Therapy-based exercise from the perspective of adult patients: a qualitative systematic review conducted using an ethnographic approach.

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Abstract

Objectives: Many patients do not meet recommended levels of therapy-based exercise. This review aims to explore how adult patients view being prescribed therapy-based exercise, the information/education they are given and receive, and if/how they independently practise and adhere.

Design: A qualitative systematic review conducted using an ethnographic approach and in accordance with the PRISMA statement.

Sources: PubMed, CINAHL, SCOPUS, EMBASE databases (dates: 01/01/2000-31/12/18).

Methods: Qualitative studies with a focus upon engagement/adherence with therapy-based exercise were included. Data extraction and quality appraisal were undertaken by two reviewers. Results were discussed and data synthesized.

Results: 20,294 titles were screened, data extracted from 39 full texts and data from 18 papers used to construct three themes. 'The Guidance received' suggests that the type of delivery desired to support and sustain engagement was context-dependent and individually-situated. 'The Therapist as teacher' advocates that patients see independent therapy-based exercise as a shared activity and value caring, kind and professional qualities in their therapist. 'The Person as learner' proposes that when having to engage with and practise therapy-based exercise because of ill health, patients often see themselves as new learners who experience fear and uncertainty about what to do. Patients may have unacknowledged ambivalences about learning that impact on engagement and persistence.

Conclusions: The quality of the interaction between therapists and patients appears integral to patients engaging with, and sustaining practice of, rehabilitation programmes. Programmes need to be individualized and health care professionals need to take patients' previous experiences and ambivalences in motivation and empowerment into account.

Introduction

Rehabilitation requires the active engagement of the patient and often their family or carers in the process to be effective.[1] For this, patients frequently need to practise skills by themselves or with others to achieve positive outcomes.[2-3] For maximum benefit patient adherence to therapy-based exercise should be high but evidence across a range of health conditions shows that patients may only achieve between 30-70% of recommended doses.[4-7]

Patients who struggle to access, understand or remember healthcare advice are less likely to follow recommended treatment programmes.[8-9] Although therapists believe patient education empowers patients and forms an extensive and integral part of their practice,[10-11] teaching and prescribing in rehabilitation settings tends to be poorly planned, and reliant on verbal, informal, and ad hoc techniques.[12]

No reviews were identified which explore therapy-based exercise practice from the perspective of adult patients who have been prescribed programmes as part of their rehabilitation. There is a need for greater understanding of why patients are not achieving recommended levels of rehabilitation to enable strategies to improve practice to be developed and evaluated and adherence to be improved. This review aims to explore therapy-based exercise from the perspective of adult patients. This qualitative systematic review uses an ethnographic approach and aims to explore how patients view being prescribed therapy-based exercise by health care professionals, the information they are given, the education they receive and if/how they independently practice and adhere to their treatment programme.

Methods

A qualitative synthesis of available literature was undertaken to develop a greater understanding of the subject than is possible from the interpretation of the individual primary research alone.[13] A seven phase iterative comparative meta-ethnography provided structure and rigour to the interpretive process of translating the findings from the different studies into one another to gain new interpretations whilst preserving the meaning and context of the primary research (Table 1).[14] The research team comprised two members with experience of qualitative synthesis (CML and AD) and a member familiar with qualitative methods but new to synthesis (SD).

Stages 1-2: Getting started – defining the focus and locating the relevant studies

A systematic search was conducted to identify papers to include in the review (SD). The search strategy (Appendix 1) was developed through discussion in the research team and with the assistance of a librarian. Three search categories were used: 'engagement/ adherence', 'exercise/therapy/allied health profession' and 'qualitative research'. Terms related to 'education/prescribing/teaching' were not included as preliminary searches revealed that these terms were not often used by the authors in their titles, abstracts or key words. PubMed, CINAHL, SCOPUS and EMBASE were searched from January 2000-December 2018 to identify studies relevant to current clinical practice.

Stage 2: Deciding what is relevant, making inclusion decisions and quality assessment

Papers were downloaded into bibliographic management software and duplicates deleted. Initial title and abstract screening was completed by one researcher (SD) based on a priori criteria developed by the research team (Appendix 2). Full texts were read where there was doubt about inclusion from title/abstract alone. Due to the heterogeneity of studies from the initial screen, and in line with the inductive and emergent nature of meta-ethnography,[15]

iterative refinement of the criteria followed discussions between the team. This narrowed the focus to the therapy-based exercise being specific and not broad healthcare advice, carried out independently and not group based, in similar healthcare settings and that the perspectives were sought primarily through interview or focus group. Based on the revised criteria (Table 2), data extraction was completed independently by two researchers (SD and either CML/AD) and entered into pre-agreed tables. This included: authors, title, source, country; theoretical framework; aim; participants, recruitment, setting; data collection method, analysis; findings, themes of interest for the review, discussion points; key quotations. Final inclusion within the synthesis was agreed through discussion.

Quality assessment was undertaken independently by two researchers (SD and either CML/AD) using the Critical Appraisal Skills Programme (CASP).[16] No papers were excluded based on this assessment alone, recognising that conceptually rich papers do not always have strongly described methods, and vice versa.[13,17] Instead the results of the critical appraisal provided a framework for discussion.

Stages 3 and 4: Reading the papers and determining the relationship between them

Little is written in the original work to guide these stages[17-19] so guidance from other authors[17-19] was also used. Each paper was read multiple times (SD) to establish familiarity and meaning in the context of this meta-ethnography. No index paper[13,18] was identified against which all others were read. Instead, categories were constructed (Appendix 3) that allowed papers with greater commonality to be read together. Key words and terms from both the original themes and quotations from each paper were identified (second order and first order interpretations respectively[20]). From these, initial codes and metaphors were developed by SD and discussed with the team. Removal of duplicate codes and comparison and grouping of terms with similar and differing meanings enabled further refinement into broad concepts. Once arrived at, each paper was re-read to consider its findings in relation

to these (SD). Through further comparison, the nature of the relationship between the papers was discussed and established by the team.

Phases 5 and 6: Translating the studies into one another and synthesising the translation

Developing concepts were expanded upon, defined and then through constant comparison, reciprocally translated into each other to form conceptual categories, looking firstly within the clustered groupings and then between them (SD). Shared meanings were explored and comparison made of how much these meanings related to that of others (SD and discussed by the team). By bringing together the translations from across the different papers, the overall aim of the synthesis was achieved with the development of a conceptual framework (Figure 2) representing a higher, third order interpretation that offers an original interpretation and understanding whilst at the same time preserving the features and integrity of the original research.

Findings

The broad search strategy meant many titles were initially returned (20,294). Figure 1 presents the modified PRISMA flowchart[21] for the review. A total of 652 papers were read in full. Data extraction and quality appraisal was undertaken on 39 studies. Following discussion, 21 were further excluded as it was deemed that they did not meet the inclusion criteria (Figure 1). In total, 18 papers[22-39] were included within the synthesis (Figure 1).

Quality of included studies

Table 3 shows the results from the CASP quality appraisal. Quality ratings were variable: some papers were rated as moderate to good with ratings of ‘yes’ or ‘in part’ given to most categories, others were poorer with ratings of ‘unclear’ or ‘no’. The 18 studies presented

more descriptive than interpretative findings and although constructs could be taken from each, none offered a significant conceptual contribution to the synthesis over any other. For interpretive rigour, all studies had a clear aim, qualitative methods were appropriate and interview/focus group schedules, locations, and durations were fairly consistently reported. Although the identity and profession of the interviewer(s) was provided in most of the papers there was little reflection by the authors on the influence of the researchers on the methods, data collection and interpretation of findings and therefore category six of the CASP 'Researchers' influence' was often rated as 'no' or 'unclear'. 'No' or 'unclear' was also often given for ethical considerations where many of the studies stated that ethical approval was given and provided little/no further information.

Study characteristics

Table 4 summarises the key characteristics from the 18 papers. Participants (n=280 women, 136 men) with sudden onset and progressive health conditions were included: stroke (n=3); head and neck cancer (n=2); mixed rehabilitation (n=2); various speech pathologies (n=1), low back or neck pain (n=7); jaw pain (n=1); chronic fatigue/ME (n=1) and older adults post hip fracture (n=1). A wide age range was represented (range where stated 20-101yrs). The exercise/activities being commented upon were either specific to the study (n=10) or not defined but undertaken at some previous stage (n=8). Fifteen studies were located in outpatient/community settings and three involved reflections on an inpatient stay. All studies explored the views of the person undertaking the practice, with one study also including the views of caregivers.[25] Three papers included the views of the staff delivering the intervention but, as these did not relate to the aim of the meta-ethnography, these data were not extracted.[25,34,38] The studies were completed in the UK (n=5), Australia (n=4), US (n=3), Canada (n=2), Denmark (n=1), France (n=1), Spain (n=1), and Sweden (n=1).

