supervisor observing my teaching session at Staffordshire University. Observation forms contained qualitative questions, with open and closed questions for detailed feedback surrounding teaching skills and abilities. Observation of two sessions allowed me to gain multiple sources of feedback surrounding my teaching abilities, skills and identify progression between the two sessions. This supports research identifying that peer observation helps to provide evaluation from multiple sources, creating complete assessment of teaching skills and practice (D’Andrea, 2002; Swinglehurst *et al,* 2007).

Student Feedback and Evaluation

Student evaluation is defined as exploration of student's views surrounding teaching content and structure (Chen & Hoshower, 2003; Morrison, 2003), with benefits including providing teaching staff with feedback on these aspects, ways in which teaching could be improved as well as what students enjoyed and benefitted from within the teaching sessions (Chen & Hoshower, 2003).

I collected student evaluation and feedback in two formats: online and paper quantitative questionnaires. Research explored that online questionnaires are correlated with an increased level of response (Swinglehurst *et al,* 2007). However, in my own experience, I found that paper evaluation forms completed during session one had a higher response with 24 out of 33 (72.72%) students completing the evaluation. Whereas the online student evaluation form from session two and HCP sessions had a lower response rate, with only 10 students out of 20 (50%) and 2 out of 4 (50%) completing the evaluation. This may have been due to me only providing the link to the online evaluation on the lecture slides which students may have found too complicated to follow. Therefore, in future I will ensure that online evaluations have direct codes for students to use to access the questionnaires allowing for ease of completion. Student evaluation forms consisted of six questions which had a Likert scale format ranging from 0 (poor) to 10 (excellent), and one open question asking for any additional comments. This ensured that evaluation was not difficult for students to complete, prompting engagement with the evaluation (Swinglehurst *et al,* 2007; University of Exeter, 2021).

Self-reflection

For self-reflection, I will be using the Gibbs (1988) model (see figure 1) to help evaluate teaching sessions using distinct stages to structure the reflective process. Research has identified that the action planning stage of the Gibbs model allows for positive development due to individuals being able to identify areas of improvement and thinking of steps to ensure development of skills (Potter, 2015). The action planning stage allowed for identification of areas of improvement which I would implement for any future teaching opportunities. I was able to reflect using the Gibbs model after teaching session one, which identified slide formatting difficulties. Using the action planning stage, I was able to identify the steps I needed to take to prevent this from happening for future teaching sessions.

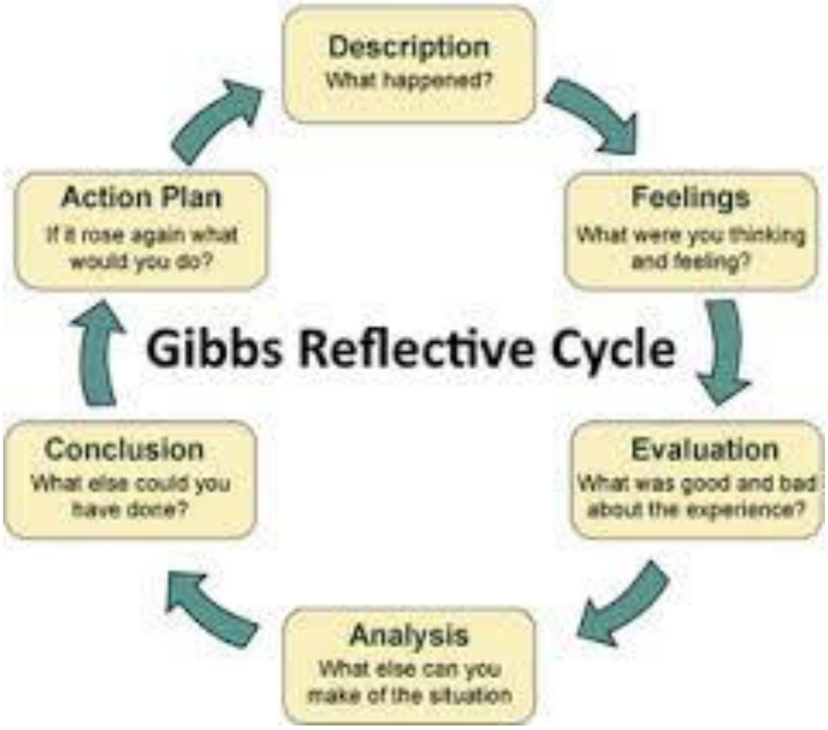

Figure 1. The Gibbs (1988) Reflective Cycle

Teaching Session 1

What went well (strengths)

Overall, I feel that the first teaching session went well, with pre-session nerves quickly fading as the session began and students were engaged from the beginning. The pre-session nerves were due to the teaching session being my first experience of teaching. I know that I struggle with confidence, therefore, I was worried that this would have an impact on my teaching. I used the Student Engagement Core Model (City *et al,* 2009) when preparing for the teaching session, exploring student, teacher, and content factors which would influence high engagement levels. The model explores that a positive rapport between student and teacher, alongside teaching content which students consider to be relevant and essential for their learning will correlate with student engagement during teaching sessions (Bundick *et al,* 2014; City *et al,* 2009).

Students asked questions within the session, highlighting engagement with the lecture content and students were confident to ask if they wanted additional information. During the session, there were periods where a more traditional lecture format was taken. When I had spoken through content heavy slides, I asked questions which were not originally in the teaching plan. This was due to reflecting on action, I wanted to ensure that students had a clear understanding of information provided as well as remaining engaged. I was able to assess that all students were engaged and understanding the teaching content, which was positive feedback as the session was running. Student engagement was identified within the observation report completed by the module lead: "*students engaged in activities throughout".* This was positive feedback to receive as I was able to confirm that students were engaged throughout the session, meaning that for future teaching I would use the same technique.

The lecture ran on time, with a comfort break of 10 minutes being included at the halfway point to ensure students were able to take time away to regain full concentration. Research has identified that comfort breaks within teaching sessions increase levels of concentration (Bautista, 2020; Butze *et al,* 2021) and promote student engagement. I found my own experience during teaching session one of giving students a ten-minute comfort break correlated with research, as once students returned from the comfort break, they were. engaged remaining throughout the rest of the session. Time management was discussed within the observation form: "*well organised including a break and allowing adequate time for students to ask questions".* Time management and organisation are skills which I have been able to develop in other scenarios such as working full time alongside education, as well as managing time for presentations for previous assessment during education. Due to being my first teaching session, I also ensured that I ran through the session during preparation to assess timings. By finishing the lecture session on time, it gave time for students to complete student evaluation forms. Time management skills and ensuring that future teaching sessions ran on time were skills which I would implement in future teaching sessions.

What did not go well (weaknesses)

The main weakness which I did not expect for teaching session one was formatting of lecture slides. Due to owning a MacBook and designing the teaching sessions on my own device, and the teaching session being delivered through a Microsoft PC, there were unexpected formatting issues including some text not being fully visible on lecture slides; important points for each slide and some diagrams were not aligned appropriately. Fortunately, I was able to change formatting of slides prior to the session, to ensure that they were organised to allow for students to see content needed. Formatting issues on lecture slides created more pre-session nerves and knocked my confidence directly before the session meaning that it took longer for nerves to settle once the session had begun. It is important to ensure that for all future sessions, formatting is checked prevent this from happening again.

There was a divided opinion between students and the observation report about the use of pre-lecture slides, provided 48 hours prior to the lecture. The observation indicated: "*pre-session version of the slides to enhance student engagement."* Whereas there was mixed student feedback from evaluation forms discussed that they did not like the pre-lecture slides due to too much information being missing "*most information was not on our copy of slides I found that I was too focused on making notes*." However, some students preferred pre-lecture slides "*not all information was included in slides which made you focus and listen properly."* For future teaching sessions I will include more information on pre-lecture slides ensuring a balance between not providing all information to students prior to the session and preventing students feeling overwhelmed with information during the session.

Teaching Session Two

What went well (strengths)

Whilst taking into consideration teaching session one weaknesses, I wanted to ensure that I improved teaching skills for this teaching session. Therefore, I ensured that formatting of lecture slides was clear on all devices including Apple and Microsoft prior to the session, to prevent information being unclear. This was evident from lecture observation feedback. This feedback meant that I was able to improve on weaknesses identified from session one, highlighting development of teaching skills.

In comparison to session one, I felt that the structure was improved, due to content flowing within the session easier, progressing in complexity throughout. I also felt that although I had pre-session nerves like session one, once the teaching session began, the nerves faded faster allowing concentration on the session rather than controlling nerves. Due to being a complex topic I ensured that I included foundation knowledge to prevent students feeling overwhelmed. The structure of the lecture was commented on positively in the observation report "*There was a clear structure throughout, building on creating an understanding.*" Students also indicated this on student evaluation forms which identified that 60% of students thought the lecture content was "*excellent*".

What did not go well (weaknesses)

The lecture finished early, with the content being delivered quicker than anticipated from the learning plan I had completed prior to the session. I think that my pre-conceptions of a traditional lecture theatre hindered group discussion meant that I moved on from group activities quicker than originally planned within the learning plan. Student feedback identified "*we didn't really discuss the menti*" which could have been the reason as to why the lecture ran ahead of time. Therefore, I need to develop my skills on encouraging group discussions post activities to ensure that students feel they can discuss answers and allow for opportunity of any post activity questions. Due to the session finishing earlier than expected, I should have prepared an additional task for students to ensure that the session ran to time and encouraged engagement and active learning. The time management was an area of improvement also identified in the observation report "*Thinking of an additional activity that students could complete if running ahead of time/schedule would be a good resource.*" Student feedback did not mention the timing of the session within their student evaluation and feedback.

Another weakness within session two was the lack of different interactive tasks throughout, identified within the observation report: "*some more variety in your tasks would be useful.*" I think that due to knowing the topic could be considered as complex, I did not want to make any activities within the session complex. The activities within the session were mainly Menti word clouds which meant that students were able to discuss their answers as a small group. There were no scenario activities or group discussions meaning that students were not able to engage as much as they could have done with the use of additional activities. The lack of different activities was apparent in student feedback, with 50% of students rating the opportunity for participation throughout the lecture between 5 (average) and 8 on the Likert scale. Research has identified that activities within teaching sessions help to encourage student engagement and learning (Groccia, 2018). Therefore, different interactive tasks are something which I need to incorporate in future sessions to ensure opportunity to participate and engagement of students.

Small Group Teaching Sessions with Healthcare Professionals

Three small group teaching sessions were organised as a mini training programme for healthcare professionals (HCPs) working within a care home setting. Due to COVID-19 outbreak within the care home, the three sessions were conducted live online, via Microsoft Teams, rather than face-to-face. Research has identified that online learning for healthcare professionals has advantages, including encouraging increased levels of social interaction within the learning environment due to collaboration of tasks (Posey & Pintz, 2006). Therefore, due to a change in delivery and taking into consideration weaknesses identified from session two, I had to ensure that there were sufficient interactive activities to encourage the collaboration of HCPs.

What went well (strengths)

All three sessions appeared to flow well due to using techniques such as time management and organisation developed within session one and two, with the content building from a foundation level of knowledge, adding complexity as each session progressed. Each session ran to time, meaning that time management issues from session two were improved and ran in line with session one to allow for all topics to be discussed thoroughly. Therefore, I need to ensure that for future teaching sessions that I can continue effective time management skills to ensure all sessions run to time. The feedback from students included "*Chloe had planned this training session well from explaining what Dementia is to explaining Health Psychology and how it can be used to improve the quality of life for people living with Dementia.*" The feedback indicated that the theme between all three sessions remained apparent, ensuring clarity throughout for HCP students. This means that for future sessions I will ensure clarity of the content and flow of sessions to encourage student engagement.

All three sessions were appropriate all levels of HCP's. The sessions had a student audience of care assistants, senior carers, and registered nurses some with little experience of Dementia. This was discussed during the needs assessment to ensure that all sessions were suitable for all students. The feedback from students included: "*set at a level for any type of healthcare professionals to understand",* identifying that teaching content suited all individuals. Thus, indicating that I can aim session content to an appropriate level for students, which is a skill I will be able to implement for future teaching sessions.

What did not go well (weaknesses)

Due to organising issues, assessing a suitable time for HCPs to be available, and organising sessions around the COVID-19 outbreak at the care home, teaching sessions had to all be conducted on one day. This meant that it was a vast amount of information for students to learn at once and I felt that my abilities to provide a good teaching session by the end of session three were not at the best of what they could have been. I know that from my own learning experiences, I struggle more on days where I have lectures online, due to struggling to maintain focus for long periods of time sitting still and looking at a screen. Therefore, I think that this was a factor which affected my ability to provide a strong teaching session by the end of the day. I think that if the sessions were run on one day, but face-to-face it may have been different due to feeling more able to move about the room and use breaks to ensure that I do not focus on screens and interact with students face-to-face. I had originally planned for sessions to be completed face-to-face on three separate days to allow for students to reflect on knowledge learnt post-session. I also planned the use of pair discussions, group discussions and interactive poster tasks, building upon the weaknesses identified from session two. However, due to change of delivery to online across one day at short notice, the variety of interactive tasks had to be reduced due to time constraints. This was frustrating due to wanting to improve on weaknesses from session two. If I was given more time to prepare, I would have included more scenario activities and online quizzes to assess level of students understanding of content.

Conclusion and Action Plan

In conclusion, completing the Teaching in Health Psychology competency has been a positive experience. I have been able to experience teaching large groups as well as HCPs, allowing for me to build skills and abilities in teaching. With strengths and weaknesses highlighted throughout all teaching sessions, I am aware that I need to improve timing within large group sessions and use a variety of activities to promote student engagement. I also need to ensure that students have opportunity to participate in lectures through tasks. This will allow for students to confirm their understanding of content, learning outcomes are being met as well as allowing for me to ensure that students are engaged. Overall, my confidence and self-efficacy in my teaching abilities have increased throughout all teaching sessions. I have secured a new job at the University of Worcester as Associate Lecturer in Psychology which is due to start September 2022. This will be a good opportunity for me to continue to develop my teaching skills.

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Chapter 5: Consultancy in Health Psychology

5.1 Consultancy in Health Psychology Case Study

This case study report outlines a piece of consultancy which I conducted between May 2022 and August 2023 for Social-Ability. Social-Ability is a company who created a technological intervention called ‘The Happiness Programme’. The Happiness Programme is a technological intervention which has the overall aim to support individuals who are living with cognitive and physical care needs within a range of care home environments through digital programmes encouraging coordination, social interaction, reminiscence, and encouraging nutritional intake (Social-Ability, 2023).

Lippitt and Lippitt (1994) define the aims of consultancy as to assist in helping either an individual, a group, or an organisation by providing external resources or enhancing internal resources to enable effective problem solving through interaction between two or more individuals. This is supported by Earll and Bath (2004, p.230) who identifies that consultancy is “*a formal relationship where one party seeks help from another, the Consultant’s role being to facilitate the process whereby both the Consultant and the Client arrive at a mutually acceptable solution.”* Earll and Bath (2004) emphasise that there must be a core set of values and ethical guidelines embedded within consultancy which will assist, guide, and support the Consultant in making decisions such as whether they should accept work from a Client and ensuring that they are only accepting work which is within their abilities and skill set. This correlates with the British Psychological Society (BPS) code of conduct, ethical principles, and guidelines (BPS, 2021) and Health and Care Professions Council (HCPC) guidelines which all psychologists should adhere to stating that healthcare professionals should “*recognise and work within limits of professional competence and adhere to guidelines on conduct, consent, and confidentiality*” (BPS, 2021; HCPC, 2023).

