Spreading HOPE: The Development of a Hope-Based Self-Management Intervention

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Spreading HOPE: The Development of a Hope-Based Self-Management Intervention

by Professor Andy Turner and Dr. Faith Martin

Introduction

This chapter describes the development and evaluation of an innovative self-management program, called “Help to Overcome Problems Effectively” (HOPE). It describes how the HOPE Programme is underpinned by positive psychology and cognitive behavioral theory and research. It further describes the importance of hope in helping to overcome the challenges of living with a chronic impairment and presents preliminary evidence of how the HOPE self-management programme has the potential to benefit people with physical and mental chronic impairment. Finally, the implications of positive psychology for self-management research are discussed and suggestions provided for future work.

Many people living with a chronic impairment want to participate more in their health care and would feel more confident with support and encouragement from their health care provider. However, the majority of individuals feel this support and encouragement is currently lacking (Department of Health, 2005). Confidence about the ability to self-care is crucial to self-management: individuals with lower confidence in their self-care abilities are less likely to seek help, follow guidance, and perform self-management behaviors (Hibbard & Gilburt, 2014). Nearly two-thirds of individuals believe that their confidence about self-care would increase with the provision of support from peers who had similar health concerns (Department of Health, 2005). In the United Kingdom (UK), the push towards greater involvement of individuals in their own care reflects the pressure on the National Health Service (NHS) from the rising number of individuals with chronic impairments. The NHS 5 Year Forward View (2014) identified the important role technology can play in supporting individuals with long-term conditions to be able to better to self-manage their own health, stay healthy, make informed choices, manage their
conditions and avoid complications. The NHS plans to invest significantly in evidence-based approaches supported by *Realising the Value Programme* (2016), which aims to promote evidence-based person-centered approaches to health, such as self-management, peer support, health coaching, group activities, and asset-based approaches.

Clark et al., (2005) suggest that successful self-management requires sufficient knowledge of the condition and its treatment, performance of condition-related management activities, and application of the necessary skills to maintain adequate psychosocial functioning. Barlow (2001, p. 546) defined self-management in the following way:

Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic impairment. Efficacious self-management encompasses ability to monitor one's condition and to effect the cognitive, behavioral and emotional responses necessary to maintain a satisfactory quality of life. Thus a continuous and dynamic process of self-regulation is established.

A broader definition was proposed by Wagner (1998) as articulated in the chronic care model (CCM), which reflected the importance of support provided by the clinician and health service. According to the CCM, one of the main objectives for health services is to support self-management, which needs to be embedded in a system that includes knowledgeable and confident individuals, prepared clinicians, and a responsive and flexible administrative structure (Wagner et al., 2001).

Dominant models of self-management interventions for individuals with chronic impairments have tended to include 5 core components: education about the impairment, psychological strategies to support adjustment, treatment implementation strategies, practical support for daily living and social support (Taylor et al., 2014). These are often delivered within the context of teaching participants how to manage the negative aspects of living with a condition.
using cognitive behavioral therapy (CBT) techniques to break the negative, downward spiral of emotional, psychological and physical despair, and feelings of hopelessness. The reasons why are obvious and understandable, given that many chronic impairments cause significant physical and psychological impairment. This mirrors the overwhelming focus of CBT and other forms of mental-health interventions (e.g., counseling) on pathological and problematic patterns of functioning and behavior. The literature on self-management interventions often reflects this focus on negative pathology and functioning aspects.

Peter Lomas, a psychotherapist has argued for a therapeutic approach, which is more balanced towards recognizing an individual’s strengths and courage and potential for positive change:

We consult a doctor, a psychiatrist, or a psychotherapist because we feel that something is wrong with us. Insofar as he is influenced by the traditional medical model the psychotherapist will, in his turn, also focus on what is wrong; he may make a diagnosis or look for defensive mechanisms. But this is not necessarily the best thing to do to someone who is already ashamed of themselves. It may be more useful to dwell on what is right, to acknowledge and celebrate the courage and ingenuity by which the patient has managed to carve out a life in the face of innate limitations and adverse experience. Contemporary teaching of psychotherapy tends to fail the student by steering him towards the negative (Lomas, 1999, p. 107).

