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Beyond standard rehabilitation programs: training people with MSs for adequate goal setting and rehabilitation treatment evaluation

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Key words:

People with MS activation, Shared decision making; Goal setting, Empowerment.

Abstract

Shared decision making occurs when the decision is 'preference sensitive'. It consists of identifying the different treatment options, including a 'do-nothing' approach (choice talk), considering the advantages and disadvantages of each option (option talk), and then supporting making the decision in the light of an individual's experiences and values (decision talk). It is most effective when working with an 'activated people with MS', that is, one who is prepared for the shared decision making role.

In rehabilitation nearly all the decisions are preference sensitive and working with people with MSs to decide what works best for them is an ethical imperative. These decisions may be framed as 'goal setting'. Skilled clinicians can support people with MSs to learn goal setting skills until the person has the skills to maintain health supporting behaviours most of the time, only seeing a clinical team at times of change or crisis. The steps in goal setting can be summarized as building empathy, creating a contract, identifying people with MS priorities, summarising the conversation, articulating the goal, defining actions, building coping plans and then reviewing progress.

Working with people with MSs can extend beyond working with individual people with MSs about their individual needs to a consideration of what people with MSs want from services. This can result in the co-production and co-design of services, as well as the identification of research priorities as exemplified by the James Lind Alliance.

Introduction

There is little doubt that the conversations in MS clinics have changed in the last 10 years. Two key reasons for this are the increase in the availability of effective treatments but also a change in the relationships between people with MS and health care professionals. Effective treatments extend beyond the significant advances in disease modification, but also include a wider range of approaches to symptom and disability management. Successful rehabilitation aims to support an individual in their personal and social roles, by managing the underpinning pathology, symptoms, and disabilities and where possible modifying the environment and other contextual factors.

A recent Cochrane review suggested that exercise and physical activities improved strength, mobility, reduced fatigue, and improved quality of life, that in-patient and out-patient multidisciplinary rehabilitation programmes led to gains at the levels of activity and participation, and interventions that provided information improved patient knowledge. In addition, there is evidence that targeted interventions can improve mood and tone [1].

Typically people with disabling MS have multiple interacting problems. Managing these problems effectively demands input from a multidisciplinary team focused on what it is the patient wants to do, and what is important to them. Goals, therefore, can be set at the level of actions, intentions, or values. The value may be 'being a good parent', the intention 'taking my son to football' and the actions include 'taking my baclofen', 'doing my exercise programme', or 'buying a light-weight chair, I can sit in while watching'. With this is mind, the evidence base around individual therapy approaches may need to be modified in the context of 'what works' for the individual. Goals allow clinicians to identify what has changed for the person with MS as a result of their intervention.

The relationship between people with MS and clinicians has also changed. People with MS have higher and more diverse demands of services. The use of technology means that people with MS have greater access to information and arrive in clinic with perspectives on the management that they want. Technology also increasingly means people with MS are able to feedback about their experience of service [2]. At the same time, the demands on health services continues to increase, so that people with MS need to be supported in self-management [3]. This suggests that the hall-marks of excellent MS services are going to be shared decision making [4, 5], and supported self-management [3]. It also suggests that patient input will extend beyond the individual experience to input into service design, development and evaluation [6].

Shared decision making

Supporting people with MS in shared decision making starts early in the patient-clinician relationship. The changes in the number and availability of disease modifying treatments for multiple sclerosis mean that the person with multiple sclerosis is aware that there are different options, and has to decide, informed by their multiple sclerosis specialist of the availability, risks and benefits of each drug, what treatment is best for them [7].

The ideal situation for shared decision making occurs when there is a clear decision to make, the person with MS has questions, evidence-based decision support tools are available and the health care professional has been trained in supporting shared decision making, including how to communicate risk for people at all levels of health literacy. When this conversation works well, the person with MS is an 'activated patient' [3] and the health care professional skilled in shared decision making conversations.

Sometimes the conversation does not go so well. The person with MS may be too anxious or distressed to be able to retain the information they are given, they may lack the cognitive or social skills to ask clarifying questions, or express their concerns, they may have been taught that 'doctor knows best', and that they should conform to a patient role deferring to clinicians. They may perceive clinicians as authoritarian and be concerned about being seen as a 'challenging' patient. Despite their best efforts, clinicians may communicate poorly. The information is complex, the environment intimidating, time is short.

