

## IS THERE A LINK BETWEEN INCREASING SELF-MANAGEMENT, AND THE RESILIENCE OF THE CARE PROVIDER? WILL EMPOWERING AND ENABLING THE PATIENT TO TAKE ON MORE RESPONSIBILITY FOR THEIR OWN HEALTH ACTUALLY HELP THE CARE PROVIDER FEEL A GREATER ACCOMPLISHMENT, AND ALLOW THEM TO LET GO OF A BIT OF THE RESPONSIBILITY?

### INTRODUCTION

*'My condition, my terms, my life'*. This phrase, coined by the Scottish Health and Social Care Alliance, sums up the essence of self-management<sup>1</sup>. Encouraging the patient to gain knowledge about their condition allows them to influence the level of support that they receive, and develop the confidence to take control of their lives back from the care-provider and into their own hands. The term 'care provider' refers to a wide variety of support services, from individual family members to whole communities, who are involved in every aspect of an individual's care during every stage of their disease. Self-management strategies therefore are also highly pertinent to the care provider. Resilience, defined in a rather sterile manner by the Oxford English dictionary as 'the capacity to recover quickly from difficulties' is also a term defining the ability to survive, adapt and thrive when challenged with unforeseen circumstance<sup>2</sup>. The challenge of this essay lies in showcasing examples of self-management, to examine firstly whether resilience of the care provider alters when the patient is engaged in effective self-management strategies, and secondly whether these strategies allow greater autonomy to both the patient and the care provider.

### STRATEGIES CHAMPIONING PREVENTION

It stands to reason that schemes advocating preventative self-management strategies will lessen the potential burden of disease on the care provider or service, thus increasing the ability of that service to deliver more flexible and less pressurised care. By adapting to the needs of individuals and delivering care when patients need it the most, the care provider is able to demonstrate increasing resilience in their ability to provide treatment. An outstanding example of this is St Wilfred's Centre, a local support group in Sheffield offering services and activities to promote the well-being, confidence and independence of vulnerable adults aged 18 to 65 years<sup>3</sup>. Through an extensive range of activities, including workshops in literacy, pottery, photography and drama, this community project aims to improve both communication and life skills. The NHS and Sheffield City Council provide a personal budget to individuals experiencing the consequences of mental health problems or learning disabilities, allowing them to gain self-directed support to overcome barriers of social exclusion. This remarkable project substantiates the link between increasing self-care and simultaneously increasing the resilience of the care provider. In this case, the 'care provider' may range from a sibling or partner to the local NHS health authority, however all parties providing care are benefiting from patients who are more knowledgeable about their condition and more willing to engage in therapy and support. For example, with the support of St. Wilfred's Centre, one patient affected by a psychiatric condition applied to become a Member of the People's Parliament run by the Disability Parliament in Sheffield, and is now in a position to help other vulnerable individuals seek help, demonstrating the sustainability of this self-management strategy.

A similar strategy highlighting the link between preventative self-management and the resilience of the

care provider is the scheme 'Munch and Move', an American health initiative promoting physical activity and healthy eating<sup>4</sup>. The first phase of this initiative took place between 2008 and 2009, delivering 52 workshops to over 1,000 children. A summary report evaluating the impact of this scheme observed that Munch and Move improved fundamental movement skills amongst preschool aged children, delivered key health information to parents and improved the confidence of preschool staff in delivering healthy eating ideas<sup>5</sup>. As the concept of self-management encompasses all health decisions made by an individual, the main success of this scheme has been to convey the importance of a balanced diet and physical activity to children at the earliest opportunity. Encouraging young people to make informed decisions about their lifestyle will reduce future health consequences, and will allow both the health professionals and the parents to take a step back from the responsibility of the individual's health.