I followed the Earll and Bath (2004) model throughout my consultancy opportunity with Social-Ability. The model highlights that Consultancy follows five key stages:

1. Assess requests for Consultancy.
2. Plan the work and negotiate the contract.
3. Establish, develop, and maintain working relationships with Clients.
4. Conduct and monitor the Consultancy.
5. Evaluate the impact of the Consultancy (Earll & Bath, 2004).

Assess requests for Consultancy.

Harrison (1995) states for consultancy "*an accurate assessment is the key to success*." Whilst being approached by a Client with a proposed piece of work, Harrison (1995) and Earll and Bath (2004) suggest that the Consultant needs to keep in mind topics such as who the client is and why have they contacted the Consultant, what is the Client asking the Consultant to achieve, is this realistic, and what is the timeframe. During the initial scoping meeting on 16th March 2022, I took these questions into consideration, to ensure that I had an accurate assessment for the Client needs, the deliverable which they were wanting to be achieved, and ensuring that the Client had a thorough understanding of what Health Psychology is and what skills as a Trainee Health Psychologist I could offer.

Both Newton (2013) and Earll and Bath (2004) identify the client is the main person who can determine whether the consultancy has been successful or not depending on the deliverable and final outcomes. Newton (2010) highlights that types of Clients usually fall under two categories: real clients and individuals who are not clients but are important to the consultancy process. Real Clients include Client interface, Underlying client, and Financial

Client. Individuals who are not clients but are important to the consultancy process include Client Stakeholders, and Client Staff (see table 1 for definitions).

Table 1. Definitions of different client types (Newton, 2020)

Term	Definition
Client Interface	An individual who first approaches a Consultant about the piece of work.
Underlying Client	This individual has no direct involvement with the consultancy process. However, they have a direct influence on the consultancy work being completed, due to being line manager of the individual who engages with the Consultant.
Financial Client	The individual who authorises bills and finances for the work completed during the consultancy process.
Client Stakeholders	External groups and organisations that have an interest in the work completed during the consultancy process.
Client Staff	Individuals who work in the Client's organisation. These individuals will review, approve, and be asked opinions about the work completed for the consultancy.

For the consultancy opportunity with Social-Ability, a member of the team was the Client interface as they attended my placement setting to complete an interactive demonstration of 'The Happiness Programme' for individuals within my placement setting. Following the demonstration, the member of the team from Social-Ability approached me knowing that I was a Trainee Health Psychologist and enquired whether I would be interested in a potential collaboration and gave me an email address of a contact to arrange an initial meeting. The underlying Client for this consultancy opportunity was the managing director of Social-Ability as he only joined two of the scheduled meetings (the initial scoping meeting and a later meeting when the deliverable had to be altered) but continued to influence the work behind the scenes with the staff at Social-Ability. Client staff included two individuals within

Social-Ability who I had the most contact with throughout the consultancy process via email and Microsoft Teams meetings.

During the initial scoping meeting on the 16th March 2022 (which was virtual via Microsoft Teams), I ensured that my approach was calm, confident, and positive to help initiate a good working relationship with Social-Ability and to make a positive first contact and impression (Kakabadse et al., 2006; Kaplan, 1976). Stumpf and Longman (2000, p. 124) identify "*the most important thing in the work of a management consultant is building and maintaining a relation with your client*." The scoping meeting was vital for building rapport and a positive relationship with Social-Ability, providing them with trust in me as Consultant to complete the work required to a high standard (Kakabadse et al., 2006). The first 15 minutes of the scoping meeting was an opportunity for me to introduce myself as a Trainee Health Psychologist, to get to know more about Social-Ability, and be introduced to the main points of contact, including the type of research which the Client staff of Social-Ability are involved in. Following this, the scoping meeting clarified the outcome/s which Social-Ability wanted throughout the consultancy process. It is vital to ensure that the question is fully clarified during the assessment of requests for consultancy (Earll & Bath, 2004; Harrison, 1995), to ensure that work completed meets the Client's needs whilst ensuring that the Client feels listened to and understood (Kaplan, 1997). I ensured that the Client felt listened to by summarising the main points towards the end of the scoping meeting, and completing written minutes, and sending these within an email communication following the meeting, also ensuring that there was a confirmed understanding of the Client's needs.

Plan the work and negotiate the contract

Whilst completing the scoping meeting, it was important for me to ensure that outcomes were specific, measurable, achievable, realistic, and timely (Earll & Bath, 2004). Therefore, through using open-ended questions (Appelbaum & Steed, 2005) within the scoping meeting, I ensured that I fully understood the Client's needs for the consultancy project as well as ensuring that it was a feasible project and within my capabilities as a Trainee Health Psychologist. I ensured that the project was within my capabilities by having supervision to discuss this consultancy opportunity including the timeframe, responsibilities and the skills required to complete the opportunity. By the end of the meeting, it was determined that I was going to conduct a piece of empirical qualitative research exploring 'The Perspectives of Care Home Staff Using Technological Interventions to Improve Nutritional Intake and Weight Gain in Dementia Care'.

Throughout this consultancy process and planning of the work, it was quickly identified that my Client and I would be working together to achieve the final deliverable. Process consultation involves the Consultant providing solutions to problems and facilitating skills with there being an equal relationship between Client and Consultant which is based upon information, knowledge, and empowerment of both parties (Rifkin & Pridmore, 2001; Schein, 1987; Schein, 1999). I implemented process consultation throughout my consultancy process with Social-Ability as it was important to identify that both parties have skills, expertise and experience which will aid the implementation and dissemination of the outcomes of the final deliverable (Marks, 2013). The positive working relationship and good rapport developed with Social-Ability throughout the consultancy which was initiated within the scoping meeting meant that all decisions were made in collaboration (Lambrechts et al., 2009; Marks, 2013).

The ultimate part of the planning stage included creating a consultancy contract and working agreement conditions document. The consultancy contract included information such as the Consultant's role, the Client's role, the deliverable, costs, academic publication and impact, intellectual property, good data management practices, communication. The deliverable was discussed within the scoping meeting and during email communications following the meeting. Social-Ability stated that they were requiring qualitative research to highlight the opinions and perspectives of service users and were happy for me to decide the topic area of the research, providing it was qualitative. This allowed for me to explore a research interest and ensure that the Client's needs were met and understood. Writing the contract and negotiating the deliverable was a new skill for me as a Trainee Health Psychologist, I completed a plan and draft of the contract which I received feedback from my Professional Doctorate supervisor and the consultancy competency module lead. Following the contract being passed, it was sent to Social-Ability. With both parties agreeing the contract and being happy with the first write-up, the contract was signed.

Establish, develop, and maintain working relationships with Clients.

Research has identified that the consultancy process is reliant on an effective and positive Client-Consultant relationship, with communication being essential for the positive relationship (Alvesson et al., 2009; Newton, 2010; Werr & Styhre, 2014). Pozzebon and Pinsonneault (2012) identify three types of Client-Consultant relationships including dependency, autonomy, and cooperation (see table 2 for definitions).

Table 2. Definitions of different types of Client-Consultant relationship (Llewellyn, 2002; Pozzebon & Pinsonneault, 2012; Schein, 1999).

Term	Definition
Dependency	The Consultant act in the role of the 'expert'. The Client within the consultancy relationship have a more passive role and agrees with what the Consultant suggests.
Autonomy	The Client has an active role within this working relationship. The Consultant is perceived to be a temporary additional member of the Client's team and has a more passive role.
Cooperation	The Client and Consultant work together in partnership, and both have an active role within this working relationship.

The cooperative Client-Consultant relationship explores both the Client and Consultant have active roles within the consultancy process, working together in an equal partnership to achieve the main outcomes of the consultancy (Schein, 1999). This was the type of working relationship which I had throughout the consultancy process, as both Social-Ability and I had our own roles and responsibilities throughout the consultancy process to achieve the deliverable and main outcome. Within this consultancy, I had a very good working relationship with Social-Ability especially the Client staff who I had regular contact with throughout via both email and virtual meetings via Microsoft Teams. Regular contact allowed for both parties to work together to monitor progress (Bruce & Docherty, 1993) and email communications allowed me to provide Social-Ability with updates between scheduled meetings.

Conduct and monitor the Consultancy.

Earll and Bath (2004) highlight that it is vital for the consultancy process to be consistently monitored. Due to the thorough planning within the scoping meeting and the contract which included all roles and responsibilities, it meant that I was able to begin conducting the work quickly and efficiently. Due to Social-Ability's awareness and understanding of the research process including ethical approval applications, there was no set deadline for the deliverable to be achieved by. This understanding was helpful as I was able to take my time and be thorough in completing the ethics application to ensure that details for proposed study were complete, accurate, and aligned with BPS ethics guidelines and conduct. This was also my first time in completing an ethical approval application for a piece of qualitative research, meaning that I sought feedback from academic staff surrounding my ethical approval forms prior to sending it into the ethical approval committee. Ethical approval for the qualitative research was granted on the 7th February 2023, and following this there was an additional meeting with Social-Ability to discuss recruitment of participants and providing the information sheet, consent form and study materials to allow for Social-Ability to begin recruitment. Due to ethics, Social-Ability acted as 'gate keeper' within the recruitment process due to service users of 'The Happiness Programme' being the population sample for the study. On reflection, I think this hindered the recruitment process as I was not able to control how individuals were contacted and recruited. Unfortunately, after two months of recruitment, only 2 participants had been recruited which was very low compared with the intended sample size of 15-20 participants (Braun & Clarke, 2022).

On the 26th April 2023, I arranged a meeting with the Client to discuss the difficulties and low participant numbers. It was agreed that recruitment would continue for another month, and during this time I would put together multiple options for a possible change in deliverable for the Client to consider before the next meeting (24th May 2023). By the 24th May, there was only one more participant, which meant the virtual meeting with Social-Ability explored a change in deliverable for the consultancy process. There were three options which I provided to Social-Ability for the change in deliverable which included: a statistical report based upon data provided by the Client to examine the effectiveness of the intervention, a report mapping the intervention to Health Psychology theory and techniques, or advice and guidance in a form of a mini report on how Social-Ability could use ongoing evaluation on a regular basis with their clients. The options were discussed within supervision prior to presenting them to Social-Ability during a Microsoft Teams meeting, and I ensured that the options captured the Client's needs from the initial scoping meeting and communication which I had had with the Client throughout the time working together. Social-Ability were very understanding of this and were happy to trust my abilities as Consultant to provide them with a different deliverable. It was beneficial to have established and maintained a good working relationship with Social-Ability as a collaborative approach was used to decide on a new deliverable and ensure that it met both parties needs.

Following the decision on a new deliverable, a revised contract was completed and signed by both parties prior to the work being begun. Due to the change in deliverable, there was a set deadline which was the 10th July 2023. Having a deadline ensured that I kept on track with the progress of the report and met all deadlines for Social-Ability. Lippitt and Lippitt (1986) identify that it is vital for a Consultant to meet all deadlines the Client. On reflection, a deadline was beneficial for both parties, as deadlines make me more focussed to complete work, therefore, the new deadline helped to maintain my focus, complete the deliverable, which maintained a positive Client-Consultant relationship.

The end of this phase was signified by the completion of the report which was emailed to Social-Ability on the 6th July. Within the report, I made recommendations as a Trainee Health Psychologist as to how Social-Ability may be able to measure the effectiveness of their intervention through quantitative measures, which ensured that I fully meet the Client's needs (Earll & Bath, 2004).

Evaluate the impact of the Consultancy

The final stage of Earll and Bath's (2004) consultancy model is evaluation which explores the Client's satisfaction.

Client Evaluation

Earll and Bath (2004) identify that to assess the success of the consultancy process, it is important to explore Client evaluation including Client satisfaction. For the evaluation element of this consultancy process, I created a Microsoft Forms questionnaire including a range of closed questions with Likert-scale ratings, and open questions for the Client to review the consultancy, my role as a Consultant, and the deliverable produced.

The Client provided feedback on my role including communication and the working relationship which was developed and maintained throughout the consultancy process:

> "*Since CR was in touch with us back in 2021 until now, communication has been excellent to explain to us every step and to guide us through any obstacles practically and clearly- this helped us greatly with internally communicating changes of plans to our team…. CR listened to our feedback at every step. We are very grateful for CR for choosing to work with us, for her patience and for her time dedication to interview clients, and for crafting a valuable, technical, balanced report for us*."

Receiving this feedback from Social-Ability demonstrates that my skills as a Consultant including communication has helped to provide a positive consultancy process experience for the Client. For the six closed-questions with Likert-scale ratings, the Client rated my skills as 10/10 for all questions, demonstrating their satisfaction with my skills as a Consultant as well as the deliverable which I produced for the Client. Within the open-ended feedback, the Client also provided specific feedback about the deliverable:

> "*The deliverable has been very useful for us- the Health Psychology report has been well received by prospective partners… Our conversations with these partners may not have been possible without this external report by CR to demonstrate the value and successful implementation of our product the Happiness Programme*."

Reflection on the Consultancy and Overall Conclusion.

Prior to this competency, I had no experience of writing a consultancy contract or creating a hypothetical budget which meant I was nervous about completing these elements. Now I have had the opportunity to complete the competency, I fully understand the processes and I have templates which I can use for future consultancy work.

The unexpected event of needing to change the deliverable of the consultancy was stressful, as I did not want to hinder the working relationship I had built with the Client. Therefore, I took an active approach in developing multiple options for the change of deliverable which I thought would meet the needs of the Client. By taking this approach, it ensured that I was able to maintain the positive relationship and collaboratively decide on the new deliverable which would be completed for the deadline. I think that although the report was 'plan B', it was a better deliverable by the end of the consultancy than the piece of research would have been. I knew I was more confident in my skills and abilities when writing the report in comparison to completing the qualitative research which meant the work was a higher quality for Social-Ability.

For future consultancy opportunities, I would approach the working relationship more confidently from the beginning of the process and communicate my needs as Consultant clearer, such as trying to enforce a deadline which will enable the consultancy process to be clearer and for both Consultant and Client in terms of what needs to be achieved. Overall, I have found this consultancy process and experience very enjoyable and working with Social-Ability has been such a good opportunity. They were a very supportive Client and wanted to understand my training as a Trainee Health Psychologist completing the Professional Doctorate, which meant that I was able to develop skills as a Consultant and achieve the deliverable which met their needs as well as mine for my Professional Doctorate.

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5.2 Contract and Working Conditions Agreement

Dated: 25th May 2022

Miss Chloe Ryder (Consultant)
Health Psychologist in Training
Staffordshire University, Science Centre, Leek Road, Stoke-on-Trent, ST4 2DF

And

[redacted] (Client)

This Agreement dated 25th May 2022 is made between:

(l) Chloe Ryder (Consultant), Health Psychologist in Training, Staffordshire University, Science Centre, Stoke-on-Trent, ST4 2DF

(2) [redacted] (Client), [redacted]

Background

(A) The Client appoints the Consultant and the Consultant agrees to act as Consultant to the Client. The Consultant agrees to provide the services which are set out in this Agreement under the terms and conditions which are set out to the Client.