Patient activation.

Patient 'activation' describes the knowledge, skills and confidence a person has in managing their own health and health care. The 'activated' patient is one who has prepared for the clinic visit. They have prepared questions, they are aware of treatment guidelines, and they will be persistent in ensuring they receive the best possible care. There is evidence the more disabled the person with MS, they more they want to engage in this shared decision making [8]. Such patients typically have more positive experiences of care, with better conversations with health care professionals. They are also more likely to adhere to medication regimes and to engage in self-management activities such as regular exercise. They report fewer care co-ordination difficulties [3].

Four levels of patient activation have been described [9]. At the lowest level individuals may feel unable to manage their own health. They will be passive recipients of care, and not understand their role in the care process. This may be a common situation at diagnosis, when individuals have little background understanding, are rapidly acquiring a new vocabulary, are experiencing multiple new symptoms, and have spoken and unspoken anxieties and fears. If they are well supported during this period they will stop being so passive but may still lack the knowledge and confidence to manage their own health. With further education and support individuals will take action, but may lack the confidence and skill to maintain these behaviours. Finally, they can acquire the skills to maintain health supporting behaviours most of the time, only needing input at times of particular stress.

Little has been written about patient activation in MS, but there is a significant literature on self-efficacy [10,11], which is the belief in one's ability to succeed in specific situations or accomplish a task [12]. Self-efficacy can play a major role in how one approaches goals, tasks, and challenges [13]. The 'activated' patient will have high self-efficacy. Self-efficacy is

supported through encouragement or coaching in the context of good patient-clinician relationship, previous experience of success in an easier or related task, vicarious learning which may include peer support, and the physiological and emotional feedback experienced by the individual during task performance. Self-efficacy can be increased by fostering and focusing on goals likely to result in success (mastery experiences); encouraging individuals about their capability to achieve goals (verbal persuasion); raising awareness that people with similar problems have succeeded in meeting similar goals by sustained efforts (modelling); correcting misconceptions about physical states that may deter the individual from pursuing a particular goal, e.g. explaining that some fatigue following exercise is to be expected (re-interpretation of symptoms).

Standardised and group based rehabilitation programmes have the advantages that they are relatively straightforward to deliver, and can result in clear benefits, for example, in strength and mobility. However, they run the risk of not supporting self-management, or building self-efficacy. A time limited exercise programme, delivered in a clinical setting, may not translate into regular daily exercise. Indeed, it may result in a passive approach because the individual believes that they can only exercise in a clinical setting, or with supervision from a physiotherapist. In contrast, there have been studies that demonstrate that it is possible to use groups to raise the level of activation, build self-efficacy and support self-management. These studies often focus on people with MS learning new skills such as fatigue management. Fatigue management groups that are based on self-efficacy focus on education, coaching, shared vicarious experience, and goal setting. These and other programmes start with the individual persons understanding of their problems and their context, encourage the individual to make choices and change behaviours. As they obtain success, they gain mastery, confidence and the ability to set and pursue their own goals [13]. In this sense the need for exercise and other rehabilitation programmes to include self-management approaches is important [14]

In the context of an MS service it is worth considering how the MS population can be segmented on the basis of both disease burden and levels of activation. People with MS with high levels of activation and low disease burden may be supported with information provision and electronic resources. People with MS with high levels of activation and moderate disease burden may be managed with peer support and group intervention. In contrast, people with

MS with low levels of activation and high levels of disease burden, demand one to one work with skilled team members [15].

Shared decision making with an activated patient results in a number of benefits including improved knowledge and understanding, better treatment adherence, improved confidence and coping, improved health behaviours and more appropriate service use [3,4]. Where clear choices exist between one treatment option and other, a decisions options tool can be developed [16], such as the MS options tool [17]. These tools focus on working together as a team to identify the options, identifying the risks and benefits, and then choosing the correct option for that individual in the light of their personal context and values.