Self-management research and practice, like CBT, has similarly tended to focus more on a person’s pathology and skills deficit. For example, Lorig’s chronic impairment self-management course (CDSMC) (Lorig et al., 1999), which is one of the most established and well-researched, peer-led interventions, is guided by breaking the “negative circle” of pain, fear, anxiety, depression, and fatigue.
Recent papers have called for more published research into the important concept of hope in self-management programs (SMPs) for individuals living with a chronic impairment (Brooks et al., 2015; Veres et al., 2014). In this chapter, the development and evaluation of an innovative self-management program, called “Help to Overcome Problems Effectively” (HOPE) is described. This program, which was co-produced by researchers and service users at Coventry University (Turner, 2010), encourages psychological and behavioral change by fostering positive emotional states such as joy, gratitude and hope. This approach to self-management is to maintain a strengths-based and well-being focus by building skills in living with a chronic impairment. Uniquely in self-management research, the HOPE programme draws on positive psychological and psychotherapeutic approaches including Snyder’s hope theory (Snyder, 2000). Neither a psychotherapeutic nor a positive psychological understanding and analysis of self-management have been well-articulated and developed. The similarity in outcomes and processes between self-management, group psychotherapy, and positive psychology suggests that these prove useful cannons of work with which to inform and improve self-management research, theory and practice.

**Hope Concept and Definition**

In contemporary mental health practice, a recovery orientation has evolved in which hope is a central concept (Slade & Hayward, 2007). Hope is considered central to the concept of personal recovery from mental health difficulties, both as a trigger and as a maintaining factor, because hope helps individuals to find the courage to start their recovery journey and the motivation to keep working on recovery despite potential obstacles (Bonney & Stickley, 2008). According to Carr (2010), the recovery approach in mental health has significant parallels with the positive psychology approach to self-management. Both are about the individual determining their own purpose and meaning in life and being supported to be an active member of their community (Carr, 2010). A central concept of recovery is based on ideas of self-determination
and self-management. It emphasizes the importance of hope in sustaining motivation and supporting expectations of an individually fulfilled life (Shepherd et al., 2008, p. 1).

Hope is also essential for resilience (Ong et al., 2006) and is consistently identified by both individuals and therapists in various settings as a key factor in psychotherapy (Schrank et al., 2008). Lambert identified the following unique contribution of four factors which predict successful outcomes in psychotherapy (Lambert et al., 2008):

- Extra therapeutic factors (e.g., clients existing strength and resources, such as level of education, income, support network): 40%
- Therapeutic relationship (therapist who shows understanding, empathy, respect): 30%
- Models/techniques (e.g., cognitive restructuring, negative thought-stopping): 15%
- Expectancy/placebo effects (hope, positive expectancy): 15%

It is interesting to see that the creation of a positive, hopeful environment is as important as specific therapeutic models and techniques to a successful outcome. Snyder and Taylor (2000) see hope as an important common factor for psychological improvement and believe hope theory offers a plausible framework for understanding how therapies can be effective.

Hope has been defined in several and wide-ranging ways, including a virtue (Barilan, 2012) and a positive goal-related state (Snyder, 2000). In describing hope as a virtue, Munday (2012) believes that “hope lies between despair and, where there is no hope at all, and extreme optimism, where hope does not have any grounding in reality” (p. 188). The former Rabbi Jonathon Sacks (2010), made a similar point in describing the difference between hope, which is an active, deliberate act to improve a situation, and optimism, which is a passive belief that things will get better, when he said:

“Optimism is the belief that things will get better. Hope is the belief, that if we work hard enough, we can make things better...Optimism is a passive virtue, hope an active one. It
needs no courage, only a certain naivety, to be an optimist. It needs a great deal of courage to have hope.”

Sacks argues that living a fulfilled life is more than optimistically thinking that things will turn out okay if we simply believe that they will. He warns of the limits of positive thinking: although optimism and hope sound quite similar, they are in fact quite different. He describes how individuals who experience chronic impairment and adversity can be "agents of hope."

Munday (2012) believes that hope can be maintained even in the face of a terminal condition, such as cancer, through the striving for development and enrichment (a hope-promotion focus), rather than simply hoping to escape death (hope-prevention focus).

A systematic literature review (Schrank et al., 2008) that looked at definitions and measurement of hope has identified some key components of the concept. Hope has been defined as primarily focused on the future, through the pursuit and attainment of valued goals, which are aided by personal activity and resources (e.g., courage, resilience) and external factors (e.g., resource availability). Snyder’s (2000) hope theory underpins the HOPE Programme intervention. Although hope theory is similar to self-efficacy theory, which is the dominant theoretical model underpinning much of self-management research and practice, there are important differences (Snyder, 2000). Whereas self-efficacy theory focuses on specific goals and behaviors, hope theory recognizes enduring cross-situational goals and behaviors, and is therefore highly relevant to the broader task of managing the diverse impact of living with a chronic impairment. Further, self-efficacy theory emphasises the role of agency beliefs, whereas hope theory proposes a broader cognitive set (Snyder, 2000). Hope has been conceptualized and defined as a “cognitive set that is based on a reciprocally-derived sense of successful agency (goal-directed determination) and pathways (planning to meet goals)” (Snyder, 2000, p. 571). Pathway thoughts describe the perceived ability to produce plausible routes to goals, whereas agency thought is the
motivational element, which focuses on commencing and persevering with goal pursuits. Pathway and agency thoughts are iterative and additive (Snyder, 2000).