(B) The Client is of the opinion that the Consultant has the necessary qualifications, experience and abilities to provide the agreed services to the Client which are set out in this contract.

1. Definitions

I .1 'Health Psychology Consultancy' is defined as "the use of specialist Health Psychology skills and knowledge to provide a service to an external business Client"

1.2'Service' means the items which are provided by the Consultant which are set out within this Agreement. This includes conducting and analysing a piece of qualitative research and composing a qualitative report.

I .3 'Intellectual Property' means the work or services which the Consultant creates during a Consultancy service Agreement.

I .4 'Academic Publication' means publishing work to an academic journal to add either knowledge or research to a particular field of interest.

2. Terms of Reference

2.1 Services

The Client hereby agrees to engage the Consultant to provide the services consisting of:

Conducting a piece of qualitative research from start to finish and producing a qualitative report, exploring the perspectives of care home staff of using technological interventions, containing psychological components, with individuals living with dementia to improve nutritional intake and weight gain. The aims of this study will be:

- To explore perceptions of care home staff of using technological interventions to improve nutritional intake and weight gain.
- To explore the barriers and facilitators for increasing nutritional intake and weight gain in dementia care home settings.
- To explore barriers and facilitators of using technological interventions (such as the Happiness Programme) containing psychological components to increase nutritional intake and weight gain.

- To explore which components of technological interventions that are helpful in increasing nutritional intake and weight gain for individuals living with dementia.

The Consultant will be leading this piece of research and writing of the report. There will be a collaborative approach between the Consultant and the Client, see Consultant and Client roles below.

2.2Consultant's Role

2.2.1 The Consultant will conduct the piece of qualitative research as a piece of consultancy and evidence for the Advanced Research Methods competency which will be used to fulfil requirements for the Professional Doctorate in Health Psychology at Staffordshire University.

2.2.2 The work conducted by the Consultant will be as follows:

- Background research prior to completing research, looking for gaps in research and what previous research has identified.
- Constructing a research proposal
- Developing a rationale for the research
- Completing an ethical approval form, getting ethical approval pending amendments, and making any amendments needed to gain ethical approval.
- Constructing a semi-structured interview schedule.
- Invite participants to interview once approached by the Client, giving information about the study, and gaining informed consent.
- Conducting interviews with 10 to 20 participants based on Braun & Clarke (2013) guidance for Reflexive Thematic Analysis.
- Writing up transcripts of all interviews.
- Analysing data using Reflexive Thematic Analysis across all stages of the analysis
- Writing up the qualitative report to a publishable standard for a Health Psychology journal (Health Psychology Open, in the first instance) using APA formatting.
- Have regular meetings and contact with the Client to keep them updated with progress throughout the qualitative research though email communication and monthly virtual meetings via Microsoft Teams.

2.3 Client's Role

2.3. I The company [redacted] have their own Clinical Researcher within the team ([redacted]). [redacted] will be the main point of contact throughout the qualitative research and during this Consultancy Project. Therefore, the Client's role will entail:

- Advising on outcomes for the research to focus on, in which the Consultant will decide the final outcomes based on these recommendations.
- Checking interview schedules.
- Providing a list of dementia care home settings which use the Happiness Programme technology and therefore could be approached for interview.
- Contacting potential participants inviting them to join the research, passing on details to the Consultant so potential participants can be invited to interview.
- Reviewing themes and codes within transcripts that the Consultant has identified whilst analysing data from interview transcripts.
- Proof-reading the final qualitative report prior to submission.

3. The Project

3.1 The Output of the Consultancy

3.1.1 The Client agrees to appoint the Consultant to provide the Client with services including conducting a piece of qualitative research and producing a qualitative report, exploring the perspectives of care home staff of using technological interventions, containing psychological components, with individuals living with dementia to improve nutritional intake and weight gain.

3.1.2 The final output of the Consultancy is a qualitative research report.

3.1.3 The Consultant shall provide the Client with an electronic PDF copy of the final qualitative research report.

3.1.4 Following completion of the qualitative research report, the Consultant will have full responsibility of attempting to get the qualitative report published to a Health Psychology journal (Health Psychology Open).

3.2 Authorship

3.2. I Authorship refers to individuals which have had a significant involvement to a piece of research, work, and journal article.

3.2.2 The authorship for this project will be as follows:

- Chloe Ryder (Lead Author)
- [redacted] (Second Author)

Doctorate supervisor at Staffordshire University, Dr Lisa Cowap and Qualitative Research Methods lead at Staffordshire University, Dr Jennifer Taylor may be considered as third and fourth authors if they have a significant contribution to the piece of Qualitative Research conducted.

3.3 Project Schedule and Timeframe

3.3. I The proposed start date of the project is May 2022.

3.3.2 The proposed end date of the project is November 2022.

3.3.3 Due to the nature of qualitative research, and the potential availability of participants, and the potential length of time for ethical approval of the project, the proposed end date may be adjusted due to unexpected circumstances. Therefore, there will be monthly meetings virtually via Microsoft Teams to keep the Client updated with progress of the project, as agreed on the initial scoping meeting. The monthly meetings will also allow for discussion if the research remains on target for the proposed end date or whether an adjustment needs to be made for the end date.

4. Costs

4.1 During an initial scoping meeting on 20th October 2021, it was agreed that no fees will be received for the Consultants' services to the Client.

4.2 The Consultant will pay for any travel costs which may need to be incurred, i.e., any travelling costs for conducting interviews or face-to-face meetings with the Client.

5. Academic Publication and Impact

5.1 The qualitative research produced as part of this Consultancy Agreement will be written up with the aim for publication for a Health Psychology journal.

6. Intellectual Property

6.1 The intellectual property shall be owned by the Consultant. This is due to the consultancy being used to fulfil the Consultancy Skills competency required for the Professional Doctorate in Health Psychology at Staffordshire University.

7. Resources

7.1 The Consultant shall use her own resources for the piece of Qualitative Research.

7.2 In cases where the Client inputs to the piece of Qualitative Research i.e., analysing data or looking at themes and codes within the data set, the Client will use their own resources.

8. Ethics and Confidentiality

8.1 It will be the full responsibility of the Consultant to gain ethical approval for the qualitative research. Ethical approval shall be sought from Staffordshire University.

8.2 The Consultant will comply with the British Psychological Society 'Code of Ethics and Conduct' (2018) and the Health & Care Professions Council 'Standards of Conduct, Performance, and Ethics' (2018) throughout the Consultancy and whilst conducting the qualitative research.

8.3 All data collected during the research process will remain confidential, with participants being given a participant identification code which will keep identities separate to transcripts. Any transcripts of interviews from participants will be stored on OneDrive which requires specific log in detail, therefore, only the Consultant will be able to view participant data with the Clients clinical researcher.

8.4 This piece of work shall be discussed during the Consultant's supervisions with their supervisor for the Professional Doctorate in Health Psychology at Staffordshire University. This piece of work shall also be examined by internal and external examiners of Staffordshire University.

8.5 The Consultant shall not either during or following the termination of the Consultancy communicate to any other individuals (except for individuals stated in article 3.2.2 and 8.4) any information in relation to the Client.

9. Good Data Management Practices

9.1 Data collected during the research must be generated using ethical, psychological, and scientific processes and techniques.

9.2 Research data must be recorded in accordance with the British Psychological Society 'Code of Ethics and Conduct' (2018) and 'Code of Human Research Ethics' (2021).

9.3 Research data and any results must be stored securely in accordance with the British Psychological Society 'Code of Ethics and Conduct' (2018) and 'Code of Human Research Ethics' (2021).

9.4 Data trails and journals must be kept allowing for individuals to demonstrate key decisions made during the research process, including dissemination of data and the construction of codes and themes for the Qualitative research report.

10. Communication

10.1 The Consultant and the Client will have monthly meetings which will take place via Microsoft Teams to review the progress of the Consultancy and piece of qualitative research.

10.2 Communication will also occur via email, this will occur if there are any updates which are needed to be communicated between monthly meetings (for example, email communication following ethical approval, or during recruitment of participants phase of qualitative research).

10.3 The following table indicates dates for monthly meetings agreed by the Consultant and the Client during a meeting on the 16th March 2022.

Date	Meeting Time	Location
22nd June 2022	12:00-13:00	Microsoft Teams
27th July 2022	12:00-13:00	Microsoft Teams
24th August 2022	12:00-13:00	Microsoft Teams
28th September 2022	12:00-13:00	Microsoft Teams
26th October 2022	12:00-13:00	Microsoft Teams
23 rd November 2022	12:00-13:00	Microsoft Teams

11. Modification of the Agreement

1 1.1 This Agreement may be modified or amended which shall be made in writing.
1 1.2 Any modifications to the Agreement will only become active once both parties have signed the amended version of the contract.

12. Termination

12.1 If' either party wishes to terminate the Agreement, that party will be required to give 30 days' notice to the other party.

12.2 Termination of the Consultancy Agreement will need to be communicated clearly through written communication (for example, via email). This is to ensure full clarity of any wishes to terminate the Agreement between the Consultant and the Client.

13. Additional Information

13.1 The Consultant is currently undertaking a Professional Doctorate in Health Psychology at Staffordshire University. As part of this Professional Doctorate, the Consultant is required to meet the following five competencies:

- Professional Competence in Health Psychology
- Advanced Research Methods in Health Psychology
- Psychological Interventions
- Consultancy Skills
- Teaching in Health Psychology.

13.2 This piece of work is in line with the Consultancy Skills competency, meaning that this piece of work will be included as a case study in the Consultants final portfolio.

13.2.1. This piece of work shall be discussed with the Consultant's supervisor during supervision for the Professional Doctorate in Health Psychology at Staffordshire University.

13.2.2. This piece of work shall be examined by internal and external examiners of Staffordshire University.

This Agreement has been completed and the details which are set out in this Agreement are agreeable both the Consultant and the Client once signed:

The Consultant
Print Name: Miss Chloe Ryder

Signature:
Date: 25th May 2022

The Client

Print Name: [redacted]

Signature: [redacted]

Date: 01/06/2022

5.3 Revised Contract and Working Conditions Agreement

Consultancy Contract

Dated: 26th May 2023

Miss Chloe Ryder (Consultant)

Health Psychologist in Training

Staffordshire University, Science Centre, Leek Road, Stoke-on-Trent, ST4 2DF

And

[redacted] (Client)

[redacted]

This Agreement dated 24th May 2023 is made between:

(1) **Chloe Ryder** (Consultant), Health Psychologist in Training, Staffordshire University, Science Centre, Stoke-on-Trent, ST4 2DF

(2) [redacted] (Client), [redacted], [redacted]

Background

(A) The Client appoints the Consultant and the Consultant agrees to act as Consultant to the Client. The Consultant agrees to provide the services which are set out in this Agreement under the terms and conditions which are set out to the Client.

(B) The Client is of the opinion that the Consultant has the necessary qualifications, experience and abilities to provide the agreed services to the Client which are set out in this contract.

1. Definitions

1.1 **'Health Psychology Consultancy'** is defined as "*the use of specialist Health Psychology skills and knowledge to provide a service to an external business Client*"

1.2 **'Service'** means the items which are provided by the Consultant which are set out within this Agreement. This includes composing a Health Psychology report.

1.3 **'Intellectual Property'** means the work or services which the Consultant creates during a Consultancy service Agreement.

2. Terms of Reference

2.1 Services

The Client hereby agrees to engage the Consultant to provide the services consisting of:

Producing a 3000-word report mapping the 'Happiness Programme' intervention to Health Psychology theory and techniques such as the COM-B model and behaviour change techniques.

The report would include:

- An introduction of the intervention
- An introduction to key Health Psychology theories and behaviour change techniques used within interventions.

- Exploration as to how the intervention can be mapped onto specific Health Psychology models and theories.
- Implications of being able to map the intervention onto Health Psychology theories, models, and techniques.
- Use of already collected participant interviews quotes to demonstrate how individuals using the Happiness Programme support the implementation of Health Psychology theories.
- Future recommendations including recommendations of pre-validated measures to use which [redacted] can use to assess effectiveness of their intervention using statistics.

2.2 *Consultant's Role*

2.2.1 The Consultant will Producing a report mapping the intervention to Health Psychology theory and techniques such as the COM-B model and behaviour change techniques. This report will be used as a piece of Consultancy which will be used to fulfil requirements for the Professional Doctorate in Health Psychology at Staffordshire University.

2.2.2 The work conducted by the Consultant will be as follows:

- Background research prior to completing the report on what Health Psychology theory and techniques can be applied to the 'Happiness Programme' intervention.
- Writing up a 3000-word report mapping the 'Happiness Programme' intervention to Health Psychology theory and techniques such as the COM-B model and behaviour change techniques.
- Provide future recommendations including recommendations of pre-validated measures to use which [redacted] (Client) can use to assess effectiveness of their intervention using statistics.
- Ensuring that the report is accessible for both [redacted] (Client) and general members of public (a lay audience).

2.3 *Client's Role*

2.3.1 The company [redacted] have their own Clinical Researcher within the team ([redacted] will be the main point of contact throughout the writing of the report during this Consultancy Project. Therefore, the Client's role will entail:

- Providing the Consultant with a vast amount of background information about the 'Happiness Programme' intervention to enable full write up of the introduction section of the report.

3. The Project

3.1 The Output of the Consultancy

3.1.1 The Client agrees to appoint the Consultant to producing a 3000-word report mapping the 'Happiness Programme' intervention to Health Psychology theory and techniques such as the COM-B model and behaviour change techniques.

3.1.2 The final output of the Consultancy is a Health Psychology Report.

3.1.3 The Consultant shall provide the Client with an electronic PDF copy of the final Health Psychology Report.

3.2 Authorship

3.2.1 Authorship refers to individuals which have had a significant involvement to a piece of research, work, and journal article.

3.2.2 The authorship for this project will be as follows:

Chloe Ryder (Lead Author)

3.3 Project Schedule and Timeframe

3.3.1 The proposed start date of the project is May 2023.

3.3.2 The proposed end date of the project is July 2023.

4. Costs

4.1 During an initial scoping meeting on 24th May 2023, it was agreed that no fees will be received for the Consultants' services to the Client.

5. Intellectual Property

5.1 The intellectual property shall be owned by the Consultant. This is due to the consultancy being used to fulfil the Consultancy Skills competency required for the Professional Doctorate in Health Psychology at Staffordshire University.

6. Resources

6.1 The Consultant shall use her own resources for the writing up of the report.

7. Communication

7.1. The Consultant and the Client will have monthly meetings which will take place via Microsoft Teams to review the progress of the Consultancy.

7.2. Communication will also occur via email; this will occur if there are any updates which are needed to be communicated between monthly meetings.

8. Modification of the Agreement

8.1 This Agreement may be modified or amended which shall be made in writing.

8.2 Any modifications to the Agreement will only become active once both parties have signed the amended version of the contract.

9. Termination

9.1. If either party wishes to terminate the Agreement, that party will be required to give **30 days' notice** to the other party.

9.2. Termination of the Consultancy Agreement will need to be communicated clearly through written communication (for example, via email). This is to ensure full clarity of any wishes to terminate the Agreement between the Consultant and the Client.

