

Institution: Coventry University
Unit of Assessment: 3
Title of case study: Better informed, more activated patients: self-management - a new approach to chronic disease management in the twenty first century
<p>1. Summary of the impact</p> <p>Long term conditions are leading causes of death and disability. Over 80% of care for people with long term conditions is self-management. In 2001, the Chief Medical Officer concluded, from evidence from the US and from Barlow and Turner's pioneering research in the UK, that the NHS should provide support for self-management through programmes such as the Expert Patient Programme. Turner and McHattie have developed self-management programmes (e.g. the Help to Overcome Problems Effectively: HOPE Programme) which have been taken up by local, national and international providers. These programmes have impacted positively on patient-reported outcome measures such as pain, fatigue and depression. They are cost-effective and produce a social return on investment.</p>
<p>2. Underpinning research</p> <p>People affected by a long-term condition are the most frequent users of healthcare services, accounting for 50% of all GP appointments and 70% of all inpatient bed days. In the 1990s, Professor Julie Barlow and Dr Andy Turner (Senior Research Fellow) conducted a randomised controlled trial of the Arthritis Self-Management Programme, demonstrating its effectiveness in improving patient outcomes including: confidence, health behaviours, and physical and psychological health [1]. Due to their pioneering self-management research, Barlow and Turner became recognised as experts and Barlow was commissioned in 1999 by the Department of Health, under the remit of the Expert Patient Task force, to undertake a review of self-management research. Barlow et al concluded that self-management programmes provide impact across several patient outcomes [2]. Barlow and Turner then collaborated with a network of voluntary sector organisations to provide evidence of the chronic disease self-management programme, which subsequently became known as the Expert Patient Programme. The Chief Medical Officer cited the review when announcing the national roll out of the Expert Patient Programme.</p> <p>Since then Barlow and Turner have continued to lead the field, undertaking a groundbreaking study of one of the longest follow-ups (8 years) of a self-management programme [3], which highlighted the potential for self-management programmes to produce sustainable patient outcomes. Barlow and Turner have also conducted pioneering research, using qualitative methods, to investigate the mechanisms underpinning improved patient outcomes [4]. They were among the first researchers to suggest that group therapeutic factors could provide the foundation upon which patient outcomes improve. This research showed that self-management programmes can also be effective for people living with depression and anxiety [4].</p> <p>Barlow and Turner continued to research the Expert Patient Programme, during which they identified some of its limitations, including: a prescriptive content and delivery style; no planned follow-up support for participants (who report feeling "abandoned" after the support from other group members is withdrawn); and the lack of health professionals' involvement in co-delivering the self-management programme, which meant that participants were unable to benefit from their expertise. This latter limitation was one of the reasons why self-management programmes were not embedded in health service delivery plans. Recently, there has been a shift towards co-delivery of self-management programmes involving professional and lay tutors. This co-delivery model was adopted in The Health Foundation's Co-creating Health Self-Management Project, which was evaluated by Wallace (Research Lead for the Health and Wellbeing Theme, within the Unit), Turner and other colleagues at Coventry University.</p> <p>Since Barlow partially retired in 2006 (finally retiring in 2008), Turner has continued to produce high quality research into self-management (described below) which is having a demonstrable patient impact. He and his colleagues have used an intervention development methodology to design and evaluate several versions of the HOPE (Help to Overcome Problems Effectively) self-management programmes [5,6]. HOPE programmes built on and extended the research begun by Barlow by directly addressing some of the limitations described above. The HOPE programmes also address national initiatives focused on improving the quality of life for people living with and</p>

beyond cancer (National Cancer Survivorship Initiative) and people affected by dementia (National Dementia Strategy).

3. References to the research

1. **Barlow**, J.H., **Turner**, A.P., & Wright, C.C. (2000). A randomized controlled study of the Arthritis Self-Management Programme in the UK. *Health Education Research* 15 (6): 665-680. (IF = 1.656; Citations = 168)
2. **Barlow**, J., Wright, C., Sheasby, J., **Turner** A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling*, 48 (2):177-187. [http://dx.doi.org/10.1016/S0738-3991\(02\)00032-0](http://dx.doi.org/10.1016/S0738-3991(02)00032-0) (IF = 2.305 Cited in Scopus 2010 **Most downloaded article in the last 90 days – accessed 29.08.2013**; Citations = 390)
3. **Barlow**, J., **Turner**, A., Swaby, L., Gilchrist, M., Wright, C., & Doherty, M. (2009). An 8-yr follow-up of arthritis self-management programme participants. *Rheumatology*, 48 (2):128-133. (IF = 4.058; Citations = 17)
4. **Barlow**, J., Edwards, R., & **Turner**, A. (2009). The experience of attending a lay-led, chronic disease self-management programme from the perspective of participants with multiple sclerosis. *Psychology & Health*, 24 (10): 1167-1180. doi (IF = 2.126; Citations = 6)
5. Martin, F., **Turner**, A., Bourne, C., & Batehup, L. (2013). Development and qualitative evaluation of a self-management workshop for testicular cancer survivor-initiated follow-up *Oncology Nursing Forum*, 40 (1): E14-E23. (IF = 2.509)
6. Martin, F., **Turner**, A., Wallace, L.M., & Bradbury, N. (2013). Conceptualisation of self-management interventions for people with early stage dementia. *European Journal of Aging*, 10 (2), 75-87. DOI 10.1007/s10433-012-0253-5 (IF 1.268)