Despite the heterogeneity across the papers, the findings from this exploration of how patients view being prescribed therapy-based exercise, the information they are given, the

education they receive and if/how they independently practice and adhere to their treatment programme were aligned and reciprocal relationships were identified. There are three main themes: ‘the guidance received’, ‘the therapist as teacher’ and ‘the person as a learner’, each of which is discussed below with illustrative quotations shown in Table 5 (Supplementary) and summarised in Figure 2.

Theme one: The guidance received – recipe and choice

The first theme reflected the perceptions about the nature of the guidance received and the process of education or prescribing that was delivered, and/or which the participants would have liked to have been delivered. Fear about not knowing or being unsure about what to do meant that participants sought not only knowledge and clarity about the specifics of the exercises, but also guidance about how to carry these out in the correct, non-harmful way. For this, a “recipe” with clear boundaries about the nature of the exercises and individualization to match and adapt the exercises to the person’s capabilities were wanted. Within this desire for rules was the perception by some that trial and error learning was burdensome and might aggravate symptoms. Participants positively appraised demonstration, observed practice, careful progression and time spent with their therapists. With time, participants believed they could be guided to reacquaint themselves with their own body, its capacities and aptitudes, develop the confidence and knowledge to cope with fear, negative emotions, and unwanted sensations, and be empowered to take risks.

Whereas many patients sought simplicity, a few wanted challenge, and whilst some desired a fixed schedule, others wanted flexibility to fit exercises around their lifestyle. While a standard programme that suited everyone would be impossible to construct, patients believed that good programmes shared certain features. These included being individualized and adapted to personal interests and motivations, offering regular feedback, guidance and correction, and not being too boring or onerous. As part of living with a long-term condition and to assist with continuance of practice, patients sought renewal and progression of their

exercise schedules. Checklists and booklets, as well as adjuncts and technology to support practice, were considered helpful for some but not all. Instead, continued review, progression and external sources of motivation were sought both by those who sustained practice and those who discontinued. Patients wanted to continue to practise in the same manner and location as when they first started. When this was not possible, clear options and quick re-access to services were desired. Patients often felt abandoned if left to continue with and progress practice alone. On-going contact and support was more highly valued than reminders to exercise. Overall, participants wanted to know what to do and how to do it, they wanted explanations and they wanted to be taught by people who attended to their concerns, anxieties, needs, experiences and feelings.

Theme two: The therapist as teacher – responsibility and being able to demand

In their desire for teaching, the second theme reflects the importance that the participants placed on the interaction and connection between themselves and their therapist as their teacher. In response to a perceived lack of exercise related experience, many patients drew on their experience of being a learner under the guidance of a teacher. With this came, at least initially for some, the hope or expectation of being rehabilitated or “fixed”, as well as the uncertainty about who was responsible for engaging and practice, and what it was reasonable to demand or expect from their therapist. Across the different studies and health conditions some patients wanted, sought, and accepted responsibility. However, this was not the case for all. Feeling ready to engage, and taking responsibility for engagement, was influenced by factors related to the individual and to their perceptions of both their teacher(s) and their place within the healthcare system. At the individual level, for example, those experiencing loss and pain needed time to realise that recovery would be slow and on-going with no quick fix. Patients who had these characteristics might be slow to engage with, and to take responsibility for practicing, their exercise; they may be resistant to self-management or considered unempowered or poorly compliant, with weak ownership attachments and/or low levels of self-determination. At the cultural level, some participants perceived that the

healthcare system, for example its structures, processes and policies, prevented them from fully engaging in practice. The analysis also suggested that perceived healthcare system-related factors and individual-level factors might operate jointly or independently and that delayed engagement could be due to multiple interacting factors that may not simply reside within the capacity of the individual to solve.

Within the context of interaction between the individual, the teacher and the culture of the system, engaging and practising were wished for within a framework of being supported. Patients wanted to be understood as people first. They looked for a therapist who was caring, warm, kind, professional, positive and optimistic. Good communication skills were valued and were influential to a person's motivation. Information needed to be accurate, trustworthy and convincing, and articulated so that it could be understood. Therapists who offered patience, praise, encouragement, belief, feedback and motivation were highly regarded. Patients spoke of their need for allies, with therapists who were able to be there and to listen and who, through their actions, demonstrated that they were on their side. Therapists who asked but did not dictate, those who supported but did not threaten, and those who shared decision-making but were also able to offer expert views and make decisions when asked, were seen as capable of making a positive contribution to the rehabilitation experience.

Mutual trust was important but patients also wanted to be valued and not judged, blamed or made to feel guilty. Some participants wanted a friend and most wanted security to build a relationship and to be enabled to see life in a different way. Anxiety and uncertainty and an individual's beliefs about their competence and confidence meant that where some were able to move away from the support of the therapist, this was not the case for all. Contradictions were seen between trying and needing to find internal motivation and to take responsibility and the strong feeling from some of wanting and needing this to come from an

external source. Overall, patients wanted and valued an expert individual, a coach and an educator, both to help them initially engage and continue with practice.

Theme three: The person as a learner – readiness and engagement

This final theme represents the patients themselves as those who were in receipt of the information giving or prescribing, and their needs, motivations and emotions as they initially engaged with therapy-based exercise and then progressed to long-term practice. Perceptions about the need or reason for practice, the expectations of this, and both the resultant ownership of responsibility and readiness, were all interwoven with comments about the process of information giving and prescribing itself. The participants involved had experienced either sudden onset pathology such as stroke or were living with long-term conditions such as low back pain or cancer. Engagement was at a point of loss, vulnerability, being overwhelmed and/or feeling fearful for some, which reflected different levels of ownership and readiness. From this, a range of expectations and motivating factors were expressed from “having no choice”, “wanting things to be different”, and not wanting “that happening to me”, to being “determined”, to “reach my former level”, to wanting to “know more”, and to having “hope”.

For many, initial engagement with exercise was associated with “starting from scratch”, with patients describing themselves as having either no idea or being unsure about how to start or what to do. This uncertainty was seen irrespective of condition or setting. Patients were often fearful about engaging in prescribed exercise, perceiving themselves as lacking in relevant experience. Within this context of uncertainty and perceived inexperience, practice was either not started, stopped prematurely or continued but only in familiar, simple and safe ways. Participants spoke about their fear and anxiety about exercising. They were concerned that if done incorrectly they could damage themselves more, that they might regress in terms of their recovery, and that exercising might make them feel worse. Participants described feeling enabled to undertake activities with others but not alone and

lacking the confidence to modify activities independently. They looked to therapists to recognise their anxiety, provide information about what to do, allay their fears, give them time to build confidence, and not to assume that they would know what to do or would be able to work it out by themselves.

Having initially engaged, patients moved into a phase where their practice needed to be sustained. Some patients were able to continue to practise because it was perceived as beneficial for symptom management, and others saw it as a means of positive coping. Others, however, perceived this ongoing phase as being “hard”, “effortful”, “a struggle”, “boring” and requiring “energy” and “attention”. Patients who did not perceive rapid enough benefit, those who expected to get better and those who did not realise that long-term practice would be necessary and did not want to persist, were less able to sustain practice. Although the perception of there being a “quick fix” changed for some over time, some continued to wish for this, not because they were looking for a short cut but as a means of escape from what was perceived as an unwelcome and difficult situation. Low mood or transitioning from supported practice to practising alone was described as overwhelming and under these circumstances practice was often discontinued.

In summary, what was of importance for exercise prescription was not only the nature of the teaching or guidance received, but also the expectations, ownership and readiness of the patient themselves as the recipient of the teaching as well as their interaction with their therapist or teacher. Apparent in all three themes were the uncertainties and contradictions both within and between individuals as they attempted to engage and continue with therapy-based practice. All patients perceived themselves as needing to engage and practise but not everyone wanted and expected to take full responsibility for this. Some looked for rules, recipes and structured practice but this was balanced against a co-existing desire for options and choice, and for flexibility and integration into activities of daily living. Some wanted to play an active part whilst others wanted to be more passive. Patients held many

contradictory positions and uncertainties which often resulted in ambivalences about engaging in and practising exercise. Under these circumstances patients either failed to engage in prescribed practice or stopped prematurely.

Discussion

The meta-ethnography explores therapy-based exercise from the perspective of adult patients, their perceptions about the prescription of therapy-based exercise by health care professionals, the information they are given, the education they receive and if/how they independently practice and adhere to their treatment programme. The findings showed that the perceived success or otherwise of engaging with, and adhering to therapy-based exercise practice was influenced by factors related to the delivery of the education or prescribing and also by factors related to the patients themselves. Engaging and continuing with therapy-based practice were perceived as endeavours that the patients hoped to experience as shared activities, with important connections between 'the person as a learner' and their 'therapist as teacher' and, based on this relationship, then 'the guidance received'. Patients often articulated uncertainties, contradictory positions and ambivalences that impacted on their ability to begin and then sustain exercise practice.