10. Additional Information

10.1. The Consultant is currently undertaking a Professional Doctorate in Health Psychology at Staffordshire University. As part of this Professional Doctorate, the Consultant is required to meet the following five competencies:

- Professional Competence in Health Psychology
- Advanced Research Methods in Health Psychology
- Psychological Interventions
- Consultancy Skills
- Teaching in Health Psychology.

10.2. This piece of work is in line with the Consultancy Skills competency, meaning that this piece of work will be included as a case study in the Consultants final portfolio.

10.2.1. This piece of work shall be discussed with the Consultant's supervisor during supervision for the Professional Doctorate in Health Psychology at Staffordshire University.

10.2.2. This piece of work shall be examined by internal and external examiners of Staffordshire University.

This Agreement has been completed and the details which are set out in this Agreement are agreeable both the Consultant and the Client once signed:

The Consultant

Print Name: Miss Chloe Ryder

Signature: ____________________

Date: 26th May 2023

The Client

Print Name: [redacted]

Signature: [redacted]

Date: 26th May 2023

Chapter 6: Health Psychology Interventions

6.1 Individual face-to-face Intervention Case Study

Individual face-to-face intervention: Improving nutritional intake for a young-adult female living with Obsessive-Compulsive Disorder.

Research in the United Kingdom (UK) has indicated that only 27% of adults are meeting the recommended 5 portions of fruit and vegetable intake per day (Association of UK Dieticians, 2016; Office for Health Improvement and Disparities, 2016). The most recent national diet and nutrition survey (Public Health England, 2020) highlighted that diet and nutritional intake quality for young adults in the UK has declined since the COVID-19 pandemic, with on average young adults eating 3.7 portions of fruit and vegetables per day, below the National Health Service (NHS) and World Health Organisation (WHO) recommended amount of 5 portions (NHS, 2022; WHO, 2020).

Healthy eating and having a well-balanced diet are a protective health behaviour (Dunton, 2018), with nutrition having a positive impact on physical and psychological health (Mangione et al, 2022; Michie et al, 2009; Shan et al, 2023). Correlations within nutritional psychiatry research have identified a link between deficiencies in iron, zinc, and magnesium with anxiety, depression, and obsessive-compulsive disorder (OCD) (Baabouchi, 2024; Grajek et al, 2022; Horn et al, 2022; Sarkar & Sarkar, 2023). Thus, highlighting the importance of healthy eating and a balanced diet for psychological health.

This case study outlines and provides a summary of an individual face-to-face intervention focussing upon improving nutritional intake and healthy eating for a young-adult female living with OCD. I sent a message on the work platform, using a poster to advertise my training and the opportunity to work one-to-one with myself for health psychology support. Lucy (pseudonym used to protect confidentiality) responded, commenting she wanted to focus on her eating behaviour. This case study describes the assessment, formulation, implementation and evaluation stages of the intervention.

Assessment

As part of an intervention, the assessment stage helps to determine an individual's difficulties in a measurable manner (Johnstone & Dallos, 2013). Within the assessment stage, there is also an open conversation between intervention facilitator and Client which helps to determine the factors which are barriers preventing the individual from changing their health behaviour (Thrower et al, 2024). The assessment took part in session one of the intervention.

Session One – Assessment & Rapport Building

To begin the first session, I re-introduced myself to Lucy and explained the Professional Doctorate, the competencies, and my work as a Trainee Health Psychologist. I gave the opportunity for Lucy to introduce herself and provide some background information which may be helpful for assessment and formulation. Although colleagues, Lucy and I work in different departments, therefore establishing rapport was essential. Positive rapport helps to build a sense of trust, encouraging individuals to have the self-confidence to try different options for behaviour change (Harman et al, 2014; Mason & Butler, 2010). This sense of increased self-confidence within a safe environment, has been highlighted to increase the likelihood of successful and sustainable behaviour change for nutritional intake (Hardcastle & Hagger, 2011).

To help build rapport during the assessment process, I implemented motivational interviewing techniques (Cole et al, 2023) and communication skills such as active listening, and summarising key points which Lucy had discussed surrounding current nutritional intake. Motivational interviewing helps to provide a positive and calming environment for an open conversation surrounding behaviour change, ensuring that a practitioner can understand their client's perspective surrounding the topic (Hardcastle et al, 2017). I asked open questions allowing Lucy to lead the conversation and explore her current nutritional intake, eating routine and the barriers and facilitators which she has faced previously. Open-ended questions ensures that individuals can reflect on their difficulties and provide information surrounding experiences (Haynes et al, 2011), ensuring the intervention is person-centered and tailored to an individual's needs.

As part of the assessment session, I asked Lucy to complete two baseline measures (see table 1) surrounding nutritional intake/eating behaviour (primary outcome) and motivation for food choice (secondary outcome). Primary outcomes for the intervention were determined during initial conversations with Lucy when she responded to the poster advertisement. Figure 1 highlights Lucy's motivation for food choice at baseline.

Table 1. Baseline Measures and Scores

Measure	Summary	Lucy's Score	Overall comments
Healthy Eating Assessment (Paxton et al, 2011)	10-item survey using a 5-point Likert-Scale. Asks individuals to recall how many times they eat specific food groups. Groups responses into Health benefit categories.	Total score = 35 Health Benefit Category = Good (within 30-39 range)	Lucy self-rated diet as "fair" Overall good balance of nutritional intake.
Food Choice Questionnaire (Steptoe & Pollard, 1995)	34-item survey using a 4-point Likert scale. Asks individuals to consider their motivations for food choice surrounding health, mood, convenience, sensory appeal, natural content, price, weight control, familiarity, and ethical concern.	Convenience: 15/20 (75%) Natural Content: 8/12 (66%) Weight Control: 8/12 (66%) Sensory Appeal: 11/16 (68%) Price: 4/12 (33%) Familiarity: 6/12 (50%) Health: 18/24 (75%) Mood: 14/24 (58%) Ethical Concern: 9/12 (75%)	Lucy is driven by health, convenience, and ethical concern the most for motivation for food choice.

Figure 1. *Lucy's Baseline Motivation for Food Choice.*

The assessment measures identified that Lucy's current nutritional intake overall was good, with having very little risk for her physical health. The Healthy Eating Assessment (Paxton et al, 2011) identified a difference in Lucy's self-reflection of her diet as "fair" compared to her self-reporting a balanced and well-rounded diet for main meals.

Formulation

Formulation is a core element within the behaviour change intervention process, ensuring that the intervention facilitator has a full understanding of all information provided by the Client during the assessment stage (Division of Clinical Psychology, 2011; Johnstone & Dallos, 2013; Thrower et al, 2024). Within the formulation process, I used the COM-B model (Michie et al, 2011, see figure 2) to explore Lucy's capabilities, opportunities, and motivations for improving her nutritional intake. Table 2 provides the full formulation using the COM-B model.

During the assessment process, Lucy spoke through influences for her nutritional intake at present and motivations for food choice, which could be themed into capability, opportunity, and motivation. This indicated that the COM-B model (Michie et al, 2011) was the most suitable to use for the formulation process ensuring this intervention was person-centered. Research has identified that healthy eating behaviour change is strongly correlated with capability, opportunity, and motivation (Willmott et al, 2021). Thus, emphasising that interventions exploring healthy eating need to include enablers and barriers to change for capability, opportunity, and motivation. Research has highlighted that nutritional intake interventions using the COM-B model were highly effective, encouraging sustainable behaviour change (improved nutritional intake; Willmott et al, 2021). Formulation using the COM-B Model (Michie et al, 2011) was completed using a co-creation (Leask et al, 2019; Popp et al, 2021) and collaborative approach with Lucy during session one to ensure that the intervention was person-centered and meeting Lucy's needs and expectations (Thabrew et al, 2018; Whatnall et al, 2022).

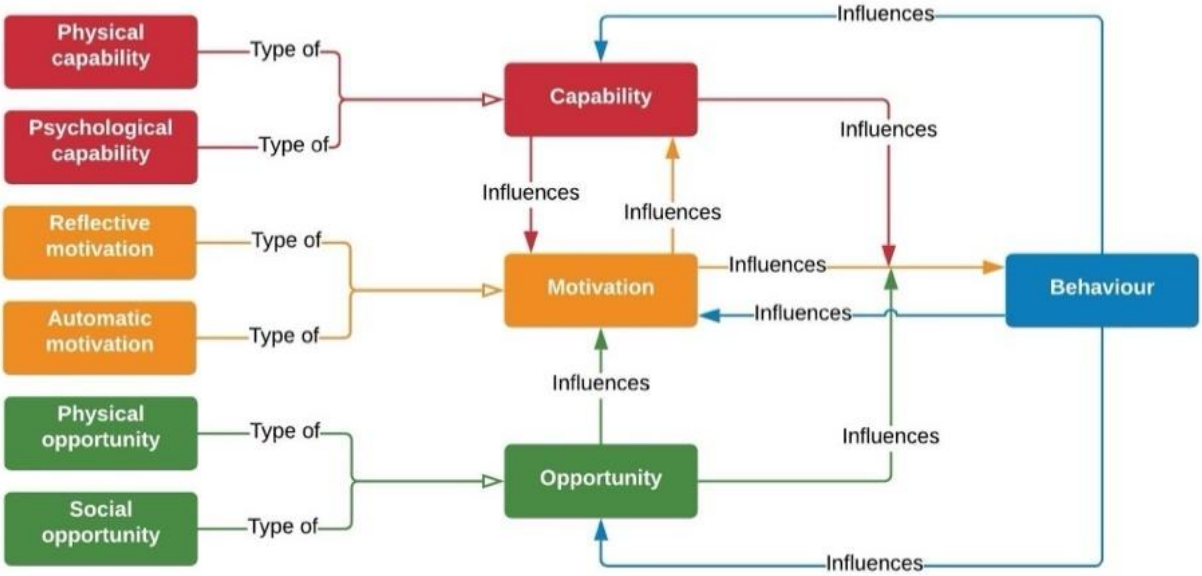

Figure 2. *The COM-B Model (Michie et al, 2011; West & Michie, 2020).*

Table 2. Formulation for Lucy’s intervention using the COM-B Model (Michie et al, 2011).

COM-B element		**Factors Explored**	**How the intervention will address this.**
Capability	Physical Capability	**Facilitator**: Knows how to cook well-balanced and nutritious meals **Facilitator**: Can follow recipes.	Not applicable – Lucy understands how to cook healthy and well-balanced meals. She enjoys following recipes for cooking meals.
	Psychological Capability	**Facilitator**: Knows how to cook well-balanced and nutritious meals **Facilitator**: Has confidence in cooking meals which she is familiar with and used to making. **Barrier**: Worries about under-cooking food which prevents her from cooking at times. Lucy reflected that this links to her OCD.	Not applicable for this intervention – capability is not something which Lucy requires support with to help with her nutritional intake. Lucy has additional support for her OCD.
Opportunity	Physical Opportunity	**Barrier**: Balance between work and home life can mean that there is “*no time*” for cooking meals from scratch. **Barrier**: Batch cooking (on a weekend) is something which Lucy finds off-putting as multiple meals which are the same get boring. **Barrier**: Lucy finds it easy to fall out of a routine	Goal setting – how to ensure that meals are manageable and allowing Lucy to see the success when maintaining a routine. Exploring the convenience of cooking meals which are balanced – avoiding takeaways.
	Social Opportunity	**Facilitator**: Having a supportive partner at home who also enjoys cooking meals. **Facilitator**: Supportive partner who also wants to improve nutritional intake **Facilitator**: Lucy enjoys having lunch with work colleagues and comparing what they have all brought with them and cooked at home.	Lucy finds social support important in her life. This intervention will incorporate social support when helping Lucy to improve her nutritional intake.
Motivation	Reflective Motivation	**Facilitator**: Lucy sees cooking for her boyfriend as an “*act of service*” and is something which she thoroughly enjoys.	Goal setting and self-monitoring– knowing that Lucy finds the small successes as confidence boosting, goal

		Facilitator: Lucy reflected on her OCD journey so far, knowing that for other opportunities, she finds that “*small wins really help”* in maintaining motivation **Barrier**: Lucy finds the thought of cooking at home “*off-putting*” which means that cooking fresh meals can become too overwhelming. This thought pattern results in her going to a convenience option. **Barrier**: Lucy feels like she needs to be “*on to the go 24/7*” which can mean that she does not feel there is time to stop and cook a meal – other factors feel too important in comparison to cooking. **Barrier**: In previous experiences, Lucy has found changing health behaviour to follow a ‘boom and bust’ cycle – where she “*goes all in*”, then quickly falls out of a routine, and struggles with motivation.	setting and self-monitoring through a food diary will be used to ensure that motivation and confidence is maintained throughout the intervention. Psychoeducation - This will help to maintain a consistent routine for Lucy and avoid the ‘boom and bust’ cycle which she has experienced before when changing her nutritional intake behaviour.
	Automatic Motivation	**Barrier:** Although Lucy reflects on a generally well-rounded diet for main meals, she finds her snacking behaviour to be problematic. She finds herself needing a sugary/sweet snack after main meals – likening this to a “*sugar addiction*”	Goal setting – snacking behaviour will be focussed upon through SMARTER goals within the intervention. Psychoeducation – ways in which snacking can be healthy but still fulfil the “sweet” cravings which Lucy experiences.

**Note: Any words presented in italics are from Lucy directly during session 1 as part of the assessment formulation process.*

The assessment and formulation process highlighted that Lucy was highly motivated to change her behaviour, but barriers and previous experiences which have not been successful reduced her confidence in being able to sustainably improve nutritional choices and diet. Lucy was reflective during session one, highlighting that she knows that her snacking behaviour was the main issue due to snacking and buying convenience meals such as takeaways and preferring sugary foods, creating an "*up and down*" diet. From this formulation process, it was evident that there were barriers for Lucy's motivation and physical opportunities, meaning that these would be focused upon throughout the intervention. Goal setting, self-monitoring, psychoeducation, and social support were key to implement throughout the intervention to ensure a positive behaviour change of nutritional choice and diet for Lucy.

Intervention Design

Following the assessment and formulation, I identified that the Theory of Planned Behaviour ([TPB] Azjen, 1991), and COM-B model (Michie et al, 2011) would be the most suitable to structure the intervention along with Behaviour Change Techniques (BCTs) from the Behaviour Change Taxonomy (Michie et al, 2013) and focussing improving self-efficacy (Bandura, 1997) throughout.

Self-Efficacy (Bandura, 1997)

Research has highlighted that individuals who identify as a healthy eater are more likely to change their nutritional intake and overall diet behaviour (Strachan & Brawley, 2009). This identity combined with high levels of self-efficacy have been correlated to increase sustainable healthy eating behaviour change (Anderson et al, 2007). Self-efficacy was identified to be low during the assessment and formulation process, which subsequently was a barrier for Lucy’s capability, and hindering motivation for behaviour change. It was essential that self-efficacy was focussed on throughout the intervention through using the TPB, psychoeducation, goal setting and BCT’s.