**Positive Psychology**

Our early evaluations of versions of Lorig’s chronic impairment self-management course (Lorig et al., 1999) identified a renewed and increased sense of hopeful thinking as one of the key improvements among some participants attending self-management programs (Barlow et al., 2005; Barlow et al., 2009; Turner et al., 2002). Our evaluation of Lorig’s arthritis self-management program included the “Positive and Negative Affect Scale” (PANAS) as an outcome measure (Barlow et al., 2000). The PANAS contains 20 adjectives to describe positive and negative emotional states. High positive affect refers to a general tendency to experience a "state of high energy, full concentration, and pleasurable engagement." Both negative and positive affect improved at 4 months, but at a 12-month follow-up, only positive affect showed further improvement. In other research, we explored the important role that positive emotions have among participants attending self-management programs in helping participants cope with their long-term health condition (Mafarland et al., 2009). We also found participants expressed positive emotions and a renewed sense of hope and a striving to use personal strengths in the pursuit of living well with their condition (Barlow et al. 2005; Barlow et al. 2009, Turner et al. 2002), which are positive psychological techniques.

Barbara Fredrickson (1998, 2001) suggests that increasing positive emotions is an efficient and often preferable approach to reducing negative. Fredrickson’s broaden and build theory (1998) suggests that positive emotions such as optimism, joy, and hope broaden an individual’s attention, thinking, and action thus enabling the building of new, creative thought and action pathways (i.e., expanding an individual’s coping skills), and the building of personal and social resources.
Professor Martin Seligman is attributed as responsible for officially launching positive psychology as a scientific endeavour during his American Psychological Association Presidential Lecture in 1998. However, as many others have noted, applied positive psychology has a research tradition that spans decades. Linley and Joseph (2004) point out that cognitive-behavioral therapists have a long tradition of using positive psychological techniques. Lopez, Edwards, Magyar-Mor, Pedrotti, and Ryder (2003) have described the potential usefulness of positive psychology to complement CBT because of the shared focus on a strengths approach to adjustment and development of the two approaches. Karwoski et al., (2006) suggest that there is considerable conceptual and technical overlap between CBT and positive psychological approaches including: developing a strong therapeutic relationship between client and therapist/coach, focusing on goals, cognitive reappraisal/mindfulness, scheduling pleasant activities, identifying and reviewing successes, monitoring mood, relaxation training, and problem-solving.

In contrast to dominant models in clinical psychology, which tends to focus on psychopathology, positive psychology is concerned with the full range of human functioning and has the dual aims of alleviating psychological distress and promoting positive well-being. Self-management research and practice has traditionally tended to focus on the former and hardly at all on the latter, with the exception of the inclusion of self-efficacy. For example, one positive intervention (Seligman, Rashid, & Parks, 2006) asks clients to write three good things that went well today and also reflect upon why they went well. This activity helps clients to end their day remembering and savoring positive events rather than negative ones. Similarly, the gratitude letter and visit (Seligman et al., 2006) may shift memory away from the embittering aspects of past relationships to savoring the good things that friends and family have done for clients. A positive intervention does not deny distressing, unpleasant, or negative experiences but rather refocuses
attention and memory on positive experiences. Positive interventions essentially are re-education of attention and memory (Rashid, 2009).

There is a growing body of evidence that suggests that gratitude improves psychological well-being and increases positive emotions (e.g., McCullough, et al., 2004; Wood, et al., 2007). Simple interventions, which are less cognitively demanding, such as gratitude diaries, have been shown to be as effective as more complex CBT techniques, such as thought monitoring and cognitive restructuring, with the additional advantage of increasing retention rates (Geraghty, et al., 2010).

In the next section, we describe how the HOPE Programme interventions were developed and evaluated using positive psychology theory, research and practice.

**HOPE Programme Development**

Between 2006-2009, in response to the shortage of tailored self-management support programs for individuals living with and affected by cancer, dementia, multiple sclerosis, HIV, and parent caregivers of children with autism, Coventry University (CU) was commissioned by various charities and NHS organisations to develop group-based, and web-based, self-management programs, which we named the HOPE Programme. Development of all versions of the HOPE Programme intervention followed a similar process. The development of the HOPE Programme for cancer survivors, which was funded by Macmillan Cancer Support (the UK’s leading cancer charity), will be used as an example of the development work undertaken, as the HOPE Programme for cancer survivors has achieved the widest reach, impact, and implementation.