## **STRATEGIES TO MANAGE EXISTING CONDITIONS**

Alongside encouraging individuals to take responsibility for their own health, strategies exist to help patients affected by chronic conditions to take a more proactive role in managing their treatment. The Expert Patients Programme (EPP) is an NHS-funded self-management strategy consisting of six weekly sessions designed to boost confidence, encourage the patient to acknowledge how their condition affects themselves and others around them, and accept some of the responsibility for treatment<sup>6</sup>. An appraisal of the EPP course by the National Primary Care Research and Development Centre (NPCRDC) concluded that it significantly advanced patient's motivation and self-efficacy, and showed a reduction in the number of overnight stays in hospital<sup>7</sup>. It is important to note that the overall number of people using health services remained the same, but EPP shifted the emphasis of care away from hospital environment and encouraged the patient to make informed choices about when they needed treatment. A survey of 1,000 participants of the EPP scheme showed that patients visited their GP on fewer occasions, and felt more prepared for these appointments. It is evident that patients who are encouraged to take the lead in the management of their condition are less likely to engage the avoidable assistance of care providers. It has long been understood that a significant factor in developing resilience is a caring and supportive relationship, and therefore the quality of the interaction between the care provider and the patient is vital in determining the resilience of the care provider. Care of chronic disease is an ongoing process that requires time and effort from both parties, and thus encouraging the patient to take control of their condition permits the care provider to take a step back, and allows the relationship between the patient and the care provider to become more meaningful in the face of challenges.

## **FAMILY RESILIENCE**

Encouraging young people to engage with their condition has proved a highly effective way of reducing the burden of their disease on the principle care providers of these individuals: their family. Diabetes UK offers a wide range of support services for patients affected by the condition, such as a Diabetes UK support holiday<sup>8</sup>. These holidays, designed for young people aged 7 to 18 years, aim to normalise life with diabetes, demonstrating that it is still possible to participate in activities (such as mountain biking) whilst making friends and learning about the importance of effective management. However, many young people living with chronic disease still struggle to adjust to the enormous responsibility of becoming

active independent decision-makers, and this struggle is often reflected in the resilience of their care providers. A case observed whilst on a paediatric placement in Grimsby illustrates this challenge.

Daisy\*, a 14 year old girl, was seen in a routine diabetic clinic appointment, during which her mother expressed deep concern that Daisy was refusing to take any responsibility for monitoring and managing her type 1 diabetes. Daisy admitted that she struggles greatly with the responsibility of checking her own blood glucose, and she often pretends that she is 'normal' and ignores her symptomatic episodes of hypoglycaemia. Additionally, her mother described the overwhelming impact of Daisy's diabetes on her own life, explaining the struggle she has to find the appropriate level of intervention; she knows that Daisy is now old enough to be taking responsibility for her illness, but at the same time she is reluctant to take a step back from Daisy's treatment for fear of the long-term sequelae. This situation epitomises the burden and challenge of managing chronic conditions, and provides an answer to the original question. The ensuing weeks of encouragement from diabetic specialists emboldened Daisy to take her blood glucose monitor to school, admit to her friends that she had diabetes, and administer insulin in an appropriate manner. Upon returning to the clinic at the 6-week follow up appointment, it was remarkable to witness the positive change in the relationship between Daisy and her mother, and also to observe the difference in her mother's manner. Enabling and encouraging Daisy to take control of her own condition did indeed allow her mother to partially let go of the responsibility for her daughter's diabetes. As one of the most important factors in developing resilience is a caring and supportive relationship within and outside the family, the ability of both Daisy and her mother to adapt and thrive when faced with unforeseen circumstances will undoubtedly be stronger now that the mother-daughter relationship has replaced the previous relationship between a care provider and a patient.

## CONCLUSION

Ultimately, the strategies showcased in this essay demonstrate that encouraging patients to take control of their condition does enhance the resilience of the care provider. Self-management allows the patient to gain confidence and take responsibility for their own health, thus allowing the care provider to lessen the level of intervention required and improve the quality of care. By taking a step back, the care provider is much more capable of providing a dynamic and flexible level of care whilst maintaining the patient's need for autonomy.

\*All names have been changed to maintain confidentiality

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