Patient education is defined as "a planned learning experience using a combination of methods such as teaching, counselling, and behaviour modification techniques which influence patients' knowledge and health behaviour".[40] Empowering patients through education is considered integral to practice and a cornerstone of therapy.[10-11] Within this synthesis, the participants' incentives, their feelings and motivations for learning and engaging and the driving force through which the quality and quantity of these were shaped, were encompassed within the theme 'person as a learner' and reflected engagement and adherence largely out of necessity as it was imposed due to ill health. Undertaking therapy-based practice at this point of life disjuncture was often associated with feelings of grief,

vulnerability and fear, and the resultant contradiction of wanting and not wanting to engage and practice. It has been recognized that learning when under threat, from need and with little choice, is suboptimal,[41] and, as was seen in the meta-ethnography, may result in passive ambivalence and either no or only partial success. For these individuals, the wish to practise co-existed with not wanting to, of wanting responsibility but at the same time not wanting it, and of wanting to be actively involved whilst also being passive. Practising is hard and requires effort and patients needed to both want, and be emotionally ready, to engage with, and practise exercise to successively adhere to their exercise programme.

'The guidance received' theme shows that where practice was imposed due to ill-health, therapy was not restricted to obtaining knowledge and skills, but included developing understanding about the healthcare system and what this allowed; about the realities of recovery and rehabilitation, what this involved and whether it was wanted; and about themselves as people living with a health condition. For some, balancing these different elements took time and for others the therapy-based exercise gave way to other aspects such as participating in family life or preparing for discharge, that were taking place.

One of the defining principles first proposed about adult learners was that adults can draw upon a depth of experience to guide their learning.[42] This was not the perception for all in respect to therapy-based practice with patients often demonstrating low health literacy for therapy-based exercise and, as a result, a feeling of a lack of experience and associated fear. Health literacy, the capacity of individuals, families and communities to make sound health decisions in the context of everyday life, is linked to self-rated health and long-term health conditions; low health literacy is associated with lower self-rated health and higher rates of long-term health conditions.[43] A review of the role of health literacy in self-management skills in long-term disease management concluded that low health literacy is also a concern since it may affect behaviours necessary for the development of self-management skills.[44] A recent review exploring health literacy and back pain management

identified that, despite the high prevalence and economics costs of this condition, only three studies directly addressed health literacy for people with low back pain.[45] This suggests health literacy is an important yet underexplored component of therapy-based exercise. To compensate for the lack of experience, and as reflected in the themes, participants often drew upon their familiar experience with the therapist as the teacher and the expert. In contrast to reported current practice of patient education and exercise prescription often being poorly planned, verbal, informal and ad hoc, patients looked for certainty, clear boundaries, recipes and rules, and for learning-orientated learning with explanation and demonstration first, then guided practice to follow. Participants were often too unsure or too frightened to work out their own programmes of exercise and in order to build their confidence, many wanted guidance and to be told and shown clearly what to do.

Although participants referred to the value of peers and family, the greatest importance was placed on the therapist as their teacher or educator and this was reflected in the theme 'the therapist as teacher'. The qualities of this person as someone who was kind and caring, and who listened and showed interest were not different from both the qualities of therapists expressed in the literature[46] and the qualities of good teachers in general. As well as a focus on the person, there was also a focus on the relationship and the clinician-patient fit. For engagement and adherence to result, the interaction, and thus the therapist, needed to be right for the learner. Through the value placed in their therapist as teacher, participants sought support and guidance to help achieve initial and sustained practice and through this, successful recovery and change.

Several limitations of the study have been identified. As the search was not limited to any specific patient group or type of exercise, broad terms were initially used for this review. The resultant retrieval of a large number of papers necessitated the iterative revision of the inclusion criteria by the team as the nature of possible papers became apparent. The final criteria arrived at meant that the papers included were specifically focused on engagement

with/practice of independent exercise, and missed those papers where participants, reflecting on wider aspects of engagement with therapy or rehabilitation, also shared perceptions on prescription and education. Nonetheless, the findings provide a foundation to start to better understand learning within the context of ill health. The broad search criteria meant that the views of participants with a range of health conditions were included in this review. The search strategy was date limited to 2000-2018. Studies prior to 2000 were considered unlikely to reflect recent and current practice since practice has changed with the use of technology and other adjuncts to support the prescription of independent exercise. It is recognized that conceptually important papers published before this time may have been excluded. The review was also limited to publications published in the English language and it is noticeable that the included studies were all from nations with well developed health care services. There was commonality in the ethos of the findings being translated and synthesized and the review is therefore unable to provide a global review of therapy based exercise. In addition, across the papers little mention was given to the socio-economic status of the participants and no comments were made about their health literacy which would be of value to explore.

Limitations also need to be considered in respect to the assumptions that are made when synthesising qualitative research and the degree to which the particular elements of individual qualitative studies lend themselves to synthesis. These include acknowledging the importance of the context in which the primary research was undertaken,[47] the particular philosophical stance underpinning each study, the methods of analysis and theoretical assumptions of the primary authors,[20] and the potential dilution of the depth of the original work.[13] These limitations should be balanced against the value of developing cumulative knowledge and new insights. Meta-syntheses do not claim to develop definitive knowledge but to offer one possible higher-order interpretation of what is considered known or understood about a particular topic. It is also important to note that the individual perspectives of the authors of this meta-ethnography will have influenced the conduct and

the findings of the review. SD is a physiotherapist with expertise in treating people with neurological conditions, CML is a physiotherapy researcher who was formerly a musculoskeletal physiotherapist and AD has a nursing background and is a researcher in older people and public health. The inclusion of a non-therapist researcher added valuable input, raising questions and identifying assumptions about therapy.

Implications for practice from this review have been identified. The conceptual model (Figure 2) for this review reflects the patient as the learner at the centre, with the therapist as a teacher operating within the healthcare system around the outside. The spokes joining the two represent uncertainties related to motivation, experience and empowerment, with a continuum from patient owned characteristics in the middle to therapist expected or desired characteristics at the edge. This model could provide a framework for clinicians to assess these uncertainties, and from this be guided as to the individual nature of a patient's particular readiness, expectation and needs for engaging and adhering to practice. By gauging this both initially and over time, the degree of stability or change could be revealed, indicating those patients who, in response to needing to engage and sustain practice, may be more passive, those who show independence and those who sit in the middle or move between these two. Understanding the patient and their particular stance towards motivation, experience and empowerment, would enable therapists to reject blanket expectations about exercise commitment which, as the patients in the meta-ethnography highlighted, can lead to judgment and blame, but instead to match their delivery of therapy to the individual and support them in a way that is relevant to the stage or moment in time.

Most of the studies included in the meta-ethnography used descriptive methods to understand how patients made sense of exercise prescription and undertaking independent therapy-based practice. There is a need for future research to improve the theoretical understanding of teaching, engagement and adherence to practice in the context of rehabilitation to optimize outcomes. Deeper insights may be developed by taking an

interpretivist stance to further explore perceptions about what is delivered and also explore what is understood and considered meaningful to people. This could help clinicians to improve their understanding and planning of treatments to take into account the tacit, often hidden, personal and cultural learning that patients undertake and how all of these shape the decisions made by patients about whether to start, stop or continue with a therapist-recommended exercise programme.

Clinical Messages:

- The quality of interaction between therapists and patients appears integral to patients initially engaging with, and then sustaining independent practice of therapy-based exercise.
- Therapy-based exercise programmes need to be individualized and health care professionals need to take patients' previous experiences, anxieties/ uncertainties and ambivalences in motivation and empowerment into account.

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Author contributions
SD initiated the study and conducted the literature assessment. SD, CMJ and AD all developed the study design, search strategy and inclusion criteria. SD conducted the initial screening with CMJ and AD also involved in data extraction, quality appraisal and final study selection. SD, CMJ, AD all discussed the results, commented upon and approved the final manuscript.