**HOPE Programme Intervention for Cancer Survivors**

We (Martin et al., 2010) completed an extensive development phase of the HOPE Programme in line with step 1 of the Medical Research Council’s (MRC) framework for testing
complex behavioral interventions (Craig et al., 2008). We used the “Antecedent Target Measure” (ATM) approach (Renger & Hurley, 2006) and “Intervention Mapping” (Bartholomew et al., 1998) to develop HOPE. This combined approach has the advantage of resulting in the mapping of intervention components and measures for success, based on both primary data from stakeholders (e.g., cancer clinicians and cancer survivors) and a supporting evidence base from existing research literature to develop the content of each program. The entire process is guided by stakeholders’ perceptions of need and priorities, ensuring that perceptions of cancer survivors and experts in cancer treatment and self-management are prioritized. The resulting intervention has a clear logic underlying the inclusion of every component, rendering areas for refinements to the intervention during the development cycle easy to locate, as each component has a clear and specific purpose.

Using the ATM approach, stakeholders described their perceived “antecedents” (condition or event that logically precedes the problem) about why effective self-management could be problematic. Our data highlighted the importance of hope and confidence. For example, many participants made statements like “Self confidence is generally low after [cancer] treatment” and “don’t feel capable after illness experience,” which they reported were reasons why it was hard to self-manage. Others talked about fear of death, destroying their hope for the future and leading some to “catastrophize” about what may happen (Martin et al., 2010).

The HOPE Programme reflects an innovative approach to self-management because it encourages positive psychological and behavioral change by fostering positive psychological emotional states and builds on participants’ existing strengths and resiliencies, rather than focusing predominantly on skills’ deficits. The HOPE Programme for cancer survivors is a 6-week, group-based, self-management program, which aims to enhance physical and mental well-being. Each session follows a similar pattern. There is a combination of psycho-education, CBT-based skills’ practice, in-depth discussions, and setting and reviewing goals.
During the introductory session, for example, participants are invited to create a common identity (universality) and instil hope by sharing examples of positive and successful coping attempts, rather than sharing problems and failures. Another distinct feature of the first session in the HOPE Programme is the introduction of the upward spiral of positive emotions and experiences, which is intended to promote well-being, resilience, and adaptive coping skills.

The HOPE Programme intervention for cancer survivors includes key behavioral change techniques, including those that have a strong evidence-base, such as person-centered goal-setting, action-planning, and problem-solving (Abraham & Michie, 2008; Michie & Fixsen, 2009). Participants set personally relevant and meaningful weekly goals, as ‘homework’ tasks, which they are invited to share with other group members and provide goal attainment or goal barrier feedback the following week. Goal-setting fosters a sense of pride and achievement and in the group setting, participants are inspired and instilled with hope when witnessing others work towards achieving their goals.

The HOPE Programme emphasises the importance of having goals and working towards goals, as well as the completion of goals. Smail (1996) has described the challenges associated with initiating behavioral change and concludes that in many cases, there is no alternative to simply “walking the plank” of change, which he suggests is less challenging in the presence of encouragement from others. In current CBT approaches, behavioral activation, which rests on the idea of increasing positively reinforcing activities, uses terminology of “acting from the outside-in” (Kanter et al., 2011, p. 127) and the idea that doing precedes feeling – that to feel better, you had to first make a behavioral change. Hope, and other positive emotional states, underpin the motivation to create this change (Corr, 2013).

Other activities include cognitive and behavioral self-management techniques, anxiety, depression and stress-management techniques, relaxation training and pacing. The HOPE
Programme also includes positive psychological evidence-based activities, such as identifying personal strengths, scheduling pleasant activities, mindfulness, gratitude diaries, relaxation training, and reviewing successes (Karwoski et al., 2006). All of these techniques are positive psychological interventions in their own right and have a growing research evidence-base. Combined in the HOPE Programme, they build a positive experience for participants and tutors alike. See Table 1 for the weekly content of the HOPE Programme for cancer survivors.

