

Myeