



## The role of expectations and future-oriented cognitions in quality of life of people with multiple sclerosis: A systematic review

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### ABSTRACT

**Purpose:** Multiple Sclerosis (MS) is a highly variable condition characterised by uncertainty of disease course which can make formation of expectations about the future difficult. This systematic review aimed to examine associations between expectations, or Future Oriented Cognitions (FOCs), and Quality of Life (QOL) in people with MS (PwMS).

**Methods:** Following PRISMA guidelines, literature up to October 2019 was searched using Medline, EMBASE, PsycINFO and Web of Science. Quantitative studies that investigated relationships between FOCs and QOL in PwMS (assessed using a standardised QOL assessment) were considered for inclusion. After data extraction, results were analysed using narrative synthesis, focusing on the valence of FOCs (positive, negative, unvalenced). Quality appraisal was conducted using the Mixed Methods Appraisal Tool (MMAT). All stages of the review were patient-led by a person with MS.

**Results:** A total of 13 studies met the review inclusion criteria, with a combined sample size of 4,179. Of these studies, 11 involved measures of positive FOCs, most commonly self-efficacy, one measured a negative FOC, with one FOC unclassified. Nine studies found significant associations between QOL and self-efficacy. Although other positively valenced constructs were less frequently reported, significant associations with higher QOL were also evidenced.

**Conclusions:** Identifying ways to foster positive FOCs, particularly self-efficacy, may have beneficial effects on QOL. More research is needed to understand the impacts of negative FOCs on QOL to determine whether these processes could be meaningfully targeted in interventions.

### 1. Introduction

Multiple sclerosis (MS) is a long-term neurological condition experienced by over 2 million people worldwide (Wallin et al., 2019, Magyari and Sorensen, 2019). While typically diagnosed in early adulthood, initial symptoms can occur at any stage of the lifespan, with women more than twice as likely to be affected as men (Wallin et al., 2019, Gilmour et al., 2018). Symptoms of MS are highly variable and can include fatigue, pain, and problems with vision, cognition, bladder function and mobility (Brownlee et al., 2017), with levels of impairment ranging from mild to moderate or severe (Confavreux et al., 2000). Although approximately half of people with MS (PwMS) require ongoing

care and support (Maguire and Maguire, 2020), advances in treatment in recent years have enabled many to live independently and manage their symptoms (Brownlee et al., 2017). Conversely, some PwMS may continue to experience losses to quality of life (QOL) despite successful disease management (Zwibel and Smrtka, 2011, Benito-Leon et al., 2002, Mitchell et al., 2005). In addition to clinical health status, a range of complex social, psychological and contextual factors influence QOL (Benito-Leon et al., 2002, Yamout et al., 2013, Yalachkov et al., 2019). Identifying these factors is an important goal when considering how best to support PwMS.

One potentially significant set of factors that may influence QOL in MS is the expectations that people hold about the future, or more

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broadly what could be termed “future-oriented cognitions”<sup>1</sup> (Bubić and Abraham, 2014). In a healthcare context, expectations may be formed in relation to the processes of treatment, the outcomes of treatment, or general management of illness (Crow et al., 1999). The benefits of positive expectations on patient satisfaction, through observation of the placebo effect, are well-established (Stewart-Williams and Podd, 2004, Thompson and Sunol, 1995). Aside from treatment expectations however, there are a range of other FOCs experienced by PwMS that may potentially influence QOL. Given the unpredictable nature of the condition, it is not uncommon for PwMS to experience feelings of uncertainty about what the future may hold, in terms of their long-term prognosis, individual capabilities, or their likelihood of experiencing symptoms on a day-by-day basis (Alschuler and Beier, 2015, Boeije and Janssens, 2004). This may be exacerbated by a lack of support in the healthcare system, or through inadequate provision of information. For example, research from the UK indicates that while the vast majority of PwMS expressed desires to learn of their long-term prognosis, almost half reported never having a conversation about this with health care professionals (Dennison et al., 2016, Dennison et al., 2018). This uncertainty may lead to feelings of worry or anxiety about the future, which may in turn impact negatively on QOL. Furthermore, uncertainty regarding the effects of treatment has been cited as one of the main reasons for PwMS delaying starting on a disease modifying therapy (Visser and van der Zande, 2011), with potential deleterious consequences for longer term health.