Table 1 The HOPE Programme for cancer survivors

<table>
<thead>
<tr>
<th>Week 1 Content</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Welcome/Introductions</td>
</tr>
<tr>
<td>2</td>
<td>Responsibilities/Ground Rules</td>
</tr>
<tr>
<td>3</td>
<td>Instilling HOPE</td>
</tr>
<tr>
<td>4</td>
<td>Diaphragmatic Breathing</td>
</tr>
<tr>
<td>5</td>
<td>Gratitude Diary</td>
</tr>
<tr>
<td>6</td>
<td>Goal Setting</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Week 2 Content</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Solution-Focused Goal Feedback</td>
</tr>
<tr>
<td>2</td>
<td>Gratitude Diary</td>
</tr>
<tr>
<td>3</td>
<td>Managing Stress</td>
</tr>
<tr>
<td>4</td>
<td>Mindfulness</td>
</tr>
<tr>
<td>5</td>
<td>Goal Setting</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Week 3 Content</th>
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</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Solution-Focused Goal Feedback</td>
</tr>
<tr>
<td>2</td>
<td>Gratitude Diary</td>
</tr>
<tr>
<td>3</td>
<td>Managing Fatigue</td>
</tr>
<tr>
<td>4</td>
<td>Sleeping Better</td>
</tr>
<tr>
<td>5</td>
<td>Guided Imagery</td>
</tr>
<tr>
<td>6</td>
<td>Goal Setting</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Week 4 Content</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Solution-Focused Goal Feedback</td>
</tr>
<tr>
<td>2</td>
<td>Gratitude Diary</td>
</tr>
<tr>
<td>3</td>
<td>Body Changes, Sexuality &amp; Intimacy</td>
</tr>
<tr>
<td>4</td>
<td>Communication</td>
</tr>
<tr>
<td>5</td>
<td>Goal Setting</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Week 5 Content</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Solution-Focused Goal Feedback</td>
</tr>
<tr>
<td>2</td>
<td>Gratitude Diary</td>
</tr>
<tr>
<td>3</td>
<td>Fear of Recurrence</td>
</tr>
<tr>
<td>4</td>
<td>Get Active, Feel Good</td>
</tr>
<tr>
<td>5</td>
<td>Goal Setting</td>
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</tbody>
</table>

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<tr>
<th>Week 6 Content</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Solution-Focused Goal Feedback</td>
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</table>
Our qualitative evaluations of self-management programs (Barlow et al., 2005; Barlow et al., 2009; Turner et al., 2002), which included interviews with self-management participants and tutors, have consistently shown that instillation of hope, universality (realizing you are not alone), group cohesion, altruism, inspirational modeling, and imitative learning are key active ingredients of self-management programs, which Yalom (2005) has described as “therapeutic curative factors.” The HOPE Programme also utilizes these curative factors. Participants observe each other and the facilitators successfully overcoming the challenges of living with cancer through achieving their weekly goals (instillation of hope), share common experiences (universality) and are encouraged to support each other through the provision of informational and emotional support (altruism).

**Delivery**

The HOPE Programme for cancer survivors can be co-delivered by National Health Service (NHS) health and social care staff (e.g., clinical nurse specialists, benefits advisors) and cancer survivors. This co-creation approach to providing self-management support is innovative, as it brings together the clinical/specialist and experiential expertise of professionals and cancer survivors respectively to support cancer survivors. The co-creation approach is highly valued by self-management participants (Sharma et al., 2013).

The growth of online groups of individuals with chronic impairments has resulted in more opportunities for gaining knowledge and social support, leading to improved health-related quality of life (Bennett & Glasgow, 2009). Older adults, in particular, are willing to share self-
care information within selected social networks for the purpose of giving and receiving impairment-specific self-management information (Capel et al., 2007). In the UK, 42% of older adults (> 65 years old) use the internet, and their use of tablets doubled and smart-phones trebled between 2012 and 2014. In 2013, Macmillan Cancer Support (MCS) commissioned Coventry University (CU) to develop a web-based version of the HOPE Programme called iHOPE.

**Improvements in Outcomes across HOPE Programme Interventions**

Several feasibility trials have shown that HOPE and iHOPE has the potential to improve important post-course (6 week) quality of life outcomes (e.g., anxiety, depression, positive mental well-being, fatigue) for individuals living with and affected by a range of chronic impairments, including cancer (Turner et al., 2012; Whiteman et al., 2015); HIV (Herganrather et al., 2013, 2008); MS (Kosmala-Anderson et al., 2016); and parent caregivers of children with autism (Joshi et al., 2013). Table 2 shows the range of outcome measures that have been used to evaluate the HOPE Programme interventions. In keeping with the underpinning positive psychological theory, we have balanced the selection of outcome measures to reflect the positive and negative aspects of living with and being affected by a chronic impairment.