Goal setting

In rehabilitation, however, there is often little robust evidence and nearly always choice. It is the individual's preference, their values and beliefs that will inform the best course of action. In this case, the language changes and we discuss 'goal setting' rather than 'shared decision making'. Goal setting describes a process of discussion and negotiation in which the person with MS and staff determine the key priorities for that individual and agree the performance level to be attained by the individual for defined activities within a specified time frame. There is little evidence that goal setting improves activity, participation or functional outcomes, but there is limited evidence that that more structured goal setting results in higher levels of self-efficacy [18]. The focus on SMART goals, which may be appropriate for identifying workplace performance, may be responsible for the failure to demonstrate benefit [19]. Evaluation has been around short term functional outcomes, not around sustainable long term change in behaviour or belief. This contrasts with the evidence around shared decision making which suggests that it can result in improved health behaviours and effective service use [3,4]. The evaluation of shared decision making, unlike that of goal setting, has not focussed on functional outcomes, but has focussed on behaviours.

However these conversations are described, the essence of the goal setting activity is to support the person with MS to identify their priorities so they can function better in their personal and social context, i.e. to support self-management. Thus, while many people will self-manage very successfully in a range of domains where they already have expertise, skilled self-management is the behaviour that follows the acquisition of a range of knowledge and skills. For example, at diagnosis, many specialist MS nurses will support people with MS in

approaches to disclosure about the diagnosis within the work-place. This is a skill which demands knowledge but supports self-management within the workplace. This can be framed as a goal, if that works for an individual patient. Later, specialist continence advisors may teach people with MS how to self-catheterise. Again, this is a self-management skill that could be framed as a goal. Being able to describe fatigue to colleagues, to understand the contribution of various factors to fatigue, to take steps to manage these are all self-management skills. Thus, goals could be set around the different levels of knowing, understanding, and implementing specific skills, as well as being able to recognise when the skills are no longer effective, and need refinement. Each level demands higher levels of engagement and activation.

One of the key aspects of both goal setting and shared decision making is an active partnership between an individual patient and professional staff where both have an understanding of the framework within which they are operating, and the use of decision support tools. This means that goals will be led by the patient rather than the health care professional. It is tempting for health care teams to allocate goals to particular professions, for example, walking is a physiotherapy goal, washing and dressing an occupational therapy goal, and urinary continence belongs to a specialist continence nurse. This approach is supported by the idea the goals are stepping stones with each step leading to the next. However, most goals need coordinated problem solving from the person with MS and the multidisciplinary team. For example, for a person who is getting out of bed on multiple occasions at night to go to the toilet, may need support from the nurse (appropriate mattress) physiotherapy (bed mobility, sit to stand, walking), occupational therapy (provision of equipment. Goal setting in this context demands a patient-centred multidisciplinary team, with a shared view of the individual's impairments and contextual factors. Only then can patient-centred goals be set. Such teams need to recognise the expertise and contribution of all individuals and identify a key-worker who acts as team co-ordinator and communicates with the patient. This means that teams need to have a shared vocabulary such as the WHO international classification of function, a structure for communication, and a forum for meeting. This is relatively straightforward for in-patient teams, more difficult for out-patient teams and challenging for community based teams. Dynamic virtual teams springing up

around an individual patient, using electronic means to share information, and teleconferencing can be an effective approach to managing these difficulties.

There are a number of formal goal setting tools, such as the Canadian Occupational Performance Measure (COP-M) [20, 21] , and the Goal - Action Planning (G-AP) framework [22] but if the aim is to support the individual in a change of behaviour which in long term supports self-management, then the core steps may be similar whatever the goal. These steps are described below and within them the potential intervention points.

Step 1. Development of trust

The first step in shared decision making is the development of trust. In clinical practice trust is a complex phenomenon. There are multiple components but credibility, reliability and empathy are key elements. Credibility may be the easiest to establish, being registered as a specialist after a rigorous training, having registration and validation systems around continuing professional development, working in a centre of excellence all offer credibility [23]. Reliability is more complex. It may be based on a match between patient expectation (what they hope will happen), entitlement (what should happen) and experience (what actually happens) [24]. Trust will be more difficult to develop if the system is unreliable. Long waits [25], cancelled clinic appointments, unexpected changes in the health care team, will undermine the patients' perceptions of reliability.

Empathy is also important in building trust. These conversations between clinicians and people with MS may set the scene for the long term relationship over the course of the disease. Listening carefully to the individuals narrative allows the clinician to understand what has happened [26] and what that means to the individual, in the context of their values, aspirations and goals. Experienced therapists highlight that goal setting is about the conversation, not the outcome [27]. As in any long term relationship trust can grow or it can breakdown. When it grows, people with MS and their MS specialists are able to work together to plan the next steps in management and evaluate the impact of treatment.

