Experiencing illness

A reflective review of coping strategies in chronic disease

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INTRODUCTION

Although recent initiatives in medical education have increasingly shifted the patient experience to the forefront of medicine, undergraduate medical education still mainly focuses on the clinical aspects of chronic diseases. A patient's subjective experience of chronic illness is incredibly diverse, with a multitude of interlocking circumstances, which inherently makes it difficult to teach and for students to grasp in a classroom discussion. During our second year of medicine, we had the opportunity to meet SG, an elderly woman who had recently developed severe heart failure. After getting to know her through multiple visits and conversations, the impact of her chronic illness on her quality of life and the changes she has had to make to accommodate for it quickly became apparent. By relating our experiences with this family to current literature about coping mechanisms, this reflective review aims to educate readers on how people cope with disease in real life both effectively and ineffectively and how healthcare professionals can assist in coaching them to regain at least a semblance of their previous functioning state.

COPING STRATEGIES

Coping strategies are approaches that are used by individuals faced with new stressors and in general can be broken down into 3 categories: appraisal-focused, problem-focused and emotion-focused.^{1,2} Appraisal-focused coping strategies focus on the thoughts, ideas and feelings a person has about their disease or life situation. Positive strategies in this category involve making positive comparisons, finding hope and maintaining optimism, often through spiritual means.³ Positive thinking alone is not an adequate coping mechanism; individuals must accept their condition and the anxiety, fear and losses associated with it before becoming optimistic.⁴ Problem-focused coping strategies revolve around adapting to external stresses, through changing or eliminating the difficulties encountered due to chronic disease. These include becoming informed about the condition, planning ahead for potential hurdles in the future and maintaining physical activity.⁵ Poor coping strategies within this category include avoiding problems rather than approaching them or modifying behaviours to avoid previous activities.³ Finally, emotion-focused strategies involve mediation or release of emotions to address the personal impact of a disease. Mechanisms such as disavowal, a "healthy denial" of new limitations, humour or emotional redirection via relaxation have been shown to be beneficial and healthy.⁶⁻⁸ However many common strategies such as denial, rejection and guilt tend to be associated with poorer health outcomes.⁹

In addition to coping strategies, psychosocial circumstances

affect the ability to cope with the burden of chronic disease, independently and through modifying the above strategies. Of particular importance is the presence of a social support network. Recent literature has indicated that the diversity of support may actually be more important than a patient's perceived strength of the social support.¹⁰ Furthermore, there is extensive evidence that social isolation and withdrawal lead to significantly worse disease-related health outcomes and prognosis.¹¹ Lower socioeconomic status makes coping more difficult by increasing levels of overall stress, increasing the likelihood of unhealthy behaviours, decreasing access to healthcare and reducing acquisition and usage of effective coping strategies. Early access to education in life has been found to be particularly important for the development of effective coping strategies.¹² A final factor to be considered is access to healthcare. Barriers to healthcare such as location, inability to afford treatment or a poor therapeutic relationship due to a lack of trust are associated with poor coping mechanisms and health outcomes.¹³

When relating this to our own experience, it is clear SG has been coping well with her heart failure symptoms. Despite displaying poor problem-based coping for her physical limitations through problem avoidance, SG also indicates how she has changed her lifestyle and improved accessibility of her home to maintain previous hobbies despite her limitations. She remains optimistic of the future and continues to find meaning in her life, and emotionally copes with her poor activity tolerance effectively through both humour and acceptance of her new capabilities. She appears to have progressed from disavowal through to other healthy strategies including optimism. Although her social support system is not exceptionally diverse, she can depend on her children, especially her daughter, for anything she needs. Despite describing several previous negative experiences with the healthcare system she continues to trust her family physician and Community Care Access Centre (CCAC) nurses to provide quality care for her and has no barriers to receiving care since home care is provided.