**Table 2 HOPE Programme outcome measures**

<table>
<thead>
<tr>
<th>Outcome measure</th>
<th>F2F cancer (N=84)</th>
<th>iHOPE Cancer (N=51)</th>
<th>F2F MS (N=21)</th>
<th>F2F Parents of children with autism (N=108)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult State Hope Scale</td>
<td>✓ *</td>
<td>✓ *</td>
<td>✓ *</td>
<td>✓ *</td>
</tr>
<tr>
<td>Quality of Life in Adult Cancer Survivors Scale.</td>
<td>✓ **</td>
<td>✓ **</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient Health Questionnaire - 9</td>
<td>✓ *</td>
<td>✓ *</td>
<td></td>
<td>✓ *</td>
</tr>
<tr>
<td>General Anxiety Disorder Scale - 7</td>
<td>✓ *</td>
<td>✓ *</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Warwick Edinburgh Mental Well-being Scale</td>
<td>✓ *</td>
<td></td>
<td></td>
<td>✓ *</td>
</tr>
<tr>
<td>Gratitude questionnaire</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-reported health</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Education and Impact Questionnaire</td>
<td>✓ ***</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The Multiple Sclerosis Impact Scale</td>
<td></td>
<td></td>
<td>✓ *</td>
<td></td>
</tr>
<tr>
<td>Multiple Sclerosis Fatigue Scale</td>
<td></td>
<td></td>
<td></td>
<td>✓ *</td>
</tr>
</tbody>
</table>
Multiple Sclerosis Self-Efficacy Scale ✓ *
Hospital Anxiety and Depression Scale ✓ * ✓ * ****
Positive and Negative Affect Scale ✓ *

*= Statistically significant improvement \( p \leq 0.05 \) (pre-test, post-test) **= Statistically significant improvement for these subscales (Negative feelings, positive feelings, cognitive problems, sexual problems, pain, fatigue, social avoidance, benefit finding, appearance concerns, fear of recurrence \( p \leq 0.05 \) (pre-test, post-test)

**= Statistically significant improvement for these subscales (fear of recurrence, fatigue, these were the only subscales included in the evaluation) \( p \leq 0.05 \) (pre-test, post-test)

***= Statistically significant improvement for these subscales (skill and acquisition technique) \( p \leq 0.05 \) (pre-test, post-test)

****= 40% of individuals with cancer had clinical levels of depression and anxiety

*** > 60% of parents had clinical levels of anxiety and >30% depression

Across several HOPE Programme interventions (cancer group and web-based; MS, parent caregivers of children with autism), hope was measured using Snyder’s Adult State Hope Scale (ASHS) (Snyder et al., 1991). The ASHS measures hope defined as “a cognitive set that is based on a reciprocally-derived sense of successful agency (goal-directed determination) and pathways (Planning to meet goals)” (Snyder et al., 1991, p. 571). The scale comprises 6 statements, three of which represent pathways (e.g., “There are lots of ways around any problem that I am facing now”) and three agency beliefs (e.g., “At the present time, I am energetically pursuing my goals”). Participants indicate the extent to which they agree with each of the 6 statements, higher scores indicating greater levels of hopeful thinking.

We combined the scores of the ASHS across four HOPE Programme evaluation studies. In total, 264 participants completed the AHS before attending the HOPE programmes and at post-course (6 weeks). Table 3 shows that there were statistically significant improvements in ASHS total scores and ASHS sub-scores (agency and pathways). The biggest improvements were reported by participants in the HOPE Programme for parents of children with autism. At baseline, these participants were the least hopeful and therefore had the greatest capacity to improve.

Insert Table 3 here
Qualitative evaluations indicated how the participants from each of the HOPE Programme Interventions became more hopeful. Participants stated that they were able to witness others doing well and thus gain confidence in their own abilities to achieve their goals, as well as seeing others who were perceived as doing not as well as themselves, thus instilling hope:

“It was helpful and inspiring to see someone that’s worse off than you and sort of witness how they cope with it”

“I’ve met some lovely people that have inspired me to keep going and have learnt to try to do that in a more positive, hopeful frame of mind.”

“Just purely being able to discuss issues with other group members gave me the courage.”