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Table 1. Summary of the main elements involved in the seven stages proposed by Noblit and Hare[14] for conducting a meta-ethnography

Stage	Focus	Stage involves:
Stage 1	Getting started	Identifying and choosing the research topic; developing the research question; determining that a meta-ethnography is the best approach to address the research interest
Stage 2	Deciding what is relevant to the initial interest	Defining the focus of the synthesis; locating relevant studies; making inclusion decisions/selecting the studies; quality assessment
Stage 3	Reading the studies	Repeat structured reading/re-reading of the papers; identification of metaphors, concepts and themes
Stage 4	Determining the relationship between studies	Pulling together/comparison of the metaphors, concepts and themes to identify a relationship that might be reciprocal, refutational or with the development of a line of discussion
Stage 5	Translating the studies into one another	Translation of meanings from one study into another with the aim of arriving at translated concepts
Stage 6	Synthesizing the translations by identifying concepts that can encompass those found in other studies	Comparison of the potentially multiple translations from across the studies, one to another, to allow the new overall interpretation to emerge
Stage 7	Expressing the synthesis	Selecting the method best suited to sharing the information

Table 2. Final Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
• Qualitative studies involving focus groups, interviews, observation and mixed methods with a defined qualitative element • Full paper published in English and post 2000 • All health conditions • Aged over 18yrs • Perceptions/thoughts/views of person living with health condition, and also for their carer/spouse • Focus of the paper related to perceptions of engagement with a specific exercise/therapy intervention and not to more non-specific health advice/broad concept, e.g. physical activity/nutrition • A theme(s)/category/section within the results that related to information giving/prescribing/ patient education	• Review papers, editorials, conference abstracts • Primarily quantitative methodology, including surveys • Primarily questionnaire based data collection • No, or very limited, section of results related to information giving/patient education • Perceptions related to undertaking a group class/activity unless specific reference was made to how skills would be carried over to independent practice at home • Perceptions related to medication management

Table 3. Final agreed quality appraisal results using the Critical Appraisal Skills Programme (CASP)

Study ref	Identified aim	Method appropriate	Research design	Recruitment strategy	Data collection	Researchers' influence	Ethical issues	Data analysis	Explicit findings	Clinical value
Cheshire et al 2018[22]	Yes	Yes	Unclear	Part	Yes	Unclear	Part	Yes	Yes	Unclear
Constantinescu et al 2017[23]	Yes	Yes	Yes	Part	Yes	Unclear	Unclear	Yes	Yes	Yes
Emmerson et al 2018[24]	Yes	Yes	Unclear	Unclear	Unclear	Part	Part	Yes	Part	Unclear
Eng et al 2014[25]	Yes	Yes	Yes	Unclear	Yes	Part	Part	Yes	Yes	Yes
Escolar-Reina et al 2010[26]	Yes	Yes	Yes	Yes	Unclear	No	Part	Yes	Yes	Yes
Govender et al 2017[27]	Yes	Yes	Yes	Part	Yes	Part	Part	Yes	Yes	Yes
Hamilton et al 2018[28]	Yes	Yes	Yes	Part	Yes	Part	Part	Yes	Yes	Yes
Horne et al 2015[29]	Yes	Yes	Yes	Unclear	Part	Part	Part	Yes	Yes	Yes
Liddle et al 2007[30]	Yes	Yes	Yes	Yes	Unclear	Part	Yes	Yes	Yes	Yes
Lindfors et al 2017[31]	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes	Yes	Yes
Maiers et al 2016[32]	Yes	Yes	No	No	No	Part	Part	Yes	Part	Unclear
Palazzo et al 2016[33]	Yes	Yes	Yes	Unclear	Yes	No	Part	Part	Yes	Yes
Rathleff et al 2017[34]	Yes	Yes	Yes	Yes	Part	Yes	Part	Unclear	Part	Part
Resnick et al 2005[35]	Yes	Yes	Unclear	Unclear	Part	No	Part	Part	Yes	Unclear
Slade et al 2009[36]	Yes	Yes	Yes	Unclear	Part	No	Part	Yes	Yes	Yes
Stenner et al 2016[37]	Yes	Yes	Yes	Unclear	Part	No	Part	Part	Yes	Yes
Stilwell & Harman 2017[38]	Yes	Yes	Yes	Part	Part	Part	Part	Yes	Part	Unclear
van Leer & Connor 2008[39]	Yes	Yes	Yes	Unclear	Part	No	Part	Yes	Yes	Yes

Table 4. Key Characteristics of the 18 Included Studies included in the review.

Study/Year Country	Stated aims	Sample	Participants People with:	Data collection	Type of Design/ analysis	Main themes
Cheshire et al 2018[22] UK	To explore differences and similarities in treatment perceptions and experiences of GES among CFS/ME participants reporting improvement compared with those reporting deterioration in their condition	N=19 17F:2M Mean 43yrs for those 'a little worse' and 39yrs for those 'much better'	Chronic fatigue syndrome	Semi-structured Interviews – either by phone or face to face	Qualitative study nested within RCT	Five themes: 1) Getting started and false starts; 2) The indeterminate phase of GES; 3) Competing commitments; 4) Interfering symptoms and comorbid conditions; 5) Maintaining motivation
Constantinescu et al 2017[23] Canada	To identify determinants of successful adherence to home-based therapy to inform design of a swallow based health app	N=10 4F:6M Mean 60yrs	Head and neck cancer	Semi-structured Interviews	No theoretical approach stated Thematic analysis	Six themes: 1)Perceptions on outcomes and progress; 2) Role if clinical appointments; 3) Cancer treatment; 4) Rehabilitation programme; 5) Personal factors; 6) Connection
Emmerson et al 2018[24] Australia	To explore patient experience of utilizing smart technology to support an upper limb home exercise program post stroke,	N=10 0F:10M Mean 72yrs	Stroke	Semi-structured interviews	Convergent mixed methods Phenomenology Thematic analysis	Three themes: 1) Exercises on the tablet helped rehabilitation; 2) Participants could use the tablet for their home exercise programme; 3) But not everyone liked the tablet
Eng et al 2014[25] Australia	To explore factors affecting ability of the stroke survivor to drive own recovery outside therapy within inpatient stroke rehabilitation	N=7	Stroke	Semi-structured interviews	Qualitative research design Conventional thematic analysis	Four themes: 1) Lack of opportunities …dead and wasted time; 2) Out of control …at everyone's mercy; 3) Knowing what to do and why; 4) Passive rehab culture and expectations
Escolar-Reina et al 2010[26] Spain	To explore how the intrinsic characteristics of home-based exercise programme or care provider' style in clinical settings affect chronic neck or low back pain patients' adherence to prescribed exercise	N=34 23F:11M 22 neck pain Mean 48yrs Range 25-70yrs	Low back or neck pain	Focus groups	Qualitative focus group design Data analysis based on grounded theory	Two themes: 1) Conditions of prescribed home-based exercise programme; 2) Care providers style
Govender et al 2017[27] UK	To identify key factors that may inform design of a new intervention to support swallow exercises in people after head and neck cancer	N=13 4F:9M 4 over 60yrs Mean 63yrs 9 under 60yrs Mean 50yrs	Head and neck cancer	Semi structured Interviews	No theoretical approach stated Content analysis	Three themes: 1) Capability; 2) Opportunity; 3) Motivation

Table 4. (continued)

Study/Year Country	Stated aims	Sample	Participants People with:	Data collection	Type of Design/ analysis	Main themes
Hamilton et al 2018[28] Australia	To explore how technologies were used and experienced in rehabilitation, when prescription was tailored	N=20 7F:13M Mean 64yrs Range 20-101yrs	Stroke, hip fracture, brain injury, generalised deconditioning	Semi-structured interviews	Qualitative aspect nested within RCT Grounded theory	Two key findings: 1) A process of patient engagement with technology; 2) Key conditions that influenced the level of patient engagement with technology
Horne et al 2015[29] UK	To assess stroke survivors' views and experiences of two patient-led therapies: mirror therapy and lower limb exercises	N=20 3F:14M Mean 63yrs Range 38-84yrs	Stroke	End treatment questionnaire and semi-structured telephone interviews at 4wk follow up	Qualitative aspect nested within RCT Framework approach	Three themes: 1) The benefits of patient-led therapy; 2) Practical difficulties and solutions; 3) Barriers to patient-led therapy
Liddle et al 2007[30] Northern Ireland UK	To investigate experiences, beliefs and expectations of a group of CLBP patients in receipt of advice and exercise as part of their treatment	N=18	Low back pain	Focus groups	No theoretical approach stated Manual analysis taking categories into themes	Five themes: 1) Effects of LBP on the individual; 2) Treatment received; 3) Limitations to recovery; 4) Expectations from Rx; 5) Patient recommendations
Lindfors et al 2017[31] Sweden	To investigate patients' experiences of therapeutic jaw exercises for treating masticatory myofascial pain	N=10 9F:1M Mean 35yrs Range 21-58yrs	Masticatory myofascial pain	Semi-structured interviews	No theoretical approach stated Analysis through Systematic text condensation	Four themes: 1) Patient adherence; 2) Symptoms; 3) Treatment effects; 4) Participation
Maiers et al 2016[32] US	To investigate patients' satisfaction with conservative treatments for BRLP.	N=174 115F:59M Mean 57yrs	Back-related leg pain	Semi-structured interviews	Qualitative aspect nested within RCT Content analysis	Four key themes: 1) Satisfaction; 2) Perceptions of home exercise with advice; 3) Perceptions of chiropractic treatments; 4) Worthwhile care
Palazzo et al 2016[33] France	To assess the views of patients with chronic LBP concerning barriers to home-based exercise programme adherence and solutions to increase adherence	N=29 Mix M&F Range 24-85	Low back pain	Semi-structured interviews	Inductive qualitative research	Seven themes: 1) Barriers to adherence; 2) Barriers associated with the healthcare journey; 3) Barriers associated with patient representations; 4) Barriers associated with environmental factors; 5) Strategies to enhance adherence; 6) Improving patient performance; 7) Expectations regarding new technologies to enhance adherence

Table 4. (continued)