Theory of Planned Behaviour (Azjen, 1991)

The Theory of Planned Behaviour (Azjen, 1991) has been frequently used within healthy eating behaviour change interventions (Brug et al, 2005) with positive results due to interventions facilitating a positive attitude and higher levels of perceived behavioural control (Khani-Jeihooni et al, 2022; McDermott et al, 2015a, 2015b). The TBP is a critiqued theory for use within behaviour change interventions due to limitations in predictive validity (Sniehotta et al, 2014), and a weak correlation between intention and behaviour; known as the intention-behaviour gap (Sheeran & Webb, 2016). Although critiqued, I mitigated limitations of the model using BCTs (Abraham & Michie, 2008) such as goal setting, feedback and monitoring, self-belief, and shaping knowledge to bridge the intention-behaviour gap. Using the TBP in combination with BCTs and self-efficacy ensured that Lucy’s attitudes, perceived behavioural control (through increased self-efficacy and confidence) and subjective norms were explored within the intervention to promote positive behaviour change.

Due to convenience being a key factor for food choice, it was important to focus on Lucy’s attitudes toward convenience food, particularly around the time and cost to help promote healthy eating behaviour change (Brouwer & Mosack, 2015; Sogari et al, 2023). Interventions promoting a positive attitude towards a healthy diet and balanced nutritional intake are likely to encourage an individual’s identity to move to a “healthy eater” encouraging increased intention to behaviour change and increased perceived behavioural control (Sogari et al, 2023). Due to Lucy living with her partner, it was essential to explore social support (both practical and emotional) to assess the subjective norms within Lucy's environment to ensure that encouragement and subjective norms were a continuous facilitator for Lucy's behaviour change.

Behaviour Change Techniques (Michie et al, 2013)

Behaviour Change Techniques (BCTs) are strategies which are used in collaboration with psychological theory and models within interventions encouraging behaviour change and overall health promotion (Abraham & Michie, 2008; Cline et al, 2025). Self-monitoring, goals and planning, shaping knowledge, and self-belief are BCTs which have been identified to promote individuals healthy eating behaviour (Michie et al, 2011; Samdal et al, 2017). Overall, used in combination with TPB, the COM-B model, and focussing on self-efficacy, BCTs help to promote healthy eating and improved nutritional intake (Spring et al, 2021), supporting Lucy to increase her confidence for healthy eating, overall balanced nutritional intake and identifying healthier motivations for food choice.

Table 3 provides an outline of the intervention plan.

Table 3. Outline of the intervention, including psychological theory and model underpinning, and Behaviour Change Techniques.

Week	Topic / Title of week	Objectives for week & Content for the week	Psychological Theory/ Model underpinning content	Behaviour Change Techniques
1	Assessment & formulation Goal Setting	• Baseline measures for nutritional intake and motivation for food choice. • Discussion of aims, goals, and reflections surrounding nutritional intake. • Building Rapport • Discussion of the plan for the intervention – milestones • Goal setting – short and long-term goals. • Provision of intervention resources for Lucy to use in session and independently (homework tasks & self-monitoring). **Homework task**: Complete food diary between session 1 and 2 for nutritional intake.	COM-B Model (Formulation) Theory of Planned behaviour: • Attitude • Perceived behaviour control	Goals and planning • 1.1 Goal setting (behaviour) • 1.3 Goal setting (outcome) • 1.9 Commitment
2	Enhancing Capability Identifying Opportunity	Nutrition education (psychoeducation): • To help identify capabilities for healthy nutrition in daily routine. • Practical skills – helping to make healthy eating feel achievable. • Meal planning & meal preparation Food awareness and self-monitoring • Reviewing food diary completed by Lucy between session 1 and 2. • Identifying patterns of nutritional intake. Social support	COM-B Model • Capability (physical and psychological) • Opportunity (reflective and automatic) Theory of planned behaviour • Normative beliefs (subjective norms)	2. Feedback and monitoring • 2.3 self-monitoring of behaviour 3. Social support • 3.2 Social support (practical) • 3.3 Social support (emotional) 4. Shaping knowledge • 4.2 Information about antecedents 5. Natural consequences • 5.1 Information about health consequences

		• Partners nutritional intake & support for behaviour change • Friends/family support – potential consideration for a nutrition buddy (i.e., a colleague at work) Exploring nutritional intake in social situations • Office day nutritional intake routine • Eating out for social occasions **Homework task**: Complete food diary between session 1 and 2 for nutritional intake. Complete a meal planner to help organise weekly nutritional intake & consider how this helps to support healthy eating during a working week.	• Perceived behavioural control Self-efficacy • Enactive mastery Psychoeducation	• 5.4 monitoring of emotional consequences • 5.6 Information about emotional consequences
3	Strengthening Motivation	Mindful eating training/psychoeducation • Importance of listening to body and hunger cues. Motivation techniques (psychoeducation) • Introducing the 80/20 rule – balancing healthy eating with the occasional treats. Helps with motivation and understanding that healthy eating does not have to be rigid. Action planning • Recognising situations and/or emotions which may cause a relapse in new habit formation for behaviour change – and how to overcome these.	COM-B Model • Motivation Theory of planned behaviour • Attitudes Self-efficacy • Verbal persuasion Psychoeducation	2. Feedback and monitoring • 2.3 self-monitoring of behaviour 3. Social support • 3.2 Social support (practical) • 3.3 Social support (emotional) 8. Repetition and Substitution • 8.1 Behavioural practice/rehearsal • 8.3 Habit Formation 15. Self-belief • Verbal persuasion about capability • Focus on past success • Self-talk.

		Reflection: • Focusing on previous successes – looking at food diary completed between sessions within the intervention. **Homework task:** Complete food diary between session 1 and 2 for nutritional intake. Implement the 80/20 rule – and reflect on how this impacts motivation for nutritional intake.		
4	Sustained behaviour change: Long-term motivation End of intervention – post intervention measures	Long-term nutrition habits • Creating a flexible plan to help with sustainability • Baseline measures for nutritional intake and motivation for food choice. • Consider whether goals set in session 1 have been met (short-term goals). • Set 1 long-term goal to complete independently post-session to maintain motivation and focus on healthy nutritional intake. • Client evaluation of intervention	COM-B Model • Motivation Theory of planned behaviour • Attitudes • Subjective norms (long-term normative beliefs) Self-efficacy	1 Goals and planning • 1.4 Action planning 3. Social support • 3.2 Social support (practical) • 3.3 Social support (emotional) 7. Associations • Prompts/cues • Associative Learning. 13. Identity • 13.5 Identity associated with change behaviour 15. Self-belief • Verbal persuasion about capability • Focus on past success • Self-talk.

Intervention Delivery and Implementation

The intervention was delivered face-to-face and within the workplace office. For all sessions, to ensure confidentiality and that Lucy felt comfortable discussing her nutritional intake and any challenges, barriers, or concerns, I booked a separate meeting room. All sessions lasted 45-minutes to 1 hour and took place weekly.

Food diary

I provided Lucy resources prior to the intervention beginning which included a food diary. Research highlights that the use of a food diary in behaviour change interventions increases likelihood of behaviour change and success of the intervention (Pears et al, 2012). This increased likelihood of behaviour change whilst using a food diary can be correlated with increased self-monitoring and self-awareness. The use of a food diary encourages an individual to focus on successes each week as part of the review and monitor process (Curtis et al, 2024; Rusin et al, 2013; Zepeda & Deal, 2008).

Each session of the intervention, I began by asking Lucy to talk through her food diary for the week, allowing Lucy to reflect on her intake, successes and any challenges faced. Initially, Lucy focussed on challenges and times where she struggled with snacking and choosing convenience and unhealthy food, lowering her confidence. I encouraged Lucy to focus on the whole week as part of the review process, identifying that she only had two days of particularly high snacking which for her first week of the intervention was excellent progress. Throughout the remainder of the intervention Lucy focussed on the whole week subsequently increasing her self-efficacy, confidence and motivation to continue with the health behaviour change process. At the end of session four, Lucy commented that she will continue to use the food diary independently, as it allows for her evaluate her progress and maintain motivation.

Goal setting

At the end of session one, I introduced goal setting and specific, measurable, action-oriented, realistic, timely, evaluated and reviewed (SMARTER) goals to Lucy. Goal setting has been identified to improve likelihood of behaviour change for healthy eating and improved nutritional intake (Locke & Lathan, 2013; Samdal et al, 2017; Swann et al, 2022). This is particularly evident for short-term behaviour change, with initial goals helping to improve self-confidence and increase motivation (Michie et al, 2009), due to reviewing and feedback being key components of goal progress throughout an intervention. With Lucy commenting in the assessment and formulation process that '*small wins*' are essential to keep her motivation levels high, goal setting was appropriate to use within the intervention to ensure continuous motivation and focus on success each week.

As part of goal setting, I asked Lucy to set three main goals: two-short term goals which can be achieved throughout the 4-week intervention, and one longer-term goal which Lucy could work on during the intervention as well as post-intervention independently to keep her motivation for improving nutritional intake. The goals which Lucy set as part of the assessment within session one can be seen in table 4.

Table 4. Goals which Lucy set at the end of session one.

Goal	Specific	Measurable	Action-oriented	Realistic	Timely	Evaluated	Reviewed	Duration of Goal
To reduce intake of sugary snacks by 50% a day	✓	✓	✓	✓	✓	To be evaluated throughout the intervention.	Lucy will be completing a food diary throughout the intervention. The food diary records breakfast, lunch, dinner, and any snacks throughout the day. Will be discussed at the beginning of each session.	Short-term
To be able to have a week of no takeaways (Note: convenience food at home – does not include eating out)	✓	✓	✓	✓	✓	To be evaluated throughout the intervention.	Lucy will be completing a food diary throughout the intervention. This will be discussed at the beginning of each session.	Short-term/ Medium-term
To lose two-stone by December 2025 through healthy eating and health behaviour.	✓	✓	✓	✓	✓	To be evaluated throughout the intervention.	Lucy will reflect on this individually (through phone app) and feedback on successes throughout the intervention.	Long-term (9-months)

During session two, I reviewed and encouraged Lucy to evaluate success for her initial goals. It was identified that the goals which Lucy set were achieved within the first week, highlighting Lucy's clear motivation to change, as well as the potential that goals set were potentially too easy. Within session two, we discussed Lucy's progress, and how she felt when completing the goals. Lucy identified that achieving the goals helped to improve her confidence as she thrives on seeing success not matter how small. Research identifies that achieving goals improves self-efficacy (Lin et al, 2022; Spring et al, 2021), subsequently maintaining high motivation levels for behaviour change. At the end of the second session, Lucy set additional short-term goals which she knew would be more challenging. These goals included:

- Goal one: To reduce snacking to only one per day
- Goal two: To have a month with 0 takeaways.

The long-term goal remained the same throughout the intervention as this would be something which Lucy would work on independently post-intervention until December 2025.

Psychoeducation

Psychoeducation is used within nutritional behaviour change interventions frequently (Barnes et al, 2017; Fristad, 2016; Wilson et al, 2021), encouraging individuals to have an active role in their behaviour change by empowering them with knowledge. Psychoeducation supports individuals to independently monitor progress, provides knowledge for coping strategies to help overcome barriers which may be faced whilst using a collaborative and person-centered approach (Barnes et al, 2017; Cezaretto et al, 2016; Morris et al, 2024).

Psychoeducation was used within sessions two and three of the intervention, with the overarching aim to improve Lucy's understanding of healthy eating and the importance of a good nutritional intake for physical and psychological health. The topics of discussion as part of psychoeducation included the role of nutrition for physical and psychological health, how to make meals convenient (role of bulk cooking), and how to overcome challenges and barriers. Psychoeducation within this intervention was supportive for Lucy, with her identifying that she found understanding her nutrition and reasoning for choosing foods particularly useful as part of the post-intervention evaluation.

Evaluation

Examining the results from the Food Choice Questionnaire (Steptoe & Pollard, 1995) and the Healthy Eating Assessment (Paxton et al, 2011) identified that Lucy's overall eating behaviour improved throughout the intervention. The Healthy Eating Assessment identified that the total score increased from 35 at baseline to 37 post intervention, both being within the 'good' category for health. At the end of the intervention, Lucy now identified her health to be in the good category and her diet to be much improved since baseline, highlighting a positive change in Lucy's perception of her diet.

Figure 3 highlights the change in Lucy's motivation for food choice overall from the Food Choice Questionnaire (Steptoe & Pollard, 1995), with mood motivation increasing by six from baseline, and natural content and weight motivation increasing by one. Lucy reflected in the final session that mood motivation score increased due to her self-reflection, self-evaluation and increased self-awareness highlighting that during times of stress and anxiety, Lucy used food as a coping mechanism. During the process of the intervention, Lucy began replacing high sugar content snacks for sweet but healthy and filling alternatives including protein flavoured yoghurts and low-calorie hot chocolate.

Convenience motivation only decreased by one, which initially was disappointing to see. However, Lucy reflected throughout session four, that although she remains highly motivated by convenience motivation, her choices surrounding convenient food have become healthier during the process of the intervention. This included bulk-cooking meals and freezing them for the working week, making home "takeaways" which are quick to cook but still taste delicious. Therefore, although the overall score only decreased by one, these were very positive changes to hear Lucy make over the four sessions.

At the end of session four, Lucy identified that her motivation to continue healthy eating was a 9 out of 10. She had signed up to a digital health intervention so that she continued to be guided post 1-1 intervention to maintain her confidence and motivation. This was an encouraging step for Lucy to take independently, and her motivation for continuing the health behaviour change process was positive to see.

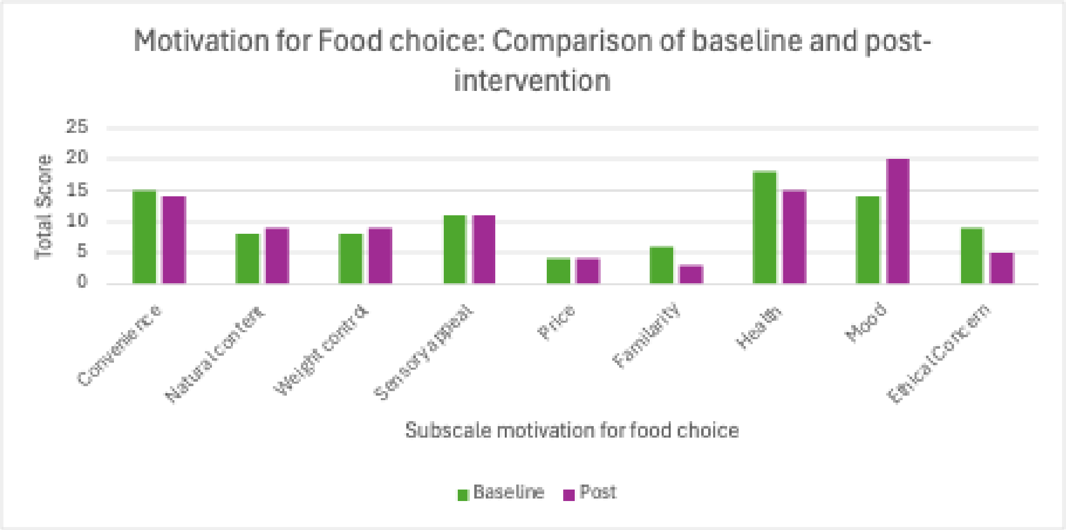

Figure 3. *Comparison of Lucy's Motivation for Food Choice from baseline to post intervention*

Evaluation of intervention process

At the end of session four, I asked Lucy to complete an evaluation form using Microsoft Forms for feedback on the intervention overall, my role as facilitator, and the resources provided prior to session one. Lucy provided in-depth feedback with only two areas for improvement highlighted; intervention effectiveness at meeting goals set in session one (rated as “satisfactory” on a scale of poor to very good) and the overall length of the intervention which was provided in the open-ended questions for qualitative feedback.

Overall conclusion

Throughout this intervention I have further developed skills for assessment, formulation and delivery of a Health Psychology intervention. Overall, I feel that my confidence for 1-1 intervention work improved throughout the intervention, and working with a Client who was talkative, and highly motivated to change their health behaviour helped this process significantly. Examining motivation for food choice and healthy eating assessment scores showed improvement in Lucy’s healthy eating behaviour, with qualitative self-evaluation from Lucy highlighting positive changes and higher levels of self-awareness for nutritional intake. For future intervention work, I will ensure I continue using the same communication skills to help build a positive rapport, allowing Clients to feel supported, listened to, and confident to independently improve health behaviour.

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6.2 Individual face-to-face Intervention Reflective Commentary

In this reflective commentary, I reflect on an individual, face-to-face intervention which I designed, delivered, and evaluated. Whilst completing the intervention, I completed reflection in-action (Schön, 1983) and after each session completed a reflection using the Gibbs (1988) cycle to help learn and adapt my approach throughout all four sessions. The Client of this intervention was a young adult female who wanted to improve her nutritional intake and explore healthy eating. The intervention included four sessions which took place weekly.

Designing and setting up the intervention

Prior to this intervention, I had previously secured a 1-1 intervention opportunity which I designed and was halfway through delivering before the Client withdrew. The overall experience with this previous intervention, as well as not having experience in conducting interventions, meant that I was very nervous and had low confidence when designing and setting up the current intervention. I was conscious to ensure that the previous negative experience did not impact my work when designing the intervention and delivering sessions with the Client. Seeking support through supervision and from peers was essential for this process due to my lack of self-confidence to deliver this intervention. Peer support has been identified to help improve confidence, encourage learning, and share experiences to help individuals not feel alone with their experiences (Fayram et al, 2018; Gidugu et al, 2015; Watson, 2017). Seeking support within supervision and peer support helped to ease my anxieties surrounding designing and setting up a new intervention. I also took time to reflect and identified that the previous intervention was not fully in my control and could not be planned for. This reflection in combination with peer support and supervision meant that my confidence increased before session one of the intervention.

I advertised the intervention opportunity at my workplace in the Public Health team Microsoft Teams chat, and within an hour a colleague asked if I could work with her. I was anxious prior to advertising the intervention opportunity, that nobody would volunteer for a behaviour change intervention. Once Lucy (pseudonym used within the case study to protect confidentiality) responded and asked for support with her nutritional intake and healthy eating, I asked if there were any specific aims which she wanted to focus upon during the intervention. This initially helped me to gain an understanding of what Lucy wanted to achieve and ensure planning and designing the intervention was as person-centered as possible.

Whilst designing the intervention, I was conscious of the time which I had spent delivering the previous intervention and how this left limited time before the deadlines. This meant that I decided to design a shorter than wanted intervention, lasting four sessions which would occur weekly. This was a factor which left me feeling uncomfortable, as I wanted to ensure the intervention was person-centered and meeting the Client's needs. However, the duration of the intervention was meeting my needs for the Doctorate rather than the Client's. For each session, I ensured that I planned as much content as possible, whilst avoiding overwhelming the Client, so that I could still include important topics which would encourage sustainable behaviour change. For future intervention work, I will ensure that the duration of the intervention including time between sessions suit the Client.

Implementation of the Intervention

The implementation of the intervention was initially quite challenging for me due to the initial 1-1 intervention opportunity making me question my abilities and reducing my self-confidence in this competency (Thériault et al, 2009). Learning from the previous intervention, I ensured that prior to the first session, I had booked in all sessions in the diary for both the Client and I so that there was a clear plan in place. Only one session (session four) needed to be changed due to the Client being unwell, therefore it was essential that this session was re-arranged to a week later to allow for the intervention to remain person-centred and ensure flexibility.

For the first session, I was quite apprehensive due to the initial intervention opportunity being quite challenging to maintain the flow of conversation with the previous Client. I was under-confident in my capabilities from this first opportunity which meant that I was anxious prior to the first session with a new client. I ensured that I learnt from this experience (Falgares et al, 2017), and prepared conversation prompts for if the Client was quiet or apprehensive within the session. I was relieved when the session begun, and the Client was very talkative, and willing to share her experiences, reflections and motivations for wanting to change her eating behaviour and improve healthy eating. This made the first session flow smoothly, meaning that I could capture detailed information for the assessment and formulation and ensure that my initial intervention plan could be adjusted to meet the needs of the Client throughout the four sessions. Following the first session, I had supervision and reflected on the first session and how it improved my self-efficacy for this competency (Maddux 2016). Talking through the positive experiences and having a successful session one, allowed for me to feel more confident going forward throughout the intervention.

Throughout the intervention, I found it challenging at times to keep the conversation focussed to the intervention aim and topic with the Client. This increased as the intervention progressed, with the Client becoming more comfortable with me. Initially, I was pleased to see this, as it demonstrated a positive rapport between the Client and I (Gair & Holder, 2024), especially considering that I was anxious about my ability to build a rapport. However, my uncertainty of when and how to steer the conversation back to the intervention, meant that the topic of conversation often went in a different direction than intended. This was something which was picked up within my observation, which highlights that for future intervention work, I need to ensure I know when and how to respond to the conversation moving away from the intended topic and become more confident in facilitating the conversation change.

Evaluation of the Intervention

The first method of evaluation was through the quantitative measures to assess Lucy's progress from baseline to post-intervention. The Food Choice Questionnaire (Steptoe & Pollard, 1995) was used to assess the Client's motivation for food choice and the Healthy Eating Assessment (Paxton et al, 2011) assess nutritional intake for specific food groups and overall health benefit of an individual's diet. I was pleased when analysing and comparing Lucy's baseline and post-intervention scores. I was disappointed to see that convenience motivation only decreased by one and that mood motivation increased by six. However, during the final session, Lucy reflected both in the food diary and in session, that her overall diet had improved, with her choosing healthier convenience options to help with a work and life balance. Lucy recognised the importance of cooking well-balanced meals on a weekend and freezing them to help with the convenience of cooking and nutritional intake. I was pleased to hear Lucy's honest reflections surrounding mood motivation for food choice and knowing that this will be something which she continues to work on post-intervention independently with higher levels of self-confidence of her capabilities and motivation.

The second evaluation method was through asking Lucy to complete a Microsoft form which asked a combination of quantitative and qualitative questions to capture as much feedback as possible. This captured feedback on quality of the intervention, aims and goals, skills and responsiveness of my role as intervention facilitator, intervention content. Qualitative questions asked Lucy to reflect on what aspects of the intervention were most useful or valuable, and what could have been done differently to improve the intervention. Feedback Lucy provided was very positive, with two areas of feedback for improvement. I knew approaching the intervention, that it was shorter that I would have liked due to time pressures for Doctorate deadlines. This was highlighted in Lucy's reflections, with her sharing that she would have preferred more time between sessions. For future interventions, the time pressure will be less of an issue, which will enable me to plan more time between sessions to allow for progress to be seen for the Client and the intervention to be person centered.

Conclusion

Overall, my experiences of the individual intervention have provided me with many learning opportunities to develop as a practitioner. This was a challenging competency to complete overall, with the first opportunity to design and delivery a 1-1 intervention reducing self-efficacy about my capabilities. Following the second intervention opportunity, I feel more confident about my capabilities to facilitate a health intervention and support an individual to change their health behaviour. This confidence will continue in any future intervention work which I complete. For future intervention work, I have conversation prompts and additional resources for if a Client finds it difficult to communicate or reflect about previous behaviour change experiences. I will also ensure that future interventions are for a duration which meets the Clients needs including the time between sessions to allow for the Client to work independently on the behaviour change and gain self-confidence further.

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6.3 Group (remotely delivered) Intervention Case Study

Ehlers-Danlos Syndrome (EDS) is a long-term genetic condition which consists of 13 subtypes (Ehlers-Danlos Society, 2024, National Health Service, 2024). Ehlers-Danlos Syndrome is categorised as a rare long-term condition, impacting 1 in 10,000-15,000 people across the globe (Anderson & Lane, 2021; Demmler et al., 2019).

Stress can be defined as "*the particular relationship between the person and the environment that is appraised by the person as taxing or exceeding resources and endangering well-being*" (Lazarus & Folkman,1984, p.19). There have been many definitions of stress, with debates on how to define it due to its subjectivity Cohen et al., 2008). Thus, what contributes to stress can vary from person to person, and may also vary on factors including personality types, individual differences and social or environmental circumstances (Luo et al., 2023). Research indicates that psychological stress intensifies EDS symptoms such as pain, gastrointestinal symptoms, and joint instability (Berglund et al., 2015; Hershenfeld et al., 2015; Krahe et al., 2017; Lumley et al., 1994), emphasising the importance of effective stress management for all individuals living with the condition.

This report outlines and provides a summary of a non-face-to-face group stress management intervention which I delivered online to five individuals living with EDS. Throughout this case study I present the stages of the intervention process including assessment, formulation, designing the intervention, delivery of the intervention and the evaluation process.

Assessment

The aim of the assessment process is to establish the nature of an individual's difficulties in clear and measurable terms (Bull & Dale, 2021; Johnstone & Dallos, 2013). The assessment allows for a baseline measurement to be established along with conversations which determine the factors which maintain an individual's problem (Magyar-Moe, 2009).
Prior to planning out and advertising the intervention, I spoke with healthcare professionals working in the field of EDS, drew on my own knowledge of EDS and stress, and reviewed existing research in this field to develop an initial outline plan. The intial outline included the overall structure to the intervention, an outline of what each session would cover including activities and how it linked to the resource pack, and how psychological theory and behaviour change techniques were underpinning each session. It was essential for this to be a flexible plan to ensure that following the assessment conducted in session 1, the intervention remained person-centered. Person-centered psychological interventions encourage individuals to feel supported, which in turn encourages increased likelihood of achieving successful outcomes from an intervention (Joseph & Murphy, 2013; McGrady et al., 2021).
Whilst planning the intervention, I decided to deliver this intervention remotely (online).
Previous research identifies the benefits of online delivery for psychological interventions including participants having higher confidence levels to discuss stress (Zetterqvist et al, 2010), and overall high levels of effectiveness of interventions delivered remotely (Heber et al, 2017).

During the sign-up process, the sign-up form asked individuals a range of questions including gender, age, EDS type, choice of pseudonym, and if individuals require any additional support for the intervention. Two individuals asked for session material to be sent in advance to allow for more time to process session content prior to the weekly session. One individual asked for comfort breaks to be set within the 1.5-hour sessions to ensure prevention of fatigue and allowing time to move from the seated position whilst engaging with the intervention to help prevent pain. This information ensured that I could accommodate additional support throughout the intervention for individuals and maintain a person-centred focus. Whilst recruiting participants for the intervention, the aim was to have a group size between 5 and 10 participants. This was to allow for the group to be able to use peer support throughout the intervention throughout either for practical or emotional support whilst discussing stress and stress management techniques (Agarwal et al, 2020).

At the beginning of the first week of the intervention, I emailed all individuals with the first Microsoft Teams meeting link. The participant demographics of individuals participating in the intervention can be seen in table 1. All individuals are referred to by their pseudonyms chosen during the signup process to help maintain anonymity.

Table 1. *Participant demographics of individuals participating in the Health Psychology Intervention.*

Individual	**Age**	**Gender**	**EDS Type**
Jessie	45	Female	hEDS*
Elodie	26	Female	hEDS
Lillia	34	Female	hEDS
Blair	35	Female	hEDS
Frances	28	Female	hEDS
Simone	53	Female	hEDS

**Note: hEDS = Hypermobile Ehlers-Danlos Syndrome*

Session 1 (Assessment)

Within session one, I conducted an initial assessment with the group. To begin this session, I introduced myself as a Trainee Health Psychologist, my role, and provided the focus of the intervention. Following introductions, I spoke through the group intervention ground rules with the aim to ensure a safe environment throughout all six sessions (Geller et al., 2020). I asked that due to this being an online intervention, that all cameras were to be on for all sessions to ensure that I could see all individuals were ok and not in distress (Aafjes-van Doorn et al., 2020; Geller et al., 2020). If individuals needed to turn off their cameras, or leave the session, I ensured participants that this was okay, with the only request that individuals emailed me so that I knew if they were in distress and needed additional support, or if they were okay but just needed to leave the session. The first session was also used to build rapport with the group, creating a positive group atmosphere and building trust between the participants and myself as intervention facilitator (Masin, 2024).

As part of the assessment process, I asked all individuals within the first session using qualitative open-ended interview style questions to reflect on their aims, goals, and reasons why they signed up for this intervention (see table 2 for overview). Open-ended questions within the assessment process allow for individuals to reflect on their personal experiences and provided detailed information (Haynes et al, 2011). By asking individuals to reflect on aims, goals, and reasons for wanting to manage their stress levels, I was able to determine an understanding of individuals intrinsic and extrinsic motivations for attending the intervention. Whilst reviewing these aims, I was able to determine that the COM-B model (Michie et al, 2011) was going to be the most effective model to underpin the intervention. This was due to participants wanting to improve skills and capability surrounding stress management and be able to identify how stress management can be incorporated into their daily routines. I also identified that psychoeducation was going to be a core element underpinning the intervention as four individuals stated that they wanted to learn more about stress, how stress can impact EDS, and the importance of stress management.

Table 2. *A table showing participants aims, goals, and reflections identified for the assessment within session 1.*

Aims	Goals
Learn more about stress and the effects it has in relation to EDS. I feel with my health issues it is harder to cope day to day anyway so with stress added it makes everything more difficult so to reduce and learn how to manage this would be very useful.	Regulate when you aren't in your safe zone or with your safe people.
Learn new techniques for stress management. (n = 4)	Become better at recognising stress in myself. (n = 2)
Better understanding of what stress is. (n = 2)	I'd like to be able to feel like I can actively engage in de-stressing activities (beyond what I already do - sometimes my mental health management tools are at odds with my physical) and find a way to be able to manage my stress in a way that works for me.
I'd like to learn anything about EDS, I'm pretty clueless. I don't really understand how it affects stress. I know when I am stressed it has a big impact on me mentally and physically. Any tips on how to better myself is the aim.	To be able to communicate to my loved ones when I'm too stressed to function.
I didn't realise how much stress was affecting me and what behaviours I have currently that relate to stress and I would like to understand this more and learn how to not "block out" and ignore my stress as much as I do now.	I am hopeful to gain techniques that will help me distress independently.

**Note: n = ... (number of participants stating the same aim or goal)*

Following discussion of the participant aims and goals, I asked participants to complete the Perceived Stress Scale (Cohen et al., 1983) to quantitatively assess stress levels and collect a baseline measure to later compare to. The Perceived Stress Scale scoring information identifies that individuals with scores ranging between 27-40 have high levels of stress (Cohen et al, 1983). Therefore, using this information I was able to identify that all participants had high levels of stress with scores ranging from 28-36 (see table 3 for baseline scores).