Studies in other patient groups have demonstrated how expectations or FOCs may impact on patient wellbeing and QOL more generally (Geurts et al., 2017, Janzen et al., 2006). It is clear that fostering accurate expectations about treatment and potential effects can be of benefit (Crow et al., 1999). Conversely, negative FOCs can lead to poorer patient outcomes. For example, fear of recurrence (FoR), which has been extensively studied in cancer survivors, has been shown to impact QOL independently of clinical health status (Crist and Grunfeld, 2013, Maguire et al., 2018). Evidence suggests that interventions targeted at reducing FoR in this population can have positive implications for survivors (Hall et al., 2018). Similar effects may be evident for PwMS in relation to worries over relapses or general progression, but the experience of fear in this group remains understudied.

To our knowledge, there has been no attempt to review how expectations and FOCs are associated with QOL in the MS population. The present systematic review aims to address this gap. Building on existing theoretical frameworks (Thompson and Sunol, 1995, Geurts et al., 2017, Kravitz, 1996), we hypothesise that a range of expectations or FOCs may be experienced by PwMS. Thoughts about the future may be unvalenced (e.g. simple predictions of likelihood of certain events or outcomes), positive (e.g. feelings of optimism, hope, or levels of confidence/self-efficacy in future capabilities), or negative (e.g. worries or fears in relation to future health or prognosis). While the distinction between unvalenced and positive FOCs is similar to that made previously between “predicted” and “value” expectations (Geurts et al., 2017), we also aim to capture associations between negative FOCs and QOL, given their known associations in other populations. As expectations and FOCs may be amenable to change, these factors merit investigation when considering interventions aimed at enhancing QOL in PwMS.

## 2. Method

The methods reported below adhere to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (see supplementary material for PRISMA checklist). The focus of the review was patient-led, having been conceptualised by the first author, who has MS. The protocol was presented at the MS Frontiers Conference in July

2019 (Maguire et al., 2019).

### 2.1. Search strategy

Search terms were identified relating to (1) MS, (2) Expectations/FOCs, and (3) QOL (see example of search in supplementary material). Given the lack of a clear consensus regarding the nature of expectations (Geurts et al., 2017, Janzen et al., 2006, Coulter, 2006), a broad range of search terms relating to FOCs and patient expectations was developed based on previous research. PsycINFO, PubMed, EMBASE and Web of Science databases were initially searched from inception to April 2019, and subsequently searched up to October 2019. Searches involved a combination of free text words or exploded subject headings using MeSH, Emtree, or PsycINFO thesaurus. Reference lists of included papers were later hand searched to identify other relevant studies.

### 2.2. Eligibility criteria

In order to be included in the review, studies were required to: (1) report primary quantitative data from an adult sample of PwMS, (2) include a standardised measure of QOL, (3) have at least one measure of an expectation or FOC, and (4) examine the relationship between the QOL and FOC measure(s). Studies with sample sizes of <30 participants, validation and feasibility studies, material published in outlets other than peer-reviewed journals, and reports in languages other than English were excluded.

### 2.3. Screening

Results from the database searches were imported into the systematic review software Rayyan (Ouzzani et al., 2016) and duplicates were removed prior to screening. Titles and abstracts of studies were then screened by two reviewers (RM and BMCK or NK), with a third (DD) in cases of conflict. Any disagreements were discussed until consensus was reached. Full-texts of articles were then obtained and assessed against the eligibility criteria by two reviewers (RM, BMCK), with a third in case of conflict (DD).

### 2.4. Data selection and extraction

The following data were extracted (BMCK, RM) from the full-texts of included studies, where available: study aims, design, country setting, characteristics of sample including sample size, gender, age, and MS characteristics (e.g. proportion of those with Relapsing Remitting MS (RRMS), level of disability, or time since diagnosis (TSDX)), FOC or expectation measure(s) used, QOL measure used, and results obtained, including other contextual information that may be relevant to the interpretation of results.

### 2.5. Quality Appraisal

In order to assess the methodological quality of the included studies, each was assessed using the Mixed Methods Appraisal Tool (MMAT) by RM and DD, which includes appraisal criteria for a variety of study designs (Hong et al., 2018). The MMAT comprises two initial screening questions, followed by five design-specific questions (which differ for quantitative descriptive studies, randomised control trials, non-randomised control trials etc.). While it is not advised to use the MMAT to produce scores (Hong et al., 2018), we adopted the following approach as a proxy for methodological strength: 4-5 criteria met = high quality, 2-3 criteria met = moderate quality, and 0-1 criteria met = low quality. MMAT scores were not used as a basis to exclude studies, but rather to indicate methodological quality.

<sup>1</sup> Hereafter, we refer to Future Oriented Cognitions as FOCs

2.6. Synthesis of findings

Following data extraction and quality appraisal, the results were analysed using a process of narrative synthesis (RM). Due to the observed heterogeneity of QOL measures and designs employed, a meta-analysis was not deemed appropriate. The process of narrative synthesis first involved categorising the FOC measures as being either, (1) an unvalenced expectation, such as judgement of likelihood about the future, (2) a negative expectation, such as fears or worries about the future, or (3) a positive expectation, such as hope, optimism or confidence in capabilities. In certain cases, these categories were subdivided further to capture subtle differences in measures (e.g. measures of MS specific vs. generalised self-efficacy). Each set of factors was assessed in terms of its relationships with QOL.

3. Results

Database searches gave rise to 3,952 articles; removing duplicates (n=848) left 3,104 to screen. Of these, a further 2,993 were excluded. Full-texts of the remaining 111 were assessed for eligibility, with 11 meeting the inclusion criteria (see PRISMA diagram, Figure 1). The most common reasons for exclusion were failure to assess the relationship between an FOC and QOL or the absence of a peer-reviewed full text. Reference sections of the 11 included studies were examined, leading to the identification of two additional studies. Thirteen studies were therefore included in the final narrative synthesis, with summary information displayed in Table 1.



PRISMA 2009 Flow Diagram

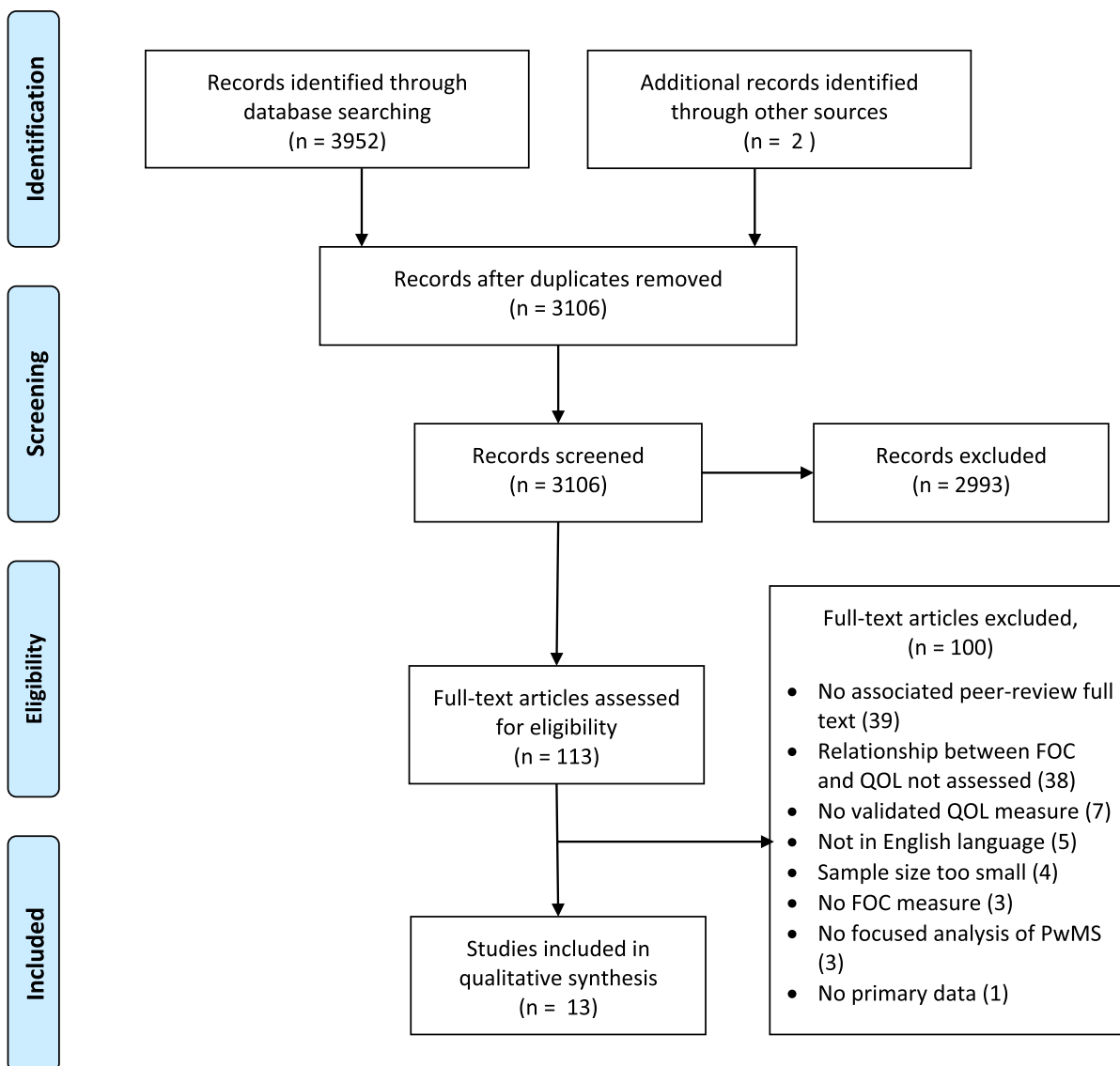


Fig. 1. PRISMA 2009 Flow Diagram

**Table 1**  
Studies included in review

Study	Aim	Design	Country	N PwMS (% female)	Age (M years)	MS characteristics	FOC measure(s)	QOL measure	MMAT score	
(Arnoldus et al., 2000)		To determine QOL of MS patients during initial 6 months of treatment with IFJN-b.	Longitudinal	Netherlands	51 (76%)	35.1	100% RRMS; EDSS 3.7	Therapeutic expectation score (seven item)	Health status questionnaire (SF-36)	3
(Calandri et al., 2018)		To describe levels of depression, positive and negative affect, optimism and HRQOL in a group of recently diagnosed PwMS.	Cross-sectional	Italy	60 (61%)	37	95% RRMS; EDSS 1-4; TSDX <3 years	Life Orientation Test-Revised Self-efficacy in MS scale	Health status questionnaire (SF-12)	2
(Goodworth et al., 2016)		To examine the contributions of patient demographic and psychosocial variables to activation levels in PwMS.	Cross-sectional	USA	163 (82%)	46.24	69% RRMS; TSDX (M)=8.3 years	Patient Activation Measure-13 MS Self-Efficacy Scale	Leeds MS QOL scale	3
(Hayter et al., 2016)		To examine the effect of health anxiety on MS patients' QOL.	Cross-sectional	UK	84 (% F not reported)	not reported	100% RRMS;TSDX<10 years; low disability	Modified version of Health Anxiety inventory	QOL index	3
(Messmer Uccelli et al., 2016)		To assess self-esteem, self-efficacy, mood and quality of life in a group of young adults with MS.	Cross-sectional	Italy	89 (84%)	24.2	TSDX (M) 5.3 years; minimal disability	General self-efficacy scale	WHO-5 well-being index	3
(Motl et al., 2013)		To examine associations between individual-level changes in physical activity, self-efficacy and HRQOL over one-year period.	Longitudinal	USA	254 (88%)	45.9	100% RRMS; TSDX (M) 10 years; Mean EDSS 2	MS Self-Efficacy Scale	MS Impact scale	4
(Motl et al., 2009)	To examine variables that might account for relationship between physical activity and QOL in PwMS.	Quasi/cross-sectional	USA	292 (87%)	48	84% RRMS; TSDX (M) = 10.3 years	MS Self-Efficacy Scale Exercise self-efficacy scale	Leeds MS QOL scale	4	
(Penwell-Waines et al., 2017)		To test the Health promotion model in explaining self-reported adherence and MS QOL.	Cross-sectional	USA	121(85%)	45.4	75% RRMS; TSDX (M) = 10 years	Self-efficacy for managing chronic disease	Leeds MS QOL scale	3
(Riazi et al., 2004)		To examine the role of self-efficacy in predicting self-reported health status in MS among two groups.	Longitudinal	UK	89 (70%)	45.4	80% RRMS (EDSS=5.8) in steroid group & 23% (EDSS=7.2) in rehab group; TSDX 12 years in both groups	MS Self-Efficacy Scale	MS Impact scale	5
(Spain et al., 2007)	To determine the relative importance of individual factors in HRQoL, in particular the role of illness perception.	Cross-sectional	Australia	580 (79%)	46.7	54% RRMS; TSDX (M) =8.5 years	Illness Perception Questionnaire (treatment and personal control subscales)	Health status questionnaire (SF-36)	3	
(Stuifbergen et al., 2000)		To test an explanatory model of variables influencing health promotion and QOL in PwMS	Cross-sectional	USA	786 (80%)	47	45% RRMS; TSDX (M) = 10.6 years	Self-Rated Abilities for Health Practices scale	QOL index	4
(Wilski and Tasiemski, 2016)		To examine the role of cognitive appraisals as correlates of HRQoL in MS	Cross-sectional	Poland	257 (67%)	48	37% RRMS; TSDX (M)=13 years; moderate disability	Brief Illness Perception Questionnaire (treatment and personal control subscales) General Self-efficacy scale	MS Impact scale	4
(Wollin et al., 2013)		To explore changes in QOL and psychosocial variables in a large cohort of PwMS	Longitudinal	Australia	1287 (79%)	55	TSDX 13.5 years; 70% did not report change in illness over 2 years; 15% worsened and 5% improved	MS Self-efficacy scale	WHO QOL-100	5

### 3.1. Quality Appraisal

MMAT scores for included studies ranged from 2 to 5, and are provided in Table 1. The majority of studies were of moderate quality (n=7), with common limitations relating to sample representativeness and risk of response bias.