Study/Year Country	Stated aims	Sample	Participants People with:	Data collection	Type of Design/ analysis	Main themes
Rathleff et al 2017[34] Denmark	To investigate feasibility and acceptability of an unsupervised progressive strength training intervention monitored by the BandCizer for frail geriatric inpatients	N=13 M<F Mean from n=15 involved in the trial 86yrs Range 71-98yrs	Frailty associated with a range of conditions including fracture, pneumonia, UTI	Semi structured interviews	Qualitative study within a feasibility trial	Two themes: 1) Advantages of unsupervised exercises; 2) Challenges of unsupervised exercises
Resnick et al 2005[35] US	To explore experiences of older women post hip fracture exposed to a home-based self-efficacy motivational intervention, the Exercise Plus Program	N=70 70F:0M Age: 81yrs +/- 6	Post hip fracture	Interviews mostly by phone	Qualitative aspect nested within RCT Naturalist or constructivist inquiry Content analysis	Fourteen themes: 1) Real and expected benefits; 2) Visual cues and knowing what to do; 3) Simplicity; 4) Individualized care; 5) Verbal encouragement; 6) Regular schedule; 7) Confidence; 8) Determination; 9) Social support; 10) Reciprocity; 11) Goal identification; 12) Unpleasant sensations; 13) Constraints to exercise; 14) Getting back to baseline
Slade et al 2009[36] Australia	To determine the experience of exercise programmes by people with chronic low back pain	N=18 12F:4M Mean 51yrs	Low back pain	Focus groups	Qualitative focus group design Principles of grounded theory	Two themes: 1) Experience of exercise; 2) Helpful and empowering skills
Stenner et al 2016[37] UK	To explore the experiences of involvement in treatment decision making, and the information and decision support needs of patients with NSCLPB who have been offered exercise as part of their management plan	N=8 4F:4M 35-74yrs	Non-specific chronic low back pain (NSCLBP)	Semi-structured interviews	Interpretive phenomenology (Hermeneutic approach of Gadamer) Thematic analysis	Four themes: 1) Patients' expectations and patients' needs are not synonymous; 2) Information is necessary but often not sufficient; 3) Not all decisions need to be shared; 4) Wanting to be treated as an individual
Stilwell & Harman 2017[38] Canada	To explore chiropractors' and chiropractic patients' experiences and beliefs related to exercise adherence	N= 6pts Mean 35yrs	Low back pain	Semi-structured interviews	Focused ethnographic design using just interviews and not observation	Four themes: 1) Diagnostic and Treatment Beliefs Motivating Behavior; 2) Passive-active Treatment Balance; 3) The Therapeutic Alliance and Patient-centered Care; 3) Exercise Delivery

Table 4. (continued)

Study/Year Country	Stated aims	Sample	Participants People with:	Data collection	Type of Design/ analysis	Main themes
van Leer & Connor 2010[39] US	To directly document patient perspectives of voice therapy barriers & facilitators, and to frame them within a theoretical and interdisciplinary context	N=15 12F:3M Range 21-76yrs	Various speech	Interviews Face to face or by phone	No theoretical approach stated Content analysis	Three themes: 1) Voice therapy is hard; 2) Learning voice techniques; 3) The (clinician-patient) match matters

Key: N= number of participants; M=male, F=female; yrs = years

Supplementary file 1. Table 5. Themes/subthemes with supportive constructs, illustrative quotes and sources

Themes/ subthemes	Supportive constructs	Illustrative quotes	Sources
The Person as a learner : starting – having to engage and learn			
Need, expectations, ownership and readiness	**Need**: persistent symptoms; worried; frightened me; no control; painful; stressed out, mentally and physically; killing me; scared for the future	'I said "I've got toothache in my leg…my back and my leg…and I just can't go on". I was worried that it was something more sinister it lasted so long!' [30] 'now I'd really got to do something about this because it was painful, so I started to take it more seriously and do it properly' [31] 'I was really stressed out, mentally and physically, and I had a really bad flare-up, and I was like, I need to go to school but this is killing me and I think it took about a week for it to resolve, so I'm kind of scared for the future, especially next year on how it's going to affect me and how I can prevent that from happening. So I think that's kind of what's motivating me to do these exercises, as regular as I am now, because I really don't have time for that next year' [38] 'I need to work harder at it. And, because, I've already been pretty sick, I don't want to get sick again' [23]	[25];[30]; [31];[33]; [38]
	Expectations/Hope: get rid of the pain; help symptoms; don't know what hoping for; don't know what to expect; previous experience; building hope; expectations different now; validation; knowing more; return to baseline; expecting a miracle	'I really had great expectations, I was sure this was gonna be it, but it's not, so I have to move forward' [32] 'To be honest I wasn't quite sure what to expect from the physio appointment other than this vague idea that I would be given exercises only because it's what I expect a physio to do…' [37] 'I thought, well, if you don't use muscles, they, sort of, stop working, don't they? I've seen it with people with broken legs. If they don't use them the muscles wither. And so I thought if that's just going to happen to my throat, I don't want that happening' [27] '…I hope to just reach my former level, for the injured leg. I don't expect to be walking around without my walker or anything. As long as it can become as it once was' [34] 'Exercise builds bone density'; 'I hope it will build my bones so nothing else will break' [35] 'I think I really wanted to know what was going on more than anything else. I wanted to know more about my back and I suppose sometimes you don't get that, I wanted more understanding' [37]	[22];[23]; [25];[27]; [30];[32]; [34];[35]; [37]
	Ownership/readiness: Determined; pushing a little bit extra each time; tenacity to get better; motivation; personal attributes/coping/ responsibility; own destinies; response/attitude from others; waiting for others; own practice; active input; quick fix; ambivalence; trust in others	'I was just determined to do them, and I was determined to walk. I was determined to do everything for myself that I could. I just knew that it was the best way to get well' [35] 'I used to do triathlon. And I knew about sort of pushing myself a little bit extra each time I trained to accomplish a little bit more… It sort of made perfect sense to me that there would be similar approach with the therapy' [22] 'It's your own tenacity to get better' [27] 'You need motivation'; 'If you're not really motivated to really want to change, you're not going to. It's hard work.' [39] 'out of control over their own recovery' [25] 'I have been to doctors, physios and chiropractors, osteopaths, acupuncture off the range, all of those were recommended to me by people' [30] 'The medication takes just one minute, while the exercises take 30 minute. Although medications may be bad for my health, they are easier to take' [26] 'Quick fix' [30]	[22];[25]; [26];[27]; [28];[30]; [33];[34]; [35];[36]; [37];[39]

Table 5. (continued)

Themes/ subthemes	Supportive constructs	Illustrative quotes	Sources
Starting from scratch – unsure, scared, overwhelmed	**No idea:** can't help myself; don't know how to help myself; not knowing what doing; starting from scratch; Inadequate understanding of why exercises; lack of clinical knowledge; suspicious; skeptical	'It's all well and good you going to a physio and them saying you have to do this…you need to help yourself, and you come out and burst into tears and think I can't help myself I don't know how to help myself…'[37] 'They say, I'll do anything to get out of here, but I just don't know what to do' [25] 'I think just for the physio not to take for granted that the person knows exactly what they're telling them without showing them how to do' [30] 'So it's hard to get…like if I was going to answer that question (how would you improve the management of LBP), if there is some sort of way that you weren't just left on your own to try and work out what's available and what's appropriate…cause I mean you're left to…' [30] 'I don't know how long the full set is. If you are doing three reps it's… it's hours a day, particularly when you've got the emphysema exercises bolted in. And that's quite hard to achieve' [27]	[22];[25]; [26];[27]; [28];[30]; [33];[34]; [35];[37]; [39]
	Sure/Unsure: avoid aggravation; no certainty; make it worse; worrying; don't know; no certainty on that; do it, but don't know why; sort of slightly kind of worrying; doing them right; lacked confidence; unsure on accuracy; prefer to stop; prior success with ex made think that could do it again;	'If I do [the exercises], will I actually avoid aggravation? Maybe so,I don't know. I have no certainty on that' [33] 'It's completely impossible to envisage what your throat and mouth and tongue might feel like if you are a healthy person. So doing things like holding your tongue and trying to swallow…you do it, but you don't know why, and it feels sort of slightly kind of worrying' [27] '(I felt) a bit nervous (during the first session), because… I didn't have much use of my limbs … So I was wondering when I'm going to fall over. It looks like the near impossible, 'Am I confident enough to do it yet?' [28] 'I wanted to do exercise for at least two weeks at the centre, but she only gave me instructions on the first day, and she did not tell me if I was doing it correctly or not. In my house I was alone and I had pain, and I did not know if I was making a mistake with the exercises or if I was doing them too hard' [26] 'At first I was a bit skeptical about whether a couple of exercises would really help my jaw...' [31] 'I didn't know how to do anything and I wasn't really interested in (the technology), so I was saying 'I don't want to do this, I'll move on' [28] 'As long as you've got someone with you, that's fine, but if, you know, if you're on your own, it's a little bit harder…Some of my family learnt them as well. If I wasn't working with it one day, at least somebody was there to help, because I used to get a bit muddled!' [29]	[22];[26]; [27];[28]; [29];[30]; [31];[33]; [34];[35]; [36];[39]
	Fear/scared: alone and scared; scared of getting hurt; unpleasant sensations; dare not to train; never been scared before but am now; things would go again as it did before; can do thing better if supported and guided	'I think reassurance is a huge part of it for any patient, they want to know that there's nothing serious' [37] 'First of all, I have to make sure I was doing it right, and sometimes I wasn't sure if I was or not … He (chiropractor) did it with me … the next time I'd come in he'd add another one in … he showed me these same exercises four or five times, which was good … I knew I was doing them right then, I felt pretty confident' [38] 'I think that every time that we are supported or guided, like in physical therapy, like the osteopath. . .We can do things better. Because when you're alone you're scared! You're scared of getting hurt; you don't know what needs to be done. In the end, that's what made me quit doing the moves' [33] 'I was very athletic. [Having experience] makes you less fearful, willing to take the risk of doing' [36]	[26];[33]; [35];[36]; [37];[38]