“Gave me courage as well. Gave me the courage to go forward and do things. I have taken away from the program what it says on the packet, ‘hope for the future’”

In Snyder’s conceptualization of hope, goals are a fundamental aspect of hope theory. The weekly process of setting and reporting goals on the HOPE Programme was an important factor in initiating self-management strategies (e.g., relaxation), achieving positive behavioral change (e.g., scheduling pleasant events, meeting up with friends), and improving quality of life (fewer negative emotions). Participants described how being held ‘accountable’ by the tutors and other participants provided the necessary motivation and commitment to undertake personal goals. The inclusion of informing the group about the outcome of weekly goal-setting meant that participants felt proud when goals were achieved and their success was relayed to the group. Participants described how they used goal-setting process to actively approach their challenges:

“It pushes you just that little bit further doesn’t it. I found that really helpful as well and I still do it now it’s there in the back of my mind and, you know, if I’ve got to do something then I will do it now rather than put it off.”
“…I told everybody I’m going to do this goal which actually made you do it, and then you felt brilliant because you accomplished it, and of course with little steps you went further and further and further, and I found it’s just, like from being in a black tunnel you suddenly can see the light at the end of the tunnel, so for me it’s been absolutely brilliant.”

“…I think because you don’t feel as if you can do anything, you haven’t got the energy or you can’t be bothered or you think oh I’ll put it off till tomorrow, but goal-setting just starting small, just something little and simple made you realize, oh I can do that after all. There’s things you can do, you don’t have to wait until you’re fantastically healthy to do anything, so it gives you that sort of self-confidence, oh I can actually do something, instead of just sitting and go oh dear, you know.”

**Discussion**

*Hope Springs Eternal*

There is growing interest in applied positive psychology promoting research and practice into factors that enables individuals, communities and societies to flourish and achieve optimal functioning. To the best of our knowledge, the HOPE Programme is a unique self-management intervention to as it draws on the theory and practice from clinical and health psychology, psychotherapy, and positive psychology. We have shown that the HOPE Programme has the potential to improve several important outcomes for individuals living with and affected by a chronic impairment (see tables 2 and 3) and improvements were seen in different delivery formats (e.g., group-based and web-based).

The HOPE Programme has the potential to reduce depression and anxiety, thereby helping to reduce the demand placed on psychological services and to reduce chronic impairment care costs. Several studies based on hope therapy (Cheavens et al., 2006; Klausner et al., 2000), which involved older depressed adults in the United States, reported a statistically significant increase
and large effect size improvement in hope and reduced feelings of hopelessness, anxiety, and depression.

The National Health Service in England transformed the delivery of psychological services through the introduction of the Improved Access to Psychological Therapies (IAPT). It was launched in 2008 to enable swift access to evidence-based CBT (Department of Health, 2008) for individuals experiencing common mental-health impairments of depression and anxiety utilizing a ‘stepped care model.’ Despite its success and consequent growth, IAPT has created significant waiting times and the level of need remains high and many individuals with mental health problems do not engage with formal psychological therapy services (Richards & Borglin, 2011). Some commentators have argued that the narrow focus on providing CBT, largely via one-to-one and/or computerized interventions, is not effective in building personally sustainable change, and that the role of mutually supportive self-help and self-management interventions involving the voluntary sector should be explored to enable services to be sustainable (Gilbert, 2010).

There is encouraging work already being undertaken involving users of mental-health service. In Australia (Lawn et al., 2007) and the United States (Druss et al., 2010; Lorig et al., 2013), research has shown that individuals with a range of severe mental-health conditions including schizophrenia found a version of Lorig’s intervention to be helpful. There is a need for self-management programs, which alleviate distress and promote hope and other positive emotional states. The HOPE Programme has the potential to be a suitable therapy for use in stepped care, for those with depression and anxiety in addition to a long-term physical condition. Further, some individuals living with depression may prefer attending the HOPE Programme because of the lack of stigma attached with something which promotes a strengths-based approach to coping and recovery, rather than a deficit-based approach.
There is a growing evidence base showing that trained peers can respond safely and therapeutically to distressing issues, which often arise on self-management programs (Barlow, et al., 2005; Kennedy et al., 2009). Recent evaluations of peer-led self-management programs have reported improvements in depression and other health outcomes for individuals with serious mental health conditions (Druss et al., 2010; Lorig et al., 2013). Participants with poorer mental health and lower confidence benefit the most from attending self-management programs (Reeves et al., 2008; Ritter et al., 2014; Turner et al., 2014). Targeting individuals with a chronic impairment, who are experiencing poorer mental health and lower confidence, would ensure that that the HOPE Programme is offered to those who have the most to gain.

**Limitations**

Across our research (Joshi et al., 2013; 2015, Kosmala-Anderson et al., 2016; Turner at al. 2013; Whiteman et al. , 2015), the differences in the hope total, agency, and pathways means between pre and post-course were generally high, which is promising; but these results need to be interpreted with caution for several reasons. The studies had no control group. Only baseline and post intervention data were collected, so that we are unable to say whether the improvements are maintained in the longer term. The samples were self-selected, highly motivated, and homogenous, with most participants being of White ethnic origin and the majority were women. It is possible that this self-selected group has a natural inclination to respond favourably to a positive psychological approach for managing their chronic impairments. Adequately powered, randomized controlled trials are needed to establish whether the HOPE Programme has the potential to provide longer-term positive effects and whether it is acceptable and useful in the longer-term (e.g., 6, 9, 12 months follow-up).