### 3.2. Sample characteristics

A total of 4,179 PwMS participated in the studies reviewed, with sample sizes ranging from 51 – 1,287. The majority of participants across studies were female (79%; range 61-88%), which is broadly consistent with population norms (Gilmour et al., 2018). Participants came from a range of ages, with mean ages from 24-55 years old across studies, although most (n=8; 67%) reported a mean age of 45-48 years. One study failed to report age or gender breakdown. Studies came from various countries, including the USA (n=5), UK (n=2), Italy (n=2), Australia (n=2), Poland (n=1), and The Netherlands (n=1).

In terms of MS characteristics, samples included different patient profiles. Three studies focused on those recently diagnosed (Calandri et al., 2018, Hayter et al., 2016, Messmer Uccelli et al., 2016), which meant a high prevalence of people with relapsing-remitting multiple sclerosis (RRMS) with typically low levels of disability. One study focused on those commencing a particular treatment (Arnoldus et al., 2000), another involved comparison of groups undergoing rehabilitation versus steroid treatment (Riazi et al., 2004), with higher levels of disability evident in the former group. Other studies incorporated a mixture of patients with RRMS, primary-progressive MS (PPMS), and secondary-progressive MS (SPMS), with mean disease duration varying from less than 3 years to 14 years. Expanded Disability Status Scale (EDSS) scores (Kurtzke, 1983) were commonly reported as measures of disability, with mean scores ranging from 2 (mild disability) to 7.5 (severe disability).

### 3.3. Study characteristics

Most of the studies involved cross-sectional research designs, with four involving longitudinal designs (Arnoldus et al., 2000, Riazi et al., 2004, Motl et al., 2013, Wollin et al., 2013). Almost all measured additional variables beyond those of interest in the current study.

### 3.4. Measures employed

Various QOL measures were used, the most common being the Leeds MS QOL Scale (Ford et al., 2001) (n=3), the MS Impact scale (MSIS-29) (Hobart et al., 2001) (n=3), the QOL Index (QLI)-MS version (Ferrans and Powers, 1992) (n=2), and the SF-36 (Ware, 2000) (n=2). Single studies also included the SF-12 (Gandek et al., 1998), the WHO-5 (Topp et al., 2015), and the WHOQOL-100 (Power et al., 1999). It should be noted that, while all these are measures of QOL, they vary in the number of items and/or QOL domains measured; some include subscales (e.g. of mental/psychological and physical health), while others capture a single QOL index.

The FOC construct most frequently measured was self-efficacy, with almost all studies including one measure of this (n=10), including all those studies which were based in the USA. Of the studies measuring self-efficacy, specific measures of MS self-efficacy were used in 5 studies, including use of the MSSE (Schwartz et al., 1996) (n=3), the SEMS (Bonino et al., 2018) (n=1), and the MSSS (Rigby et al., 2003) (n=1). Two studies included the General Self-Efficacy Scale (Schwarzer and Jerusalem, 1995); one used the Self-Efficacy for Managing Chronic Illness Scale (Lorig et al., 2001). Two studies employed self-efficacy measures in specific contexts, namely the Self-Rated abilities for Health Practices Scale (Becker et al., 1993) and the Exercise Self-Efficacy Scale (McAuley, 1993).

Other FOC measures included the “control” subscales of the Illness

Perception Questionnaire (Leventhal et al., 1980) and the Brief-Illness Perception Questionnaire (Broadbent et al., 2006); the Patient-Activation Measure-13 (Hibbard et al., 2005); the Life-Orientation Test (Scheier et al., 1994); an adapted version of the Health-Anxiety Questionnaire (Salkovskis et al., 2002); and a bespoke seven-item measure of treatment expectations regarding beta interferon (IFN-b1). Studies employing these measures were all based in Europe, with the exception of one study based in Australia which examined illness perceptions (Spain et al., 2007). Four studies reported more than one FOC measure (Calandri et al., 2018, Messmer Uccelli et al., 2016, Goodworth et al., 2016, Motl et al., 2009).