Key Research Grants

- Wallace L, **Barlow** J, **Turner** A. (2007) Clinician/patient self-management and service redesign: An evaluation of The Health Foundation's Co-creating Health initiative. The Health Foundation. £909,721
- **Barlow**, JH, Wright CC, **Turner** AP, Doherty M. (2005) Long-term follow-up of the arthritis self-management programme. Arthritis Research Campaign, £16,500
- Martin, F., **Turner**, A., Wallace, L., Bradbury, L. Graveney. M. (2009) Development of a Self-Management Intervention for People with Early Dementia: Modelling Phase Warwick and Coventry Primary Care Research: £19,972
- **Turner**, Martin & McHattie. (2010). Development of a short self-management workshop for survivors of colorectal cancer (STC) Macmillan Cancer Support: £12,699

4. Details of the impact

Impact summary

Barlow and **Turner** have provided the evidence base for self-management programme research. This unique body of research has enabled charities, healthcare professionals and others to implement self-management programmes in a wide variety of settings, and for those with different individual problems, on the basis of clear evaluative evidence that the interventions work. In the past five years, **Turner** and colleagues have developed several bespoke HOPE self-management programmes and trained over 300 health professional and patient tutors. The HOPE roll-out has occurred on a local, national and international scale and has impacted on several underrepresented groups, such as people (and their care givers) affected by: cancer, dementia, multiple sclerosis, HIV, and for parent caregivers of children with attention deficit hyperactivity disorder. HOPE addresses key quality of life indicators such as living well with a long-term condition and positive mental well being as set out in the National Cancer Survivorship Initiative (NCSI) and the National Dementia Strategy.

Impact on public policy and services

The HOPE Cancer Programme is cited as an example of self-management support for cancer survivors within the NCSI Vision document (2013) [a]. In response to the Government "refresh" of the Carers Strategy document, Macmillan encouraged dialogue with the government and local

Impact case study (REF3b)

authorities to explore the potential of the HOPE Carer Programme [b].

The research undertaken by this team has had a strong impact on the evidence base, as demonstrated in the report *Helping people help themselves: A review of the evidence considering whether it is worthwhile to support self-management* which examined over 550 self-management studies, 13 of which were conducted by **Barlow** et al [c]. The report concluded that self-management improved people's behaviours, quality of life, clinical symptoms and use of healthcare resources. Self-management programmes are also cost effective and provide a social return (e.g. increased employment) on investment (see Kennedy & Philips, *SelfCare* 2011:2:10-20).

Impact on health and welfare (measures of improved wellbeing for people affected by a long-term condition)**HOPE cancer survivors**

Macmillan Cancer Support commissioned **Turner**, based on his expertise, to develop a flexible self-management programme co-delivered by cancer survivors and health professionals to replace their existing lay-led self-management programme. HOPE for cancer survivors has been rolled out across the UK since 2012. Over 100 HOPE programmes have been delivered to over 1,000 cancer survivors and carers in the community and as part of the cancer care pathway [d]. The cancer survivors report enhanced generic quality of life (e.g. negative and positive moods) and cancer specific quality of life (e.g. fear of recurrence). There have been several media reports, including BBC online [e] describing the positive life enhancing impact of attending HOPE. Macmillan have commissioned and piloted HOPE self-management programmes for people from black and minority ethnic backgrounds and for people with learning difficulties.

In an extension to the cancer HOPE programme, forty patients who have completed treatment for colorectal and testicular cancer have attended HOPE self-management workshops at University Hospital Southampton. Participants have reported improved confidence in managing their follow up, and have made improvements in physical activity and healthy eating [f].

HOPE MS

HOPE programmes have been delivered to 30 people affected by MS. Participants have reported improvements in fatigue, depression and hope [g]. A self-management website specifically for MS patients of child-bearing age (<http://www.mumsandms.org.uk/>) has over 300 registered users, including people from the USA and Canada, and has had over 5,000 visits since 2012.