**Implications for Self-management Research and Practice**
We are limited in our knowledge about the mechanisms of action on self-management interventions outcomes. Self-efficacy theory has been the defining model underpinning much self-management research. Improvements in self-efficacy have been shown to mediate important self-management outcomes (Lorig et al., 1989). However, some self-management studies have found improvement in outcomes independent of an improvement in self-efficacy (Kendall et al., 2007). This suggests that there may be other theoretical explanations and other factors behind the improvements in self-management intervention outcomes. From the therapeutic perspective, hope has been put forward as a common factor that explains client improvement. Our research suggests that a self-management program based on a positive psychological hope theory can lead to consistent improvements in hope and other important outcomes. Research is needed to explore the extent to which hope creates changes in behaviors and/or impacts on other important and relevant outcomes. Further research should explore to what extent self-management, both in terms of condition-specific health behaviors and more general well-being related behaviors, can improve if hope is low.

Our research suggests that a self-management intervention based on positive psychology, CBT, and psychotherapy has the potential to improve important outcomes for individuals living with and affected by a chronic impairment. Importantly, the HOPE Programme intervention also appears to have the potential to assist individuals who are experiencing clinical and non-clinical levels of mental health problems, which means it can have a wide appeal to a broad range of individuals.

**Conclusion**

To our knowledge, no other studies (e.g. Barlow et al., 2000; Buszewicz et al., 2006; Kennedy et al., 2007; Lorig et al. 1999, 2013; Osborn et al., 2007) have evaluated the potential of self-management interventions to promote and improve hope. The HOPE Programme is an
innovative self-management intervention combining positive psychology theory and practice and CBT. Our research suggests that the HOPE Programme has the potential to improve a range of important outcomes for individuals living with and affected by cancer, MS, and for parents of children with autism. Improvements were seen across delivery formats that are group-based and web-based. Further robust evidence of the impact of the HOPE Programme is needed.

In describing the “neglected importance of hope” (p. 79) in self-management theory and practice, Veres et al. (2014) call for more research into how to design and deliver programs to foster hope and the related concept of resilience. The role of self-management and hope in mental health recovery-focused services has also been described as important components for making services fit for the twenty-first century, which help service-users to lead a more fulfilling life (South London and Maudsley NHS Foundation Trust and South West London, 2010)
References


Sacks, J. (2010). *Optimism is all very well, but it takes courage to hope.* (http://www.rabbisacks.org/credo-optimism-is-all-very-well-but-it-takes-courage-to-hope/)


Table 3 Adult State Hope Scores across Four Samples

<table>
<thead>
<tr>
<th>Outcome variable</th>
<th>Total sample (N=264) How many courses in total</th>
<th>F2F* cancer (N=84) Courses</th>
<th>iHOPE** Cancer (N=51) Courses</th>
<th>F2F MS (N=21) Courses</th>
<th>F2F Parents of children with autism (N=108) Courses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD) Baseline</td>
<td>M (SD) Post-course</td>
<td>ES***</td>
<td>M(SD) Baseline</td>
<td>M (SD) Post-course</td>
</tr>
<tr>
<td>Hope Total score (6-48, ↑ = better)</td>
<td>27.5 (10.0)</td>
<td>35.3 (8.1)</td>
<td>0.8</td>
<td>30.2 (10.0)</td>
<td>34.2 (9.9)</td>
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<td>Hope agency score (3-24, ↑ = better)</td>
<td>12.8 (5.7)</td>
<td>17.3 (4.4)</td>
<td>0.8</td>
<td>14.3 (5.6)</td>
<td>16.7 (5.4)</td>
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<tr>
<td>Hope pathways score (3-24, ↑ = better)</td>
<td>14.7 (4.8)</td>
<td>18. (4.0)</td>
<td>0.7</td>
<td>15.8 (4.9)</td>
<td>17.6 (4.7)</td>
</tr>
</tbody>
</table>

* F2F = Group-based face to face courses

** Web-based course

***Effect sizes (Cohen’s d) were calculated as follows: the mean score at 6 months minus the mean score at baseline divided by the standard deviation at baseline. Boundaries recommended by Cohen (1998) were used to determine small (0.2), moderate (0.5) and large effect sizes (0.8).