Table 3. A table showing baseline scores following completion of the Perceived Stress Scale (Cohen et al., 1984).

Participant	Baseline Stress Score
Jessie	31
Elodie	36
Lillia	33
Frances	34
Simone	28

Formulation

Formulation is defined as "*the process of making sense of a person's difficulties in the context of their relationships, social circumstances, life events, and the sense that they have made of them*" (Johnstone & Dallos, 2013, p.1). Formulation is essential within the intervention process as it helps to ensure that the assessment process has captured a full understanding of the Client's experiences and difficulties which informs the intervention plan (The Division of Clinical Psychology, 2011; Thrower et al, 2024). Research identifies that psychological models such as the COM-B model, cognitive behavioural therapy, and acceptance and commitment therapy can help to inform the formulation process (Selzer & Ellen, 2014). I used COM-B model (Michie et al, 2011) within the formulation process to ensure that participants capabilities, opportunities, and motivation were discussed throughout the intervention which were identified as areas of need for improvement for participants within the assessment process.

Formulation was completed within session one, collaboratively with all participants. Research emphasises the benefits of collaborative formulation including increasing compassion and empathy within the group, ensuring representation for all participants within the group, and improving the therapeutic relationship (Dudley & Kuyken, 2006; Thrower et al, 2024). To help guide the formulation process, I used the '5 P' Model (Macneil et al, 2012) which considers biological, psychological, and social factors which are used to explain an individual's behaviour. Although usually used within mental health practice, this model of formulation can be seen as effective for group interventions exploring stress management (Gibbons, 2021). By using this model and completing formulation within session 1, it enabled a collaborative process and helped to develop a positive group dynamic. The participants providing reflections, aims, and goals throughout the assessment and formulation process throughout session 1 ensured that I the information that I had was accurate, ensuring the plan for the intervention was group-centered.

Table 4. The 5 P Model (Gibbons, 2021, p.61)

Element of Model	**Definition**
Presenting Problem	*"The presenting problem itself, and how the person's life is broadly affected at the time of the presentation."*
Predisposing Factor	*"Vulnerability factors from the longitudinal history."*
Precipitating Factor	*"The significant events preceding and triggering the onset of the difficulties."*
Perpetuating Factor	*"Those factors that are currently maintaining the difficulties and their lack of resolution."*
Protective Factor	"*Strengths and resilience factors that mitigate the effect of the disorder and contribute to improving prognosis and recovery."*

The Intervention

After completion of assessment and formulation, developing and conducting the intervention included identifying aims of the intervention, applying psychological theories and techniques and ensuring a supportive group environment for all individuals. The final aims of the intervention were:

- To educate participants about stress, the impacts of stress, and how stress can impact EDS.
- To help and encourage participants to consider their current behaviours when experiencing high stress levels, and factors which may be triggering stress.
- To support participants with implementing stress management techniques to reduce stress levels.

I facilitated this intervention implementing psychoeducation (Sarkhel et al, 2020), motivational interviewing (Miller & Rollnick, 2013), psychological theory (the COM-B Model, Michie et al, 2011) and behaviour change techniques (Michie et al, 2013; Michie et al, 2015) to help participants engage with a variety of stress management techniques and reduce stress levels.

Rationale for using the COM-B Model, Motivational Interviewing, Psychoeducation, and Behaviour Change Techniques.

The COM-B Model

The main psychological model used to structure this intervention was the COM-B model (Michie et al, 2011) which focusses upon an individual's capabilities, opportunities, and motivation for behaviour change. The COM-B model signifies that for an individual to change their behaviour, or to perform a particular behaviour, an individual must have the capability, opportunity, and motivation (Social Change UK, 2022; West & Michie, 2020). Figure 1 shows the COM-B model and the types of capability, opportunity, and motivation which an individual may have to help promote behaviour change.

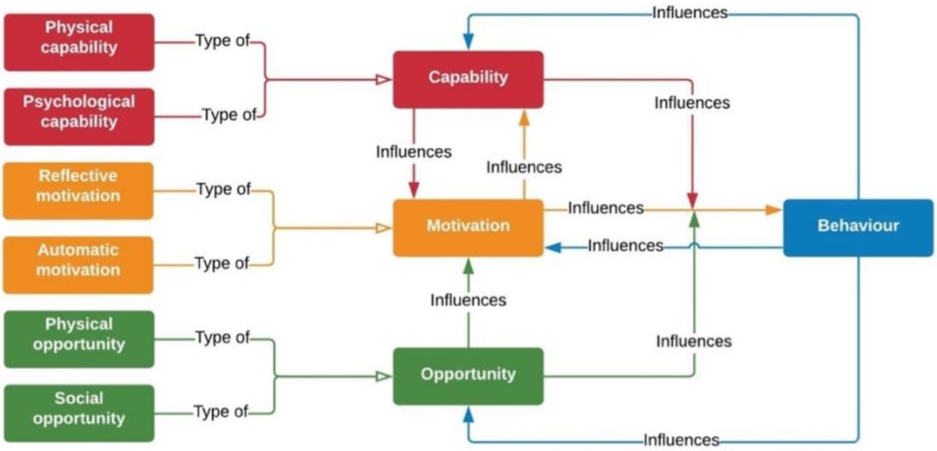

Figure 1. The COM-B Model for behaviour change (West & Michie, 2020).

Table 5. *Definitions of capability, opportunity, and motivation of the COM-B Model.*

Element	Definition
Capability	Capability explores whether an individual has the knowledge, skills, and abilities on a physical and psychological stance to engage in a particular behaviour (Social Change, 2022; West & Michie, 2020).
Opportunity	Opportunity explores physical and social opportunities which an individual has to make a particular behaviour possible (Social Change, 2022; West & Michie, 2020).
Motivation	Motivation refers to an individual's internal processes which influence decision making and behaviours (Social Change, 2022; West & Michie, 2020).

The COM-B model was determined to be the most effective model to use within the stress management intervention as it allowed for a collaborative approach with the group to explore capabilities, opportunities, and motivations to engage in stress management and reduce stress levels (Michie et al., 2011). Throughout the intervention, the COM-B model was focussed upon within sessions, and the group and I worked in collaboration to identify facilitators and barriers which were influencing capability, opportunity and motivation for stress management. This allowed for a collaborative approach for goal setting, planning, and monitoring of stress levels throughout the intervention.

Motivational Interviewing

Motivational interviewing (MI) was used throughout the intervention and can be defined as a communication style which involves collaboration and goal setting to encourage change (Miller & Rollnick, 2013). Motivational interviewing also promotes an individuals motivational by ensuring commitment for behaviour change whilst within an accepting and compassionate therapeutic environment (Miller & Rollnick, 2013; Rubak et al, 2005). Motivational interviewing has four fundamental processes which were considered beneficial for the health psychology intervention including: partnership, evocation, acceptance, and compassion.

Table 6. *Definitions of partnership, evocation, acceptance, and compassion and how all elements were utilised within the intervention.*

Process	Definition	Utilised within the intervention
Partnership	"*MI is a collaborative process. The MI practitioner is an expert in helping people change; people are the experts of their own lives*" (Motivational Interviewing Network of Trainers, 2013).	MI is a collaborative process with the facilitator and client having levels of power and expertise. As the Trainee Health Psychologist, I had expertise in the field of EDS. As the participants, all individuals were experts in their lives, experiences of stress, and experiences of living with EDS. These were used in

		a partnership to help support all individuals with stress management.
Evocation	"*People have within themselves resources and skills needed for change. MI draws out the person's priorities, values, and wisdom to explore reasons for change and support success*" (Motivational Interviewing Network of Trainers, 2013).	Evocation was used to identify the capabilities and skills which participants already had in relation to stress management. This was used within a positive framework to help build self-confidence and self-efficacy, so individuals remained motivated to engage in stress management.
Acceptance	"*The MI practitioner takes a nonjudgmental stance, seeks to understand the person's perspectives and experiences, expresses empathy, highlights strengths, and respects a person's right to make informed choices about changing or not changing*" (Motivational Interviewing Network of Trainers, 2013).	It was vital that as a Trainee Health Psychologist, I took a non-judgemental stance and understood all individuals' perspectives within the group surrounding stress. This enabled individuals to accept their emotions, beliefs, and attitudes surrounding stress.
Compassion	"*The MI practitioner actively promotes and prioritizes clients' welfare and wellbeing in a selfless manner*" (Motivational Interviewing Network of Trainers, 2013).	As the Trainee Health Psychologist and facilitator of the intervention, I actively promoted and prioritised the Client's psychological wellbeing throughout the intervention.

MI was considered an effective technique to use throughout this intervention, as it empowers individuals to change behaviours by allowing them to focus on their own meanings, beliefs, and motivations whilst demonstrating the importance of having the capacity to change (Miller & Moyers, 2017; Miller & Rollnick, 2013). Thus, MI links efficiently with the COM-

B model to help support all participants to engage with stress management and lower stress levels.

Psychoeducation

Psychoeducation (PSE) is a technique often used to manage stress (Ahmad et al, 2022; Van Deale et al, 2012) and help protect psychological wellbeing. PSE helps individuals to learn about stress and other topics (such as a long-term condition which they're living with) and how they can reduce stress and develop new skills and capabilities (Van Deale et al., 2012). Interventions which use PSE for individuals living with long-term conditions such as EDS enables individuals to learn more about their condition, and different techniques of how they can manage symptoms of their condition. For EDS specifically, psychoeducation can help individuals learn new techniques of how to manage stress, chronic pain, fatigue, and how to live with the condition to protect psychological wellbeing (Song et al., 2023). PSE has been demonstrated in previous research to be more effective in group environments and interventions (Van Deale et al., 2012) due to peer learning and support. Interventions which use PSE should identify and reduce stress rather than preventing or stopping stress (Ahmad et al., 2022; Van Deale et al., 2012; Song et al., 2023). Therefore, PSE encourages empowerment for individuals to develop new skills which can reduce stress, improve physical and psychological wellbeing. This demonstrates that PSE is effective to be used in collaboration with the COM-B model and MI.

Behaviour Change Techniques

A behaviour change technique (BCT) is a strategy which helps an individual change their behaviour and encourages promotion of better health (Abraham & Michie, 2008; Bradbury et al, 2019). BCTs have also been defined as a small, observable, and reliable component of interventions which are designed to help an individual redirect their health behaviour (Abraham & Michie, 2008; Martin-Martin et al, 2021). Research has identified that BCTs are effective for stress management interventions, helping to improve success and reducing stress levels for individuals (Alhasani et al, 2022; Michie et al, 2008; Petley et al, 2022). Overall, in combination with PSE, MI, and the COM-B model, BCTs promoted the effectiveness of the intervention in promoting stress management (Petley et al, 2022) and reducing participants stress levels.

An overview of the intervention can be seen in table 7 including BCTs used within this intervention.

Table 7. *A table providing an overview of each intervention session.*

Session Number	Date	Aim	Overview	Behaviour Change Techniques Implemented
1	17.07.2024	Assessment and Formulation	• Introduction of the intervention including timeline of the intervention & resource pack. • Psychometric stress assessment (Perceived Stress Scale). • Asking individuals about their beliefs, attitudes, and behaviours surrounding stress and stress management.	1. Goals and Planning • 1.1. Goal Setting (behaviour) • 1.3. Goal Setting (outcome)
2	24.07.2024	Capability and Psychoeducation	• Introduction to Stress and chronic stress. • Physical health implications of stress, specifically linking to EDS. • Explore concerns that individuals have about stress management and their capabilities to reduce stress levels. • Psychoeducation on evidence-based stress management techniques including mindfulness-based stress reduction, mindfulness breathing, and the Stress Bucket.	4. Shaping Knowledge • 4.1 Instruction on how to perform the behaviour • 4.2 Information about antecedents 5. Natural Consequences • 5.1 Information about health consequences
3	31.07.2024	Opportunity and Motivation (Motivational Interviewing)	• Opportunity: identify social and environmental factors and daily routines of participants that may help individuals engage stress management, as well as identify possible barriers.	3. Social Support • 3.2 Social support (practical) • 3.3 Social support (emotional)

			• Use social support (group support) and positive framing to help work through any concerns for opportunities. • Consider practical and emotional support to identify opportunities and motivation for stress management. • Define motivation and explore individuals’ motivations for stress management.	11. Regulation • 11.2 Reduce negative emotions • 11.3 Conserving mental resources
4	07.08.2024	Self-efficacy, motivation and behaviour change. (Psychoeducation and Motivational Interviewing)	• Introduction to self-efficacy, self-confidence, self-esteem, linking concepts to increased motivation for engaging in stress management. • Asking individuals to reflect on their confidence levels in relation to stress management, and the reasons behind their rating. • Introduction of SMARTER, HARD, and CLEAR goals to help maintain high levels of motivation.	13. Identity • 13.1 Identification of self as role model • 13.2 Framing/reframing • 13.4 Valued self-identity • 13.5 Identity associated with changed behaviour 15. Self-Belief • 15.1 Verbal persuasion about capability • 15.3 Focus on past success • 15.4 Self-talk 10. Reward and Threat • 10.9 Self reward • 10.4 Social reward
5	14.08.2024	Maintenance of behaviour change.	• Review of initial aims and goals set in session 1 and 4. Reflection to	2. Feedback and monitoring

			celebrate successes and positively working through any setbacks or difficulties. - Collaboratively working with the group to think about future situations which may lead to increased stress (triggering situations), and how to work through these to keep stress levels low.	- 2.3 Self-monitoring of behaviour - 2.4 Self-monitoring of outcome(s) of behaviour - 2.6 Biofeedback 8. Repetition and substitution - 8.1. Behavioural practice/rehearsal - Habit formation 12. Antecedents - 12.3 avoidance/reducing exposure to cues for the behaviour
6	21.08.2024	Maintenance and Reflection (Final Session)	- Reflect on individual's experiences throughout the intervention. - Second psychometric assessment measure of the Perceived Stress Scale. - Refer to intervention resource pack, charities, organisations for further/additional support.	9. Comparison of outcomes - 9.3 Comparative imagining of future outcomes

Implementation

The implementation and delivery of the intervention went to plan with all sessions following the initial outline plan and I ensured that the intervention met the goals of all participants identified in session 1 for assessment and formulation.

The attendance from each participant was good overall throughout the intervention. Following session 1, one participant withdrew from the intervention via email, meaning that five individuals continued with the remainder of the intervention. For participants who could not attend sessions, I pre-recorded the content and uploaded to a GoogleDrive folder so that individuals could access intervention content and continue to engage with the intervention. I thought this suitable for this intervention, due to EDS being a condition which includes flare ups of symptoms, meaning that participants may have felt unwell, or too fatigued to attend the live session. Table 8 provides a summary of attendance from all individuals.

Table 8. *A table showing participant engagement throughout all intervention sessions*.