HOW HEALTHCARE PROFESSIONALS CAN HELP

Different healthcare professionals (HCPs) can play significant roles in helping patients to cope with chronic disease. The first significant role to be played is education. The importance of this step should not be understated. Patients often rely on physicians to identify concerns and provide solutions, but information solely provided by physicians will not always be sufficient.¹⁴ This is where allied health professionals can play a significant role. Registered dietitians can advise patients on meal plans and optimizations to their diet, social workers can help make arrangements and adjustments to patient's daily routine and physiotherapists and occupational

therapists can help directly with management of physical symptoms including mobility concerns. The combination of HCPs working together allows patients to better understand what changes in their functioning are to be expected, helping them to adjust and cope. Access to these services would be ideal but can be unavailable at times and consequently, some patients feel they could receive more education from their healthcare team.¹⁴ A patient's willingness to change how they perform daily activities to accommodate their new physical capacity is a very important initial step when coping with a sudden life change, as exemplified by the impact heart failure has on daily functioning. Nursing support, through encouraging and educating patients about how to manage their lives, can act as a strong incentive to maintain and strengthen physical ability.¹⁵ Nursing staff in particular can play a key role in breaking the vicious cycle of inactivity and decreased physical ability that is so commonplace in heart failure. Maintenance of quality of life and return to previous functioning are goals that should be encouraged by building the patient's confidence and educating about what to realistically expect during the rehabilitation process.¹⁵

HCPs should always encourage self-care since no matter how much advice and help they give, they are only in the patient's lives for a small fraction of time, making it is an extremely necessary and effective coping strategy.¹⁴ This emotion-focused coping can further be included into a more global problem-focused coping strategy with research indicating that that problem-based coping encouraged by HCPs is most effective when combined with acceptance in maintaining physical self-care.⁸ Encouraging use of problem-focused coping through concentrating on stopping existing maladaptive coping strategies, creating a sense of control and building the patient's confidence in handling problems in a 10-hour course of "brief strategic therapy" significantly reduced perceived stress for patients coping with a recent heart attack.¹⁶ The reduction in stress was associated with not only increased psychological well-being, but also decreased mortality due to reinfarction,¹⁶ demonstrating that psychotherapy can certainly play a role in developing healthy coping strategies which can have further impact on an individual's general health.

Reflecting this evidence back to our personal conversations with SG and her family, we can see areas where her healthcare team succeeded, and others where perhaps increased involvement and intervention could potentially have further improved her level of function. SG definitely understands her disease and its prognosis and is surprisingly pragmatic about her heart condition, and her life in general. She is accepting of her condition and while it has significantly impacted her ability to enjoy her previous outdoor activities such as gardening, her outlook on life remains optimistic. She has faced her fears about her condition and in our opinion, is coping in an effective, healthy manner. Regarding her physical activity, it is apparent that different strategies than those recommended by her healthcare team could have been used since she is more focused on her limitations than her abilities. SG struggles with spending any time outside due to symptoms of her heart failure and a more pronounced effort from her healthcare team on breaking this cycle

of inactivity will likely continue to improve her daily functioning and quality of life. Although she is appreciative of the comprehensive care that her physician and CCAC nurses are providing, she occasionally feels that they focus on activities that she is capable of, such as cleaning and cooking, at the expense of concentrating on improving her physical capacity. SG accepts her decreased ability to spend time outside her home, but it seems to bother her since the outdoors were such a significant part of her life prior to the onset of the disease; increased focus on improving coping for this aspect of her illness would likely benefit her.

CONCLUSION

The combination of our literature research and reflection on our conversations with SG and her daughter have made it clear that although there are many individual factors that influence our ability to cope with a chronic medical condition, the healthcare team is instrumental in providing guidance and education that can help influence the adoption of beneficial coping strategies. This opportunity has provided us important insight into the patient experience and how we as future physicians can reduce the increasing burden of chronic medical conditions as the Canadian population shifts towards a more elderly demographic. While it is difficult to universally recommend how this can be approached due to the diversity of the illness experience difference people have, the general idea is to reinforce healthy coping strategies during follow-up visits. Taking the time to educate patients at each visit about their condition, how it could affect them and what they could do about it is an important step that unfortunately may not always work its way into a standard visit. Encouraging healthy coping strategies mentioned above through humour, optimism, adjusting the environment to adapt to physical limitations, overall self-care and referral to appropriate additional services will benefit any patient with chronic disease—as we can see in the case of SG and her effective coping strategies.

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