### 3.5. Narrative synthesis

We categorised FOCs by their valence (specifically whether they measured positive, negative or unvalenced FOCs/expectations). Table 2 illustrates that most studies (n=11) measured positively valenced FOCs, including self-efficacy, optimism, patient-activation, or personal/treatment control. Nine out of the 11 studies measuring positive FOCs demonstrated significant relationships with QOL. In contrast, one study (Calandri et al., 2018) found both optimism and self-efficacy to relate to mental health, but the association was not evident with physical health, and self-efficacy did not predict QOL when controlling for other known associates. There was mixed evidence for the role of perceptions of treatment control in QOL. While positive relationships were found in one study (Wilski and Tasiemski, 2016), another reported control as a significant predictor of only two subscales of the SF36, specifically vitality and emotional role functioning (Spain et al., 2007), although these differing results may be attributed to the different measures used.

Generally, however, scores indicative of more positive FOCs were associated with better patient QOL in both physical and psychological domains (Wollin et al., 2013, Wilski and Tasiemski, 2016, Motl et al., 2013, Casey et al., 2018). While the majority of studies involved cross-sectional designs, those employing longitudinal designs suggest that positive expectations, specifically MS self-efficacy, are predictive of later higher QOL (Riazi et al., 2004, Wollin et al., 2013, Motl et al., 2009, Motl et al., 2013), and studies employing regression analyses suggest that self-efficacy is an independent predictor of higher QOL when controlling for other known associates (Penwell-Waines et al., 2017, Wilski and Tasiemski, 2016).

Only one study in the review examined a negative FOC in relation to QOL (Hayter et al., 2016); those with higher levels of health anxiety had lower QOL after controlling for degree of disability.

We were unable to obtain the full seven-item measure of therapeutic expectations in relation to beta interferon (IFN-b1) treatment (Arnoldus et al., 2000), so cannot make an assessment of its valence. No significant association between this measure and QOL was found.

## 4. Discussion

In this review, we aimed to systematically investigate associations between FOCs/expectations and QOL in PwMS. The current weight of evidence suggests that thoughts about the future play a role in QOL, although there is still some uncertainty regarding the precise nature of these associations. As we discuss below, shedding light on these processes may aid the development of supports for those living with MS.

### 4.1. Positive expectations and self-efficacy

The most robust finding from studies included in our review is the strong associations uncovered between positive FOCs and QOL. In particular, published research provides good evidence for links between QOL and self-efficacy, including both general and disease-specific self-efficacy (Calandri et al., 2018, Messmer Uccelli et al., 2016, Riazi et al., 2004, Motl et al., 2013, Wollin et al., 2013, Goodworth et al., 2016, Wilski and Tasiemski, 2016, Motl et al., 2009). Broadly speaking,

**Table 2**  
Results summary

FOC Valence	Specific FOC	Significant relationships with QOL (p <0.05)	No relationships with QOL (p>0.05)
<b>Not classified</b> <b>Positive FOCs</b>	Therapeutic expectations		<ul style="list-style-type: none"> <li>(Arnoldus et al., 2000) – no relationship with therapeutic expectations for beta interferon and SF36 scores.</li> </ul>
	Self-efficacy (general)	<ul style="list-style-type: none"> <li>(Messmer Uccelli et al., 2016) – SE correlated with WHO-5 (r=.53)</li> <li>(Wilski and Tasiemski, 2016) – SE correlated with MSIS-29 (-0.419) and, in regression model controlling for other known associates, predicted general HRQoL (beta=-0.22), physical (beta = -0.3) and psychological (beta= -.02) domains of MSIS-29.</li> </ul>	
	Self-efficacy (MS specific)	<ul style="list-style-type: none"> <li>(Calandri et al., 2018) – SE correlated with mental health domain of SF12 (r=.26).</li> <li>(Goodworth et al., 2016) – SE correlated with LMSQL (r=.62)</li> <li>(Motl et al., 2013) – Baseline MSSE functioning and control correlated with MSIS-29 physical (r=.616; r=.615) and psychological (r=.427; r=.602) domains at follow up.</li> <li>(Motl et al., 2009) – SE correlated with LMSQL (r=.73) + predicted LMSQL in regression analysis (ybeta=.07).</li> <li>(Riazi et al., 2004) – Baseline MSSE function and control associated with physical (r=-.56; r=0.61) and psychological (r=-0.41; r=0.61) domains of MSIS-29 at follow up. Regression analyses showed both baseline and MSSE changes to independently predict MSIS-29 scores.</li> <li>(Wollin et al., 2013) – SE at baseline correlated with overall WHOQOL-100 at follow up (r=.71), as well as with the psychological (r=0.71), independence (r=.72) and environment (r=.63) domains. Along with perceived stress and social support, SE predicted WHOQOL-100 in regression model (beta = .18).</li> </ul>	<ul style="list-style-type: none"> <li>(Calandri et al., 2018) – SE not correlated with physical health domain of SF12. Also SE was not a predictor of either mental or physical health when controlling for other factors in regression analysis.</li> </ul>
	Self-efficacy for illness management	<ul style="list-style-type: none"> <li>(Penwell-Waines et al., 2017) - SE predictor of LMSQL after controlling for known associates including anxiety, depression and stigma (beta=-.19)</li> </ul>	
	Self-Rated abilities for Health practices	<ul style="list-style-type: none"> <li>(Stuifbergen et al., 2000) – SE correlated with QLI-MS (r=0.54).</li> </ul>	
	Exercise self-efficacy	<ul style="list-style-type: none"> <li>(Motl et al., 2009) – EXSE correlated with LMSQL (r=.38)</li> </ul>	
	Optimism	<ul style="list-style-type: none"> <li>(Calandri et al., 2018) – optimism correlated with mental health domain of SF12 (r=.33)</li> </ul>	<ul style="list-style-type: none"> <li>(Calandri et al., 2018) – optimism not correlated with physical health domain of SF12.</li> </ul>
	Patient activation	<ul style="list-style-type: none"> <li>(Goodworth et al., 2016) – patient activation correlated with LMSQL (r=.42)</li> </ul>	
	Illness perception (Treatment control)	<ul style="list-style-type: none"> <li>(Spain et al., 2007) – regression analysis controlling for known associates showed small effect on vitality (beta = 0.099) and emotional role functioning (-0.10) subscales of SF36</li> <li>(Wilski and Tasiemski, 2016) – treatment control related to MSIS-29 (r=-.154).</li> </ul>	<ul style="list-style-type: none"> <li>(Spain et al., 2007) – regression analysis did not show effect of control on any other SF36 subscales than those reported.</li> </ul>
<b>Negative FOCs</b>	Health anxiety	<ul style="list-style-type: none"> <li>(Hayter et al., 2016) – difference in QLI scores in low vs. high HAI groups after controlling for disability.</li> </ul>	