Step 2. Goal setting.

Once trust has been developed the person with MS is more likely to tell the health care team what it is that is worrying, what they want to happen now, and what is important to them in the future.

The next steps in shared decision making are described as negotiated agenda setting and prioritizing. Within this there will be information, communicating and management of risk, and then summarising and making the decision.

Each of these stages may be operationalised within a goal setting framework, and each one can be considered an opportunity to moving the individual with MS along the pathway from a passive participant in their care to an active one with the skills to self-manage. Supporting the patient to do so demands coaching skills. Patient activation and shared decision making will lead to an individual who is able to set goals that support self- management, and lead to better outcomes.

Step 2.1 Establish a contract: The first element of this, which is often neglected, is preparation for the work that will be done together. In coaching terms, this would be establishing the contract, which includes an explanation of the process, and the ideas of accountability for both the individual with MS and clinician [28]. It should describe what is meant by goal setting framing it as a collaboration, what the individual with MS can contribute (experience of the illness, their personal context, values and beliefs), what the clinician will do (bring knowledge about the disease, and services), what the service can and cannot offer, and that all options will be considered in terms of the risks and benefits, advantages and disadvantage, before a decision is made.

Step 2.2. Prioritize. The next step is a conversation about what is important to the individual with MS. Different approaches can be used to do this. Goal setting tools such as Canadian Occupational Performance Measure may help frame the conversation [20]. One of the earliest goal setting tools was Wade's Life goals questionnaire [29]. More recently people have used an approach based on acceptance and commitment therapy, particularly in the context of mood disorder [30]. Value-based goals may be seen as a profound motivation for positive change, and some people with MS will want to focus on value driven goals. However, for some individuals it is easier to focus on small, 'SMART' goals, particularly if they are feeling overwhelmed. Linking lower-order goals or activities with higher-order values will help self-regulation.

Step 2.3. Negotiate the next steps. These need to be tailored to the individual's degree of activation, and readiness to change. Goal difficulty will vary from person to person. Some people enjoy challenging goals, others are frightened by them. People with MS with lower levels of self-efficacy who are less activated may want to take very small steps where they are likely to experience success. If the individual is made anxious by goal setting then 'microgoals' may be helpful, as may summarising what has been achieved in each session. Challenging goals may not be achievable but there is no evidence that 'failing' goals is bad for people. Goal disengagement is normal [31].

With patients with lower levels of activation the clinician needs to focus on building self-awareness and understanding behaviour patterns, and begin to build self-efficacy through small steps, recognising that not everything has to be tackled at once. Once an individual has experienced success they may be able to take larger steps. What is important is the relationship with the higher order goals, as this makes the goal meaningful. For example 'walking for 6 minutes on treadmill' may be a lower order goal which is achievable, but which may be boring and unmotivating unless it is associated with a larger goal of 'being able to walk in the park with my children'

Step 2.4. Summarise the conversation, and articulate the goal. At this stage it may be clear the person with MS has identified the issue they want to address, but are not sure if they are able to do so. Identifying two goals can be helpful, of which one is a 'do nothing' goal.

Step 2.5 Develop coping strategies, or 'if-then plans'. These recognise the experiences people have previously had can help them identify potential barriers to goal achievement and support persistence towards the goal [32, 33]. Once the behaviour is embedded in everyday life then the coping strategies need to focus on difficult situations such as a deterioration in function caused by infection, or disease progression.

Step 3. Goal review. Having achieved the goal, undertake a review. What happened, what went well, what worked and what did not work for a particular person and feed this information into the next set of goals. At this stage the coach might support patient activation by reflecting back to the individual what they have done well and build on that. These positive affirmations recognise what the person with MS has already done and are important because they build self-efficacy. Further goal reviews can take this further. The

behaviour can be fully developed, so that the final stage results in identifying strategies that the individual can use if they lose confidence or the ability again.

Box 1. Examples of goal setting talk

Building Empathy

Please tell me what has been happening to you?

What do you think would be helpful?

What are you concerned about?

What were you hoping for from coming to the clinic today?

