The Role of Expert Patients in Improving Care

Dr. Gulen Addis
Faculty of Society and Health
Buckinghamshire New University
England
Some Statistics

• Around 15 million people in England have a long term condition
• People with long term conditions account for:
  ➢ 50% of all GP appointments
  ➢ 64% of all outpatient appointments
  ➢ 70% of all inpatient bed days
  ➢ In total around 70% of the total health and care spend in England is allocated to caring for people with long term conditions (DOH 2012)
The History of the Expert Patient Programme (EPP)

- The EPP course was based on the Chronic Disease Self-Management Programme which was developed by Kate Lorig at Stanford University in California.
- In 1999 the Department of Health white paper *Saving Lives: Our Healthier Nation* announced that an Expert Patients Programme would be established to help people living with long-term conditions to improve their quality of life.
- To support this in 2001 a national task force produced a report outlining the benefits of the introduction of an Expert Patient Programme.
- The EPP piloted between 2001-2004 and mainstreamed between 2004-2007. Before 2007 it was administered by Primary Care Trusts and after that by a community interest company (CIC).
- So far over 100,000 people have attended an Expert Patients Programme and 1,700 people have been trained as tutors.
• Health professionals have identified that people with a chronic illness frequently demonstrate a better understanding of their condition and related care management than the professionals themselves.
• The knowledge, skills and experience held by such patients represent a potentially unused and valuable resource that could be utilized for the benefit of others.
• This would accord with the shift to placing patients at the centre of healthcare decisions thereby resulting in patient empowerment (Fox 2005).
Pre-set Topics in Expert Patient Programmes

- Relaxation
- Cognitive symptom management
- Exercise
- Fatigue
- Nutrition
- Problem solving
- Action planning
- Communication with healthcare professionals.

(DOH 2001)
Benefits of EPPs

• Many healthcare professionals say that “my patient understands their disease better than I do”.
• Self-management or expert patient programmes are not simply about educating or instructing patients about their conditions.
• Such programmes are based on developing the confidence and motivation of patients to use their own skills and knowledge to improve the quality of life with a chronic illness and work in partnership with health professionals.
• As the Chief Medical Officer observed, expert patients are “people who have the confidence, skills, information and knowledge to play a central role in the management of life with chronic diseases”. (DOH 2001)
Patients Opinions

• “The EPP course has made me able to look after myself more and that’s why I rarely take time off sick from my job.”

• “Before EPP, I rarely attended my scheduled appointments. Since taking more control of the management of my health condition, I go now.”

• “I rarely go to my doctor now because I have learnt a lot of self-management techniques on the EPP course. These have helped me to look after my health.”

(EPP CIC 2013)
• EPP programmes are delivered by tutors who themselves have a chronic condition. All tutors must have undergone an EPP and a training programme.
• Barlow et al. (2005) showed that benefits and challenges of being a tutor include:
  ➢ Being valued and adding value
  ➢ Increased confidence
  ➢ The challenges of course delivery (having to have rigid protocols, keeping participants focused, administration work, marketing etc.)
Healthcare Professional Opinion

- Nurses are seen as having a key role to play in long term conditions.
- Wilson et al. (2006) qualitative study showed:
  - The majority of nurses were uncomfortable with the idea being challenged by knowledgeable patients
  - In contrast nurse specialists appeared less anxious about expert patients
  - GPs and consultants appeared comfortable in acknowledging patient expertise
  - The majority of expert patients were aware of the need to develop a non-threatening relationship with health professionals
Who Benefits Most

- Expert Patient Programmes appealed most to white middle class, educated patients and those who were already good self-managers.
- They appealed less to those living in deprived areas who placed a higher value on relationships with GPs. For example, the effects on the health status of Bangladeshi patients were marginal due to moderate uptake and attendance (Griffiths et al. 2005).
- Participants with lower self-efficacy and health-related quality of life at baseline demonstrated more positive health outcomes.
- Younger people benefited substantially more than older people (Reeves et al 2008).
After 6 months of being on an EPP patients (total 629) benefited in terms of:

- Moderate gains in self-efficacy
- Small gains in energy
- Improvements in quality of life equivalent to one additional week in perfect health over a period of 12 months
- Small gains in secondary outcomes such as psychological wellbeing and partnerships with doctors
- High satisfaction with the course
- No impacts on routine health service use (e.g. GPs, practice nurses and outpatient visits)
Some reductions in costs of hospital use (inpatient and day case)

Increases in out of pocket costs (for e.g. payments for alternative therapies, domestic help and special dietary needs)

No major increases in overall costs because the costs of sending people on the course were recouped from savings elsewhere in the system (NPCRDC 2007)
Cost Effectiveness

- Full cost benefit analysis of EPP is difficult because there is considerable uncertainty around the estimates of costs.
- Kennedy et al (2007) used EuroQoL EQ-5D instrument for calculating quality-adjusted life years (QALY). They estimated the cost reduction to be between £27 and £422.
- In contrast EPPCIC estimate the savings to be around £1800 per patient per year on the basis of reduced consultations with GPs, nurse specialists etc.
• 17 RCT trials involving 7442 participants
• Lay-led self-management education programmes may lead to small, short-term improvements in participants’ self-efficacy, self-rated health, cognitive symptom management, and frequency of aerobic exercise.
• There is currently no evidence to suggest that such programmes improve psychological health, symptoms or health-related quality of life, or that they significantly alter healthcare use.
• Future research on such interventions should explore longer term outcomes, their effect on clinical measures of disease and their potential role in children and adolescents (Foster et al. 2007).
Criticism of the EPP

- The evidence shows generally the benefit of EPP are small and do not meet the original aim of the programme.
- EPP mostly benefit people who with higher income and often have a better health and better control of their disease.
- EPP has been shaped by conceptualisations of self-management as a one size fits all (Lindsay and Vrijhoef 2009).
What the Future Holds

• Now Primary Care Trusts have been abolished the funding they used to provide for EPPs has disappeared.
• Changes to EPPs are likely because of the increased role of GP commissioning which makes them independent budget holders. GPs will decide whether to fund such programs and this matters because of the pressure to cut costs.
• Further research may be needed to determine the effects of the new NHS system for EPPs.