self-efficacy is an example of an outcome expectation relating to an individual's confidence in their own abilities, and involves physical, social and self-evaluative components (Morrison and Stuijbergen, 2014, Motl et al., 2009). This confidence may be generalised or domain specific, both forms of which were captured in our review.

In MS, self-efficacy has been researched most frequently in the context of physical exercise (Morrison and Stuijbergen, 2014), but more broadly has been shown to predict self-reported functioning in relation to physical, social and cognitive domains (Schmitt et al., 2014). Papers included in the review used a variety of measures of self-efficacy, suggesting that confidence in a range of future abilities in different domains and at different levels of specificity have an influence on the QOL of PwMS. This is also consistent with early research showing that self-efficacy predicts adjustment to MS more strongly than other outcome expectations (Wassem, 1992), as well as being consistent with the patterning of relationships between self-efficacy and QOL in other patient groups (Bentsen et al., 2010, Mancuso et al., 2010, Cramm et al., 2013).

Other positive FOCs associated with QOL in MS share some overlap with self-efficacy, as they relate to patients' perceptions of control, which may be particularly important in PwMS given the uncertainty of disease course and symptom variability. These may include illness perceptions (Spain et al., 2007, Wilski and Tasiemski, 2016), and patient activation (Goodworth et al., 2016), for example, a patient's expected engagement in their own healthcare management. Two studies (Calandri et al., 2018, Spain et al., 2007) reported inconclusive findings, which might be explained by differences in the measures used. However, taken together, the review's findings suggest that fostering positive expectations in one's ability to manage the effects of MS and treatment may enhance QOL.

Previous reviews of psychosocial interventions in MS have found evidence for the benefits of patient education and goal setting on well-being (Malcomson et al., 2007), both of which might offer ways of increasing self-efficacy. Indeed, increases in positive efficacy expectations could be a key mechanism through which these interventions operate. Further research is needed to understand the optimal delivery of supports in terms of timing and duration, particularly in light of the evolving challenges encountered in MS. Our review suggests that self-efficacy is an important predictor of QOL regardless of disease duration or progression, with associations between QOL and self-efficacy found in studies which varied in the proportion of people with RRMS and progressive MS respectively. In light of these findings, we suggest that identifying ways of (1) encouraging positive efficacy expectations at diagnosis, and (2) maintaining positive expectations throughout the disease trajectory, may be beneficial in helping patients cope with the wide-ranging challenges encountered at different stages of the disease.