Creating a contract

We work through a process called goal setting. Goal setting allows us to work together. You tell us what is important to you, and what you want to work on now. We can then work out together how to make that happen, what you need to do, and what I need to do. Normally we work by meeting more often at the beginning, say, every two weeks, and then less frequently as time goes on. When we meet we can review what has been happening, what's worked well, what hasn't worked so well, and plan the next steps. Does that sound about right to you? Or do you think we should meet more or less often?

Prioritise

Talk me through a day…

What is easy, what is more challenging, what would you like to change?

Summarising the conversation

I think you have bought the goals questionnaire with you, that's really helpful. If there is one thing that we could work on what would it be?

So, if I have this right the most difficult thing is…

But the most important thing is being is…..?

Articulating the goal

So the goal would be for ….

And the critical thing would be bringing your tone under control, and making your walking easier?

On the one hand you want to do this, or the other hand, you think it may not be possible because…. What would happen if you did nothing?

How would you like me to describe this goal?

Actions

I will ….

The therapist will see you and ….

You will ..

Everyday, when you do this, you will also….

If then plans

If this occurs, instead you will do….

Goal review

What worked well? What was more difficult? What have we learned?

I know ….. was a real challenge for you, and you have done really well.

Do you think now is the time to try….?

That went really well. Now is the time to put that in the diary and make a weekly commitment.

I am impressed by the way you have stuck to that goal. It shows real commitment.

How can we build on this?

Let's think about what you could do, if you start to find this difficult again.

Patient engagement

Activated patients may also provide insights into the service as well as their individual treatment. Stanisewska and colleagues [34] have produce a conceptual framework; the Warwick patient experiences framework, which highlights patients as expert participants, the responsiveness of the service, the lived experience, continuity of care and relationships, communication, information and support. This may be used to support an agenda around the development and evaluation of treatments and services and focus on outcomes important to patients.

This suggests that if patients were true partners in their own health care they would be actively involved with the commissioning, design, delivery, management, monitoring and evaluation of services [35]. There are examples of elements of this in different settings but at present in most areas people with MS are not engaged in the development and delivery of services. More effective partnership has the potential to improve services by utilising the expertise of people with MS. engaging with patient networks such as the MS societies, creating a wider range of services and thus more choice and by reducing waste by not delivering unwanted or unnecessary services [35].

The research process can also benefit from active engagement of people with MS. Focusing on specific conditions or healthcare settings, the James Lind Alliance (http://www.jla.nihr.ac.uk/) facilitates priority setting partnerships which bring together

patients, carer and clinician as equals to identify and prioritise important treatment uncertainties. This results in a list of jointly agreed research priorities which then shapes the research agenda.

This shaping of the clinical and research agenda will also demand the use of patient reported outcomes. The MS in the 21st Century Steering Group devised a set of themes that require action with regard to patient engagement in MS, including increasing the importance placed on QoL and patient concerns through patient-reported outcomes (PROs) [36]. Traditionally PROs have been developed in many chronic conditions by exploring a specific construct with patients and experts. The measure is then assessed in terms of its psychometric properties. This may lead to items being discarded because they are redundant in measurement terms. However, this can mean that the measure, while an excellent measure, does not capture issues that are important to patients. If this measure is then said to evaluate a service then the danger becomes that the service evolves to fit the measure and does not address issues of importance to people with MS.

Thus the first question is what health outcomes should be measured. There are two potential approaches. First, patient involvement in determining which outcome is measured by including all the patient suggestions; and second, patient involvement in determining which outcome is measured by working with people with MS help develop frameworks or domains.

A recent study with patients of clinical genetics services highlighted that patient benefits from clinical genetics could be summarized using a new construct, empowerment [37-39] defined as the beliefs that one:(1) Can make important life decisions in an informed way (decisional control). (2) Has sufficient information about the condition, including risks to oneself and one's relatives, and any treatment, prevention and support available (cognitive control). (3) Can make effective use of the health and social care systems for the benefit of the whole family (behavioural control). (4) Can manage one's feelings about having a genetic condition in the family (emotional regulation). (5) Can look to the future having hope for a fulfilling family life, for oneself, one's family, and/or one's future descendants (hope).

MS services that work with people with MS to deliver such outcomes would be a highly effective services. Empowered people with MS engaged in their own care, and across the spectrum of commissioning, design, delivery, management, monitoring and evaluation of services and research should result in the best possible outcomes for themselves and others.

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