Table 5. (continued)

Themes/ subthemes	Supportive constructs	Illustrative quotes	Sources
	Information – need to understand; desire for information; lack of knowledge; motivated when received explanation; given information but don't know why; overwhelmed; bombarded with stuff	'Loads and loads of stuff was happening that was unfamiliar and a bit scary, and so, you know, I, sort of, felt a bit bombarded with stuff' [27] 'I think I felt the same as when I was prescribed painkillers because I felt that there was a fairly vague explanation of what might be wrong with my back I wasn't sure whether what was being suggested was targeted enough' [37] 'There were no explanations with any models as to why I'm getting the current problem…' [37] 'I was given some leaflets on swallowing exercises and told that I would probably get a dry mouth and that would cause problems with swallowing' [27] 'I need you to come with me today because I don't feel it or hear it unless I'm thinking about it' [39] 'When I went to the clinic and asked the professional what I had, he explained it clearly, so I truly participated in the treatment' [26]	[22];[23] [26];[27]; [31];[36]; [37];[38]; [39]
The Person as a Learner: Continuing – having to adhere and practice			
On-going needs, expectation, ownership and readiness	**Needs/expectations:** Stopping when better/ perceived as better; didn't think needed to do it anymore; wish it was just like…quick fix; capacity in lives to keep going; don't see any more progress, not doing this anymore; rapid progress providing motivation	'I wish it was just like…quick fix' [39] 'I feel much better, my hip is doing better, and I didn't think I needed to do it anymore' [35] 'I don't see any more progress, I'm not doing this anymore' [23] '…because when the pain goes…you think you are out of the woods you know that's it…you just carry on just doing what you were doing…previously' [30] 'I think my expectations are different now certainly from when I first took back pain because my expectation was a ''quick fix'' and that (it) would be okay just, you know, ''fix me'' do something to me and I'll go out and I'll never have it (the pain) again. I don't expect to be pain free after eh treatment em I expect it to take time so it's a different attitude to it, I don't expect the 'quick fix' [30] 'Yes, if the pain has sort of eased and you're more or less back to normal, with just a niggle here and there, you feel well that's it over and done with 'til the next time, type of thing' [30]	[23];[30]; [31];[35]; [39]
	Have to keep going: become negligent, low back pain returns; easier if perceiving benefits but hard if not; not doing me any good; good to know what to do if pain returns; do all of the exercises because they are going to help	'I used to do the exercises at home because then I could better move my arm. I did them for a long time, until I realized that my arm was not aching and my hand was no longer numb. Since then, I have not done the exercises' [26] 'I wasn't really doing the stretching stuff anymore, because it wasn't doing me any good' [33] 'I started the stretching at home and then I introduced just a couple of minutes further walking. I'd just found, it was just enough to tip me over the edge really. … Towards the end I sort of said I can't do this and you know it was impacting on me and obviously my family in turn quite massively. So, I think I gave it a fair go but I was happy to stop' [22] 'It was a bit random; I would just do it when I remembered, some of the time' [27] 'If you don't do your homework there's no sense to come and see you (for therapy)' [39]	[22];[23]; [26];[27]; [28];[29]; [30];[31]; [33];[35]; [39]

Table 5. (continued)

Themes/ subthemes	Supportive constructs	Illustrative quotes	Sources
On-going needs, expectation, ownership and readiness	**Ownership/readiness:** have to do it; commit 100%; gotten to point when can't quit; have to continue it…on my own; stubborn; more aware more motivation	'…one should not think well I'm all done doing these voice exercises. I have to continue it…on my own' [39] 'My goal was to be able to keep one foot in front of the other. The trainer told me that if I stop exercising I would be back to where I started in 2 weeks. I thought, I have gotten to this point I can't quit…' [35] 'The discipline, it must be done, accept it. So I set a challenge every day and that's the reward. I love it' [36] 'I try to exercise every morning, because I just think it makes so much of a difference' [30] 'The exercise just generally makes me feel better'; 'There is an emotional lift to doing the exercise' [35] 'It required discipline and I'm not a real disciplined person; I had to work at keeping that as part of my routine' [32]	[22];[23]; [26];[27]; [29];[30]; [31];[32]; [33];[35]; [36];[39]
Practising – unsure and hard	**Hard/effortful: h**ard to continue; hard to motivate; hard work; forgetting to do exercises, no system of keeping track; degree of attention; awareness and compliance needed; lack of support; effort involved	'Perhaps if someone called you back, just to see how you were progressing, and how things were going' [30] 'If you're not really motivated to really want to change, you're not going to. It's hard work' [39] 'It was all because of the exercises and the awareness. You do have to be aware. Seriously, you're like in my mind' [39] 'Jogging is easier - takes less concentration than voice. My focus needs to be there to know if I'm doing it wrong' [39] 'You learn what's good and bad pain. In that sort of tension that goes with doing exercise is a sort of good pain so you then start to differentiate between them' [36] 'I'd get home and you'd hand it to me, like do this, this and this, and I'd go, 'Well that's so simple' Good God. And I'd get home and go… 'What, what (...) oh man, I don't remember, I don't know what this means, and I'm not gonna phone because this is grade 3 instructions' know what I mean?' [23] 'I have a lot of problems with my memory. So, even remembering to do these things, it is the hardest part really' [22] 'because you're being taken care of in such a good way and after that, you're back into the wild on your own' [33] 'It may sound completely ridiculous that it can be such a bloody big problem to do this three times a day...it's mad really. But hell, I'm just bad at it' [31] You tended to get left alone to your own devices, and I think sometimes it would have just been, you know, a little prompt keeping people going…and remind to do the exercises…It's hard to self-motivate, you know, to keep going [29]	[22];[23]; [26];[27]; [28];[29]; [30];[31]; [33];[34]; [36];[39]
	Embarrassing **Bored:** didn't ask what thought and wanted **Sad/lonely/miserable/ despondent:** initial improvement, plateau, exercises tougher to complete	'Silly', 'weird', 'unnatural'; 'teasing'; 'That sounds so affected' and 'Oh, is that how you're going to talk now?' [39] 'So there is an embarrassment factor that you have to get over. But I just go down into in my room in the basement and sortta, I guess isolate myself a lot to do certain exercises' [23] 'I have my rehabilitation sheets that I really struggle to follow every day, because it's so boring' [33] 'After a bit you get bored…you were repeating, repeating…you constantly are up and down and, say well lifting fingers and that, for half an hour that is so boring' [29] 'It's like being fed up. I can't spend all my life doing this all the time…When am I getting better?' [33]	[23];[27]; [29];[31]; [33];[39]

Table 5. (continued)