Participant	**Session 1**	**Session 2**	**Session 3**	**Session 4**	**Session 5**	**Session 6**
Jessie	Y	Y	Y	Y	Y	Y
Elodie	Y	Y	Y	Y	Y	X
Lillia	Y	Y	Y	Y	X	Y
Blair	Y	W	W	W	W	W
Frances	Y	Y	Y	X	X	Y
Simone	Y	Y	Y	X	X	Y

**Note: Y = Attended, X = Absent from Session, W = Withdrew from intervention*

Evaluation

Examining the scores collected from participants completing the Perceived Stress Scale (Cohen et al, 1983) identified that all participants at the beginning of the intervention were experiencing chronic stress with all scores being over 30. Upon completion of timepoint 2 measurement (at the end of session 6, and completion of the intervention), all participant stress scores had decreased (see figure 1). Overall, the groups mean stress score at timepoint 1 was 32.40 (SD = 3.04) which reduced to 26.80 (SD = 4.32) at timepoint 2. This identifies that as a group, mean stress scores reduced by 5.60 from baseline to immediately post intervention at session 6. Although for two participants, stress scores had decreased by only 1 point on the scale. This may be to be expected due to stress management being a longer process for reducing stress levels (Kriakous et al, 2021; Nielsen et al, 2007) and reviewing qualitative participant feedback identified that some participants were undergoing a stressful period within their personal lives whilst completing the intervention.

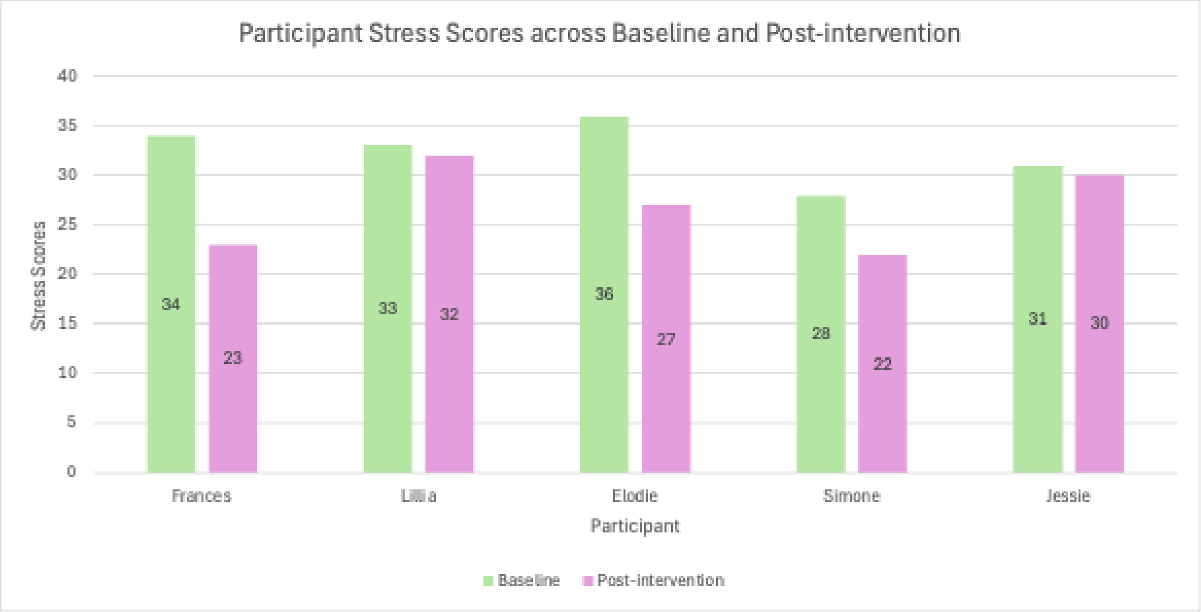

Figure 1. Participant stress scores across timepoint 1 (baseline score) and timepoint 2 (immediately post-intervention).

One-month post-intervention, timepoint 3 scores were collected using the Perceived Stress Scale. For this timepoint measurement, only 3 participants completed the scale and results indicated that for one participant stress scores had slightly increased with the other two participants scores decreasing (see figure 2). Due to two participants within the group not completing the timepoint 3 measurement, it was not possible to compare mean scores across timepoints to assess the overall group reduction in stress one month post intervention.

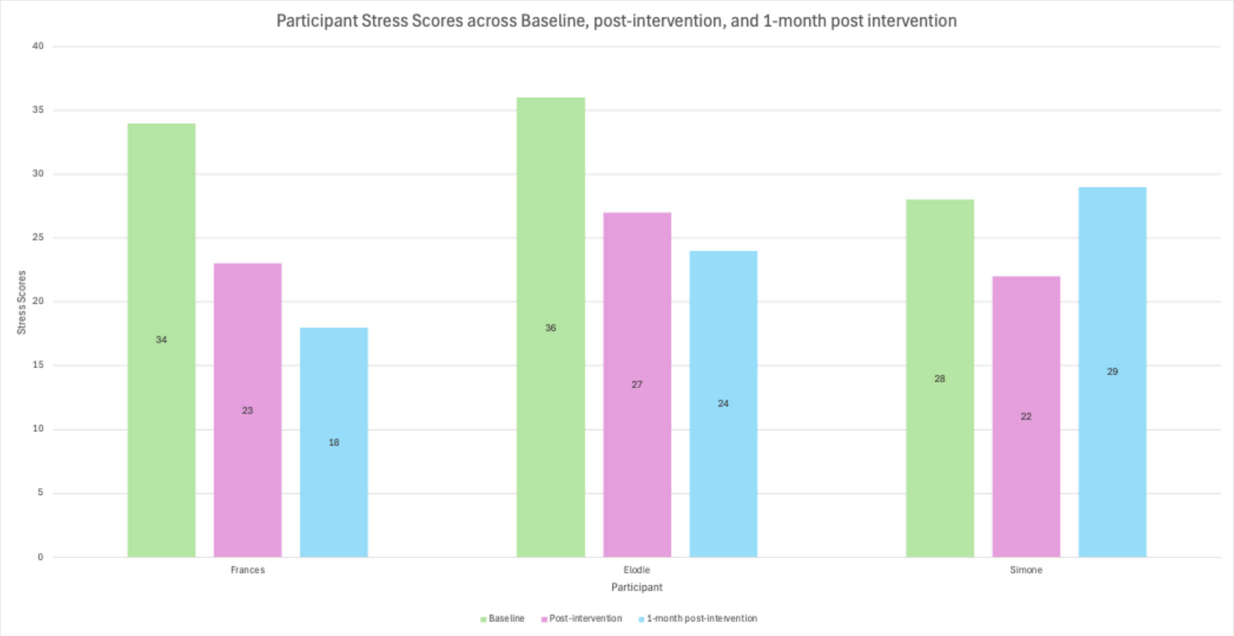

Figure 2. Participant stress scores across timepoint 1, 2 (immediate post intervention), and timepoint 3 (1-month post intervention).

Evaluation of intervention process

Following the end of session 6, participants were asked to complete a Google Form to collect feedback on the intervention, my delivery as the facilitator, and the intervention resource pack. All participants completed and provided both positive and constructive feedback to help aid my future development related to health psychology interventions.

Feedback from participants identified that the overall quality of the intervention (ranging from excellent to very good), delivery of intervention (ranging from excellent to very good), the supportiveness intervention resource pack (ranging from strongly agree to neutral), and support from myself as facilitator (ranging from excellent to very good) were effective for helping participants to begin the process of stress management. Other feedback highlighted the success of the intervention including the use of Menti to allow for the group to discuss difficult topics and learning more about EDS and stress management. Overall, both qualitative and quantitative feedback from participants was positive indicating success of the intervention.

Overall conclusion

Throughout this intervention, I have developed a lot of skills surrounding assessment, formulation, and delivery of a Health Psychology intervention, due to this been the first intervention which I have completed. Overall, the intervention went to the original plan and all participants engaged throughout the intervention via either attending the live sessions or listening to the pre-recorded sessions if they were unable to attend a particular session. Examining stress scores of participants at baseline compared to timepoint 2 (post intervention) and timepoint 3 (1-month post intervention), the intervention was effective of achieving the aims of supporting individuals to reduce stress levels. For future intervention work, I will use the same communication styles to encourage a positive rapport and create an intervention environment which feels safe for the participants to reflect openly without judgement to begin the behaviour change process.

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6.4 Group (remotely delivered) Intervention Reflective Commentary

Within this reflective commentary, I reflect on a group-based online (non-face-to-face) psychological intervention which I facilitated for six weeks throughout July and August 2024. The intervention aimed to reduce stress levels for individuals living with Ehlers-Danlos Syndrome (EDS). I used the Gibbs (1988) reflective cycle to guide my reflections both in-action (Schön, 1983) throughout the intervention, and upon completion of the intervention.

Setting up & Advertising the Intervention

Prior to setting up and advertising this intervention, I was very nervous due to this being my first intervention to plan, design, and facilitate. Whilst planning the intervention, there were a few factors to consider which were challenging. This included deciding on the dates to deliver the intervention. Due to wanting to complete this during the summer break for my placement at University of Portsmouth, I had to consider that most individuals also go on holiday during this time and how this may impact how many individuals participated in this intervention. To help accommodate this, I set the intervention for six weeks from 17th July to the 21st August, with the understanding that if individuals could not attend a session, I would record the full session and send this separately to the individual so they did not miss content.

I also had to consider the time of the intervention delivery, due to having healthcare professional contacts within the EDS field based in the UK, and the USA, I did not want to limit individuals' opportunity to complete the intervention. Research has indicated that when planning online interventions which can be accessed globally, a barrier can be time zones (Marcu et al, 2022; Wozney et al, 2016). I had to ensure that time was not a barrier for participation, and therefore set the intervention at 18:00-19:30 (UK time) so individuals living in the USA could participate. I received feedback whilst advertising the intervention that this was not a suitable time due to it being evening mealtime for individuals in the UK, however, I had 1 individual from the USA participate along with 4 individuals from the UK.

Assessment and Formulation

Due to this being the first intervention which I facilitated, it was my first time completing assessment and formulation. The process of completing an assessment and formulation to begin with felt quite overwhelming. However, I sought supervision for support surrounding assessment and formulation, along with asking for feedback on my initial intervention plan. Supervision within psychology has three main purposes: supportive purpose, qualitative purpose, and development purpose (Carroll, 2011; McMahon & Errity, 2012; Wosket, 2006). Following supervision and feedback on my intervention plan, my anxiety and lack of self-confidence surrounding the intervention and completion of assessment and formulation improved which allowed for me to approach this process positively.

As part of the assessment process, I asked for individuals to complete a reflection task, reflecting on their motivations for attending the intervention, along with aims and goals for this intervention process. For this reflection, I provided participants with an anonymous Padlet link for individuals to add their reflections, aims, and goals into. Research shows that online tools such as Padlet are primarily used within an academic setting allowing for individuals to provide answers anonymously and gain feedback which improves self-confidence and engagement (Bakar et al, 2022). With working in academia, I knew how Padlet helped to encourage self-confidence for students and wanted to create a safe space within the online intervention, especially for reflective tasks. Whilst using Padlet for this reflection as part of the assessment process, I also offered the opportunity for participants to verbally communicate their reflections. However, all participants provided reflections in detail via Padlet which indicated that participants preferred to use this anonymous platform especially whilst making personal reflections to an unknown group, indicating its success. For future assessment sessions for group interventions, I will ensure to use an online tool such as Padlet to ensure that participants feel comfortable to share experiences, aims, and goals for what they are hoping to achieve within the intervention.

Implementing the intervention and building rapport

Due to this being an online intervention with six individuals, I wanted to ensure that I created a safe and trustworthy environment throughout the intervention. Research has identified that online interventions can impair the therapeutic relationship, hindering rapport and the ability to build an environment which feels safe and trustworthy (Brahnam, 2014; Oshni-Alvandi, 2019; Peuhs et al, 2023). To encourage rapport building, I began session one by introducing myself also as an individual living with Hypermobile EDS (hEDS) and mentioned a couple of my hobbies. Research has identified that self-disclosure helps to build trust and a positive rapport within the therapeutic relationship (Audet & Everall, 2010; Peterson, 2001) whilst maintaining the boundaries as a practitioner. The self-disclosure of living with hEDS was to help show understanding of what it is like living with hEDS, encouraging individuals to feel supported and understood. The positive rapport was evidenced when a participant emailed me asking for advice surrounding healthcare professional communication which was a big triggering factor for her stress levels. I gave the participant advice and stated she could take notes from session two slides (based on psychoeducation of stress and EDS). Following a successful appointment with her healthcare professional, the participant emailed once again stating how much a relief it was to have been listened to and thanked me for supporting and providing guidance. On reflection, if I was to conduct an intervention with individuals living with EDS in the future, I would use self-disclosure surrounding my diagnosis of living with hEDS. I believe this helped with building a positive rapport and trust with the group, and immediately demonstrated my understanding of the condition from both a professional and personal viewpoint.

When implementing the intervention, I was aware of the fatigue levels for individuals living with EDS (Castori et al, 2012; Hakim et al, 2017), so wanted to ensure that there was a balance between length and number of sessions. I decided not to provide any additional tasks for participants to complete between sessions, with not wanting to add any additional pressure within daily lives and add to fatigue levels. I was nervous about not adding 'homework' tasks due to most interventions adding these tasks to encourage behaviour change (Pinder et al, 2018) and felt apprehensive as to how this would impact the effectiveness of the intervention. However, to accommodate for this, I provided an intervention resource pack to participants, including resources linking to sessions which participants could complete if they wanted to outside of the session. This provided a balance between not making tasks mandatory and ensuring that participants could implement behaviour change engaging in stress management independently from the intervention sessions. One participant provided feedback surrounding it would have been beneficial to have homework tasks. Therefore, for future interventions working with individuals living with EDS, I will ensure I use homework tasks between sessions. The homework tasks will supplement the resource pack which may help to increase overall support and effectiveness of the intervention.

Evaluation of the Intervention

I used two points of evaluation to determine the effectiveness of the intervention which included:

1. Use of psychometric scales (Perceived Stress Scale, Cohen et al, 1983), at three time points including baseline, post intervention, and 1-month post intervention.
2. Participant qualitative feedback post intervention.

Overall, the timepoint two measurement showed a reduction in the groups stress scores from baseline to immediately post intervention at session six. This quantitative feedback provided evidence of effectiveness of the intervention. For the timepoint three measurement, I was a little disappointed to see that only three out of five participants had completed the one-month post intervention measure as it meant it was not possible to compare overall group scores between timepoints one, two and three. Out of the three participants who completed the measurement, two out of three participants stress scores continued to decrease showing the effectiveness of the intervention and the implementation of stress management techniques into daily routines. One participant's score had increased to above their baseline measurement, and on identification of this, I emailed the participant to signpost additional stress management support.

Overall, I was pleased with the qualitative feedback from participants which I received at the end of the intervention. Following the feedback, I reflected on the feedback that in future group interventions, I need to ensure that I guide group discussions more actively. Removal of the online platforms as the intervention progresses would encourage participants to communicate as a group more throughout each session.

Conclusion

To conclude, although I was very apprehensive at the prospect of planning, designing, and implementing this group online intervention, I have overall enjoyed the process. The process of learning and developing new skills such as completing assessment and formulation has improved my confidence in facilitating future health psychology interventions. For future intervention work, I will take into consideration how group interventions online may hinder the therapeutic relationship, using the skills I developed from designing and delivering this intervention and considering other factors to help create a positive rapport. I will also ensure that for future interventions, I improve my facilitation of group discussions by reducing as many online resources and encouraging group discussion between participants.

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