HOPE Parent caregivers

Seventeen HOPE programmes have been delivered to over 150 parent caregivers of children with Attention Deficit Disorder, recruited by Coventry Carers Centre [h]. Participants experience less depression, anxiety and more positive emotions and gratitude after attending. One of the tutors, who was a former participant, has described the positive change HOPE had on her confidence, self-esteem and psychological resilience in magazines about autism. The tutors have also produced a video diary (see <https://www.hopeprogramme.co.uk/hope/facilitators.aspx>) describing the positive benefits of HOPE.

Dementia Self-Management Programme

Over ten group-based and one innovative Skype (Internet Video Conferencing) programmes have been delivered to over 50 people living with dementia and over 25 caregivers in the West Midlands. People with dementia experienced a reduction in stigmatisation and social exclusion. Caregivers benefitted from an enhanced and deeper understanding of dementia. The Skype group learnt how to use the technology to connect with family who lived abroad. Birmingham and Solihull Mental Health Foundation Trust have incorporated the dementia self-management programme into the 'menu' of early interventions as part of the assessment/diagnosis pathway.

Impact on practitioners supporting people affected by a long-term condition

An important element of the impact of this research has been in the way it has influenced changes in the provision of self-management support in targeted areas within the UK. Front line staff from a range of professional groups have been trained in motivational interviewing and behaviour change techniques. The National Cancer Survivorship Initiative and Birmingham East and North Primary Care Trust service improvement project tested the HOPE cancer survivors' self-management programme as part of a project redesigning the aftercare pathway for breast cancer survivors at

Impact case study (REF3b)

Good Hope Hospital [i]. Specialist breast care nurses were trained to co-deliver with cancer survivors. Delivering HOPE raised their awareness of the benefits of self-management programmes for patients, made them aware of a range of service delivery issues which patients wanted improving, and widened and enhanced their own knowledge, skills and attitudes.

Reach of self-management programmes

HOPE is demonstrating international reach, as it has been implemented in Greece in 2009 for women with a long-term condition [j] and a self-management programme developed for gay men living with HIV has been delivered in the US since 2008. Feedback from both programmes has shown positive outcomes. Men attending the HOPE HIV self-management programme reported improved medication adherence, satisfaction with life, self-esteem, confidence to find employment, more hope and were less depressed and anxious [k].

In order to extend the reach of HOPE to long-term condition patients we have used social media tools, such as Facebook (<https://www.facebook.com/HOPE.Programme>) and Twitter (@hopeprogramme). More than 50 parent caregivers who attended the HOPE Parent caregivers have set up their own HOPE Programme Facebook Group.

Conclusion

Turner and colleagues have collaborated with NHS and charity sector partners to develop and evaluate a diverse range of innovative self-management programmes, which have had a significant positive impact on the quality of life of a diverse range of people living with and affected by a long-term condition. In summary, **Turner** and colleagues have helped provide the evidence base for self-management in the UK. The following quote is indicative of the positive impact of HOPE.

"It really prepared me for the big operation - and I definitely wasn't as panicky as I was for the first operations. The surgeon said afterwards that I'd make a 'remarkable recovery' and I put that down to feeling more positive and more relaxed about it all.

5. Sources to corroborate the impact

- a) Department of Health, Macmillan Cancer Support & NHS Improvement (2013). Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision) (<http://tinyurl.com/d4wy4m3>)
- b) Macmillan Carers Strategy (p3) <http://tinyurl.com/omldusq>
- c) de Silva, D (2011) Helping people help themselves A review of the evidence considering whether it is worthwhile to support self-management. Published by the Health Foundation ISBN 978-1-906461-26-3 <http://tinyurl.com/67u94xe>
- d) Davies et al (2010) HOPE: Supported self-management programme for post-treatment breast cancer survivors - a pilot study. (<http://tinyurl.com/oy8ru55>)
- e) <http://www.bbc.co.uk/news/health-17938502>
- f) Lynn Bateup. Macmillan Cancer Support Survivorship Update (Autumn 2012)
- g) **Turner** A, McHattie D, Harker V, Robertson K. The HOPE MS Self-Management programme improves quality of life of people affected by multiple sclerosis: A pilot study. Midlands Health Psychology Network, 9th Annual Conference. 14th February 2013
- h) Coventry Carers Annual Report 2012-13 <http://tinyurl.com/nmesboa>
- i) Torjesen I. (2011). Supported Self management. Meet the activated patient. Health Service Journal. 121;(6252): Suppl 6-7
- j) "Hope for people with chronic conditions in the town of Oreokastro from the HOPE Programme" <http://news.disabled.gr/?p=21497>
- k) Hergenrather, K., Rhodes, S., **Turner**, A., **Barlow**, J., Bardhoshi, G., & Cowan, C. (2008) 'Enhancing Employment for persons with HIV/AIDS through Self-management Behavioral Coaching.' *European Health Psychology Conference & BPS Annual Health Psychology Conference*. University of Bath, UK