Themes/ subthemes	Supportive constructs	Illustrative quotes	Sources
The Guidance Received			
	Recipe: boundaries; limits; specificity; ambiguous; being told what exercises to do and how to do them helpful; what to do, how to do, when to do	'Ambiguous" limits and guidelines' [25] 'Every time I tried to do it myself, just from what other people had said to me I just always overdid it and ended up having to stop so…I thought right the only way I'm going to do this is by sticking exactly to this plan of like increasing it slowly' [22] 'The types of exercises that were given and then explaining how to do them, when to do them…that process I think has helped…making the commitment that, yep, that's a daily thing that's going to be done' [32]	[22];[23]; [25];[29]; [32];[35]; [39]
	Routine: routine and/or having a trigger to do the exercises; routine and structure key to facilitate recovery outside of therapy; information on how to structure day; clear, step by step; explicit education; strategies; exercise at desk, when hoovering	'Either when I get up in the morning or when I'm going to bed, that's when it's easiest...you remember because it's a kind of routine when you're getting ready for bed or before you get up' [31] 'a continuation of this really structured program" inside of therapy to outside of therapy' [25] 'I would say my problem is to find out when to do it actually. Because in the morning, I have a hard time getting started…Getting up is difficult enough, and then at the end of the day, after work, I am too tired' [33] 'I just think I need to get myself on a schedule and do the exercises in the morning before I do anything else. Otherwise there is always something else that comes up and happens…' [35] 'Having the booklet with the exercise helped. I would open that up and do them; I plan to continue to keep a calendar and write it down when I exercise. If I don't write it down I know I can let something slide for a couple of days' [35] 'At first, I'd get up in the morning and do them, kind of when I did my meds and stuff and try and get rid of all that at the same time' [23]	[22];[25]; [26];[27]; [31];[32]; [33];[34]; [35];[36]; [37];[39]
	Personalisation, individualisation: person more important than the exercises; exercise matched to level of ability – both high enough and low enough; individualized objectives	'Looking at different background with exercise and finding out where somebody comes from, so you can actually base the programme on what people are used to' [36] 'They'd think about what would help me instead patients one, two, three, four or five' [39] 'Everybody's an individual and you cannot make one size fit all, and most of us have probably found we have been put in 'one size fits all' [36] 'It did feel like it was four exercises and that's what they gave to everybody…' [37] 'In broad terms it felt very conveyor belt. I think it was very generic, it was 'ok so you have got back pain, yeh your movements are not great, you are tall and thin and people like that suffer…I'm going to give you some exercises' [37]	[22];[23] [30];[32]; [33];[35]; [36];[37]; [39]
	Complexity/attractiveness of programme: simple v complex; functional, relevant; schedule v fits with lifestyle	'We almost have 10 exercises. It's too much. There should be a limit: 3 or 4 max' [33] 'There was a book with more elaborate things which I did not do as well…I did them when I could get through them but they were really just too complicated' [35] 'What would be nice is to have exercises you can do while sitting at the office, or doing something else, or vacuum cleaning...' [33] Maybe if you change the program after so many weeks, it might crank (create) more interest [28] 'He only gave me a couple… And they're part of my repertoire, and they do work. Just simple stuff' [38]	[22];[23]; [25];[26]; [27];[28]; [29];[31]; [32];[33]; [34];[35]; [36];[38]

Table 5. (continued)

Themes/ subthemes	Supportive constructs	Illustrative quotes	Sources
	Teaching: pace/timing; demonstration; feedback; supervision; observation; renewal; exercise more difficult when care providers failed to observe; more difficult if lack of feedback, inadequate instructions leading to poor adherence because insecure and lacked confidence in whether properly doing exercises at home or not	'If they demonstrate it on your body you tend to remember. It does help your image in your mind later on' [36] 'Doing the ex with her helped me believe that I could do them when alone' [35] 'With the personal trainer I learnt what I had to do in a non-hazardous, for me, way. It basically turned my life around. I don't think I ever really knew what it was I had to do before. He was an educator…' [36] 'Feedback is useful' [39] 'I don't know. Maybe pictures with diagrams or something to show what part of your tongue you should be tensing up, like more emphasis on when you are swallowing, because you weren't sure really…' [27] 'I guess, in my case, he could explain what would happen and where everything would position and how that would help you long term to get better…Instead of just printing off some exercises and just doing them sort of thing. Just explain what's important…' [38] 'I asked her (therapist) because she was telling me (verbally) and I said Could you write it out for me?' [28] Heaps of explaining, telling you why you're doing this particular exercise. I think just having things explained to you is very important. Tell me why, tell me why. Explain it to me' [36]	[22];[23]; [25];[26]; [27];[28]; [30];[31]; [32];[33]; [34];[35]; [36];[38]; [39]
	Adjuncts: likes/dislikes; supportive; motivation; interest; reminder; apprehension; easier to follow; self-correction; cueing	'Written checklists with tasks they could tick off' [25] 'I had a form from the team and I used to mark down how many - on a Monday, four times, I'd mark it off four times, Tuesday four times, all the way up to Thursday. And I didn't do them on Friday. It was a Friday morning. I had it marked out on the chart and you give the chart when you come in for the exercises, she'd have a look at it. She'd say, 'Yes, you are doing well' [27] 'I said, 'Oh well I might as well just use those (exercise on paper)'. It's easier. I just look at it (rather than) mucking around with that (iPad). Touching this and that, and sliding that' [28] 'A video, that would be good really… that would be perfect…it's a simulation straight from the rehab department' [33] 'Oh I guess it's more interesting watching a screen rather than reading a boring sheet of paper' [24]	[23];[24]; [25];[26]; [27];[28]; [33];[35]
	Support/feedback/monitoring access to staff for guidance, instruction and safety; role of clinical staff as fundamental to equip with the knowledge /understanding of what could do independently outside of therapy; confidence; improvement; motivation	'But he had a plan, he said 'this is where I expect us to be' and she (previous practitioner) never really had that plan…' [38] 'I see it differently, It's not about what we want as we can have misconceptions, I think we need to be told what we need and what we are going to get and be realistic' [37] 'He worked with stepping it up a little bit to show that you're able to (do more)…I suppose it was goals' [36] 'She (therapist) adjusted it (the settings of the technology) as I got better...So I had to do a little bit more work but…not enough that I'd fall over…That's been good' [28] '(...) you slide into bad habits pretty fast. If you're not constantly monitored' [23] 'When I went in the morning and he asked me, 'have you done the exercises,' or 'have you felt some improvement,' I got motivated to do the exercises' [26]	[23];[26]; [27];[28]; [29];[30]; [33];[35]; [36];[37]; [38];[39]

Table 5. (continued)

Themes/ subthemes	Supportive constructs	Illustrative quotes	Sources
The Therapist as Teacher			
	Characteristics of person Kind; caring; nice; interested; valued; believed; trusted; non-judgmental; helpful and empowering; effective educator, motivator and communicator; praise; enthusiastic; gentle; understanding; role of the care provider's style	'Yes I was really pleased with the first meeting, with the way they dealt with me and how much they knew it felt professional and well thought-out it feels that you're in good hands and that they understand your problems' [31] 'I think the trainers were very caring people, and we were very compatible. There was no time that I was resisting what they were asking me to do. They were good at recognizing what I could and couldn't do' [35] 'He was motivating; he didn't make me feel guilty for being in the situation that I was in. He was encouraging, and every little step was an achievement' [36] 'Trust in where you go. Personability, how they react to you, and be non-judgmental; not you're an idiot for doing that or how did you get to this situation' [36] 'She sat there and talked to me…Such a gentle way she's got. I just sort of felt 'Yeah, sounds alright to me'...There was just something about the way I was told. I had confidence' [28] 'Just a bit of care from them (therapists), particularly to start with. … They're not all as useless as me, and there's a lot of smart people. All you (therapists) want (to do) is determine which one's you're working with now, whether you're working for the goodies (people who have experience/easily understand technology) or the baddies (people with less experience/difficulty understanding technology)' [28]	[22];[26]; [28];[31]; [32];[35]; [36];[39]
	Relationship: therapist on one's side; helping to get through it, in it together; my spirit you are taking care of; physiotherapist close to me; asking me what I think not telling me what to do; listening; not judging; trust; helping me get through this	'You're helping to get through it…if you didn't do that I wouldn't…try…I wouldn't try as much' [39] 'It's a partnership, it really has to be a partnership…' [38] 'Asking me what I think, not saying this is what you should do' [36] 'I'm only starting to learn to be more assertive and I've now realised that you go to this person and say: 'I want that from you' [36] 'It's all well and good you going to a physio and them saying you have got to do this, if you don't do this it's not going to get any better you need to help yourself, and you come out and burst into tears and think I can't help myself I don't know how to help myself. You can try and do the exercises but you haven't got the motivation there' [37] 'I wasn't given any contact details, and the minute I walked out and the doors closed behind me I felt I was in a prison when I walked out and I couldn't get back in. I had to go and see the doctor which I had bad experiences with trying to get physio in the first place' [37] 'You're helping to get it there though…if you didn't do that I wouldn't try… I wouldn't try as much'' [39] 'The physiotherapist, she was just amazing, she was so encouraging and understanding. I mean I just, yeah she was phenomenal. There was a part of me that was, I know this is working but you really need to clone this particular woman to make it work. …The thing also, once it got started, because it was like every fortnight and someone was taking interest in what I'd been recording because I felt so isolated, it was almost like I wanted to do a good job for my teacher!' [22]	[22];[26]; [27];[28]; [30;][31]; [35];[36]; [37];[38]; [39]