Only one study included in our review investigated optimism, with associations between mental, but not physical, QOL domains reported (Calandri et al., 2018). Previous work has pointed to the benefits of optimism in aiding adaptive coping strategies in MS (de Ridder et al., 2000). Other work suggests that the physical health of PwMS depends strongly on positive expectations, including optimistic beliefs (Fournier et al., 2002). This, however, may depend on the controllability of disease. Specifically, when self-care options for controlling disease are limited, positive unrealistic thinking may be of benefit. In contrast, positive efficacy expectations may be more useful when self-care is possible (Fournier et al., 2002). Similar effects have been observed in other chronic illness populations, with optimism showing stronger associations with QOL in those limited by disease, compared to those who are not (Maguire et al., 2019). While our review found similar benefits for self-efficacy expectations in a range of PwMS, including those with progressive forms of the disease, examination of the broader literature implies that the benefits of fostering positive expectations may depend on individual health-related characteristics and other contextual factors.

#### 4.2. Negative FOCs

Only one study which met the review inclusion criteria examined negative FOCs, specifically, the effects of health anxiety on MS QOL (Hayter et al., 2016). This contrasts with research in other conditions such as cancer, where fears and worries about the future are extensively researched in relation to QOL. While MS is a very different illness, patients may experience a range of fears regarding their symptoms and prognosis (Finlayson, 2004), which could potentially be alleviated through the provision of information and support. Although some studies examine such experiences, for example fear of falling (Peterson et al., 2007), more general worries appear to be under-investigated in relation to MS QOL.

We could not classify the valence of one FOC measure (Arnoldus et al., 2000), and no studies in the review examined patients' predictions of prognosis in relation to QOL. This is an issue which is worthy of further investigation as qualitative research suggests that many PwMS form expectations about their prognosis without HCP input (Dennison et al., 2016). A large scale study suggests that preferences for prognostic information may influence QOL (Dennison et al., 2018), suggesting again that the provision of appropriate information may facilitate adjustment for some, but not all, PwMS. Patient preferences are likely to be important in this context. While it has been suggested that delivery of prognostic information may lead to placebo effects (Heesen et al., 2018), we found no studies in our review to support this assumption, at least in terms of QOL impacts.

#### 4.3. Limitations

While we attempted to capture as broad a range of measures of expectations and FOCs as possible, our search terms may have excluded some constructs that could potentially be viewed as FOCs. Our review only focused on the relationships between FOCs and QOL, and did not examine other measures of psychological wellbeing (e.g. depression and general anxiety). Given that these are commonly reported problems in PwMS (Boeschoten et al., 2017, Jones et al., 2012), it is possible that FOCs may also influence these experiences. For example, those with higher risk perceptions have been found to be more bothered by MS-related thoughts, which relates to increased anxiety and depression independently of disease status (Janssens et al., 2004). The heterogeneity of methodologies, sample characteristics and measurement tools employed means that any comparisons made between findings should be interpreted with caution. Our review focussed on quantitative research studies; examination of findings from qualitative research designs may provide a more in-depth insight into the processes involved. Finally, the majority of the studies included involved cross-sectional designs, with only four longitudinal studies. Caution is needed in interpreting possible directionality of these results. While methodological quality was generally high, some studies may have been at risk of bias, particularly relating to the composition of samples.

#### 4.4. Conclusions

Currently, the treatment of MS tends to focus on clinical aspects of the disease and symptom management, with less attention paid to psychological experiences of coping with disease. There is a growing recognition that the expectations patients form about illness may influence a range of outcomes, including health attitudes and behaviours, as well as treatment satisfaction, adherence and decision making (Coulter, 2006). Our review suggests that thoughts about the future may also influence many aspects of QOL in MS, and that recognising this is an important aspect of MS care, especially given the unpredictable nature of the disease. In particular, our findings highlight the importance of fostering positive expectations in patients, including self-efficacy in one's abilities to manage the effects of MS and treatment. These findings have implications for both clinicians and PwMS. For example, based on

these results, we recommend that clinicians acknowledge the feelings of uncertainty that may be experienced by PwMS and carefully consider how to foster positive FOCs regarding treatment and symptom management during consultations, without setting unrealistic expectations. Similarly, we recommend that PwMS identify ways in which they may be empowered to feel in control over aspects of their condition while also learning to accept their diagnosis. While the development of such expectations may be aided by the provision of education and support, needs for these supports continue to be unmet (McCabe et al., 2015). More research into the influence of other forms of expectations, such as negative or unvalenced FOCs, may give further insight into how best to develop interventions tailored at supporting PwMS.

## Declaration of Competing Interest

Authors have no conflicts of interest to declare.

## Supplementary materials

Supplementary material associated with this article can be found, in the online version, at [doi:10.1016/j.msard.2021.103293](https://doi.org/10.1016/j.msard.2021.103293).

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