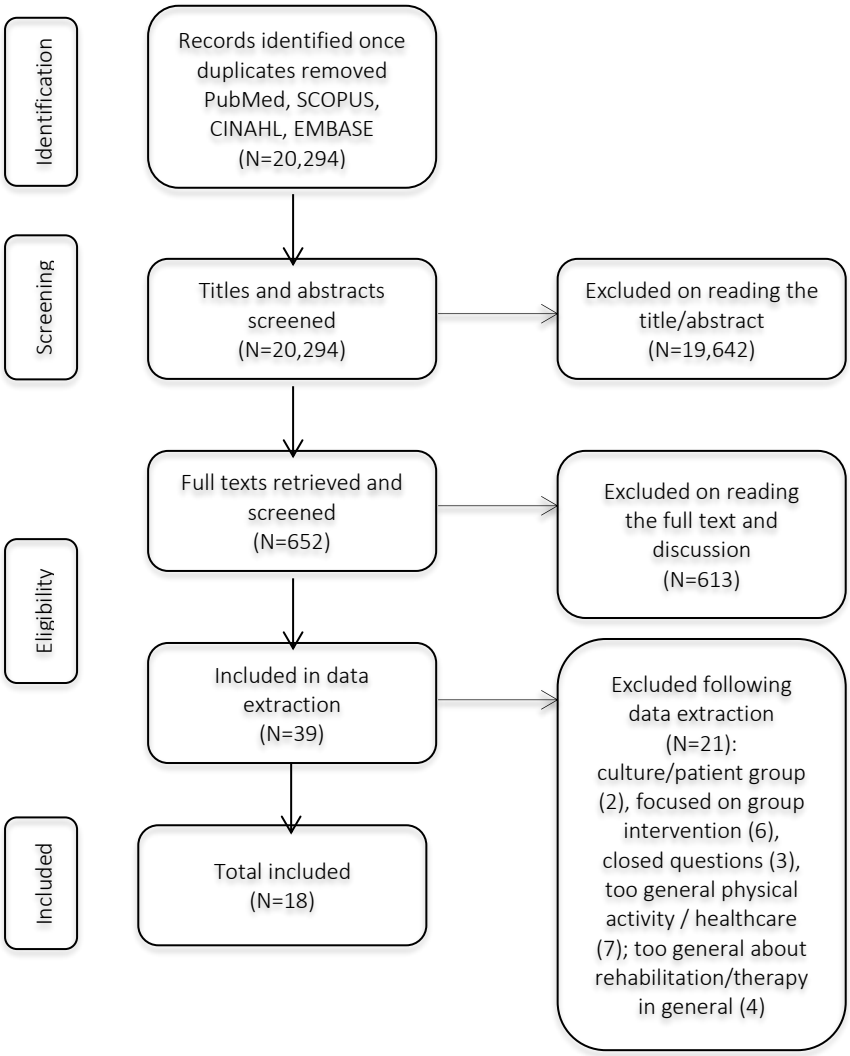

Figure 1. Modified PRISMA Flow Diagram[21] representing the identification, screening and inclusion/exclusion of studies

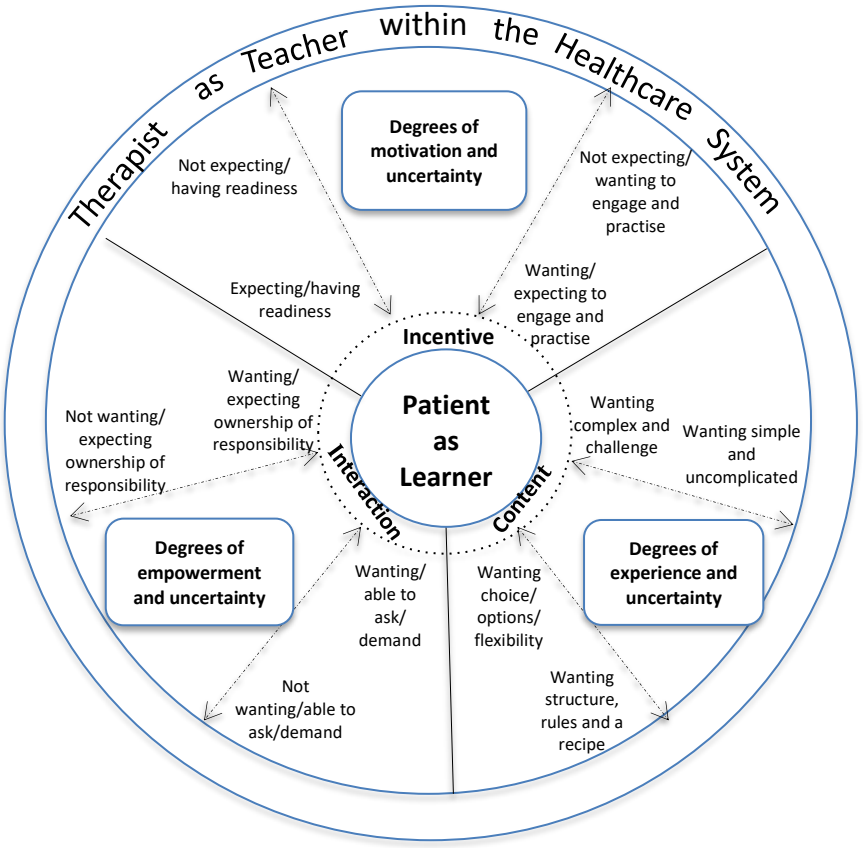

Figure 2: Conceptual model developed to illustrate the connection between the patient/learner and their therapist/teacher and the uncertainties and contradictions related to motivation, experience and empowerment perceived by patients when engaging with therapy-based practice

Appendix 1. Search Strategy developed for PubMed

1. Patient participation[mh] OR patient compliance[mh:noexp] OR compliance[tiab] OR complying[tiab] OR engag*[tiab] OR empower*[tiab] OR concordan*[tiab] OR adher*[tiab]
2. Exercise[MH] OR exercise therapy[MH] OR exercise movement techniques[mh:noexp] OR physical activity[mh:noexp] OR motor activity[MH] OR exercis*[tiab]
3. Physical therapy modalities[mh:noexp] OR physical therapy specialty[MH] OR physiotherap*[tiab] OR physical therap*[tiab]
4. Occupational therapy[MH] OR “occupational therapy”[tiab] OR “occupational therapist”[tiab]
5. Rehabilitation of Speech and Language Disorders[MH] OR Speech Disorders[MH] OR speech therap*[tiab] OR language therap*[tiab] OR oral motor therap*[tiab]
6. Dietetics[MH] OR diet therapy[MH] OR nutritional therapy[MH] OR dietitian[tiab] OR dietician[tiab]
7. Qualitative research[mh] OR Interviews as topic[mh] OR Focus groups[mh] OR Nursing methodology research[mh] OR Life experiences[mh] OR Attitude to health[mh] OR Qualitative[tiab] OR ethno*[tiab] OR phenomenolog*[tiab] OR focus group*[tiab] OR interview*[tiab] OR “grounded theory”[tiab] OR “narrative analysis”[tiab] OR “lived experience”[tiab] OR theoretical sampl*[tiab] OR purposive sampl*[tiab] OR ricoeur[tiab] OR spiegelberg*[tiab] OR merleau[tiab] OR field stud*[tiab] OR fieldnote*[tiab] OR field record*[tiab] OR field note*[tiab] OR snowball[tiab] OR “maximum variation”[tiab] OR audiorecord*[tiab] OR taperecord*[tiab] OR videorecord*[tiab]OR videotap*[tiab] OR “action research”[tiab] OR metasynthes*[tiab] OR meta-synthes*[tiab] OR meta-summar*[tiab] OR metastud*[tiab] OR meta-stud*[tiab]
8. 1 AND 2 AND 7
9. 1 AND 3 AND 7
10. 1 AND 4 AND 7
11. 1 AND 5 AND 7
12. 1 AND 6 AND 7

Appendix 2. First stage a priori screening criteria

Category	Description
Setting	Delivery of the information/intervention/therapy teaching/prescription to participants within an inpatient, outpatient or community environment
Perspective	Those living with any health condition; family/caregivers of those living with the health condition; not healthy young people or children with or without a health condition.
Intervention/ exposure	Exposure of the person or their caregiver to some recommendation/intervention regarding their healthcare that was to be followed as independent practice – either at the time of the study or at some previous stage
Comparison	Not applicable
Evaluation	Experiences, thoughts, perceptions, needs, preferences related to information giving/teaching/patient education and subsequent engagement with/adherence to independent structured exercise
Study design	Any established qualitative methods e.g. interviews, focus groups and questionnaires with open ended questions, either as the entirety or in conjunction with quantitative methods as long as the two could be separated; qualitative method in relation to data collection and analysis Published in a peer reviewed journal

Appendix 3. Categories for grouping and structuring of how the studies were read

Setting	• Studies based mainly in inpatient settings or reflecting back to this and those based in outpatient/community settings
Participants	• Pathology group/nature of participants
Intervention/ exposure	• Studies with either contemporaneous comments about the early stage of rehabilitation or overtly reflected back to this • Studies where participants commented on the receipt of exercise/therapy specific to the paper and those where participants commented on having been in receipt of exercise/therapy at some stage in the past • Studies where participants had been part of a group and then progressed to independent exercise
Other	• Studies where participants commented particularly on the practical aspects of engaging/adhering • Studies where participants commented particularly about the psychology of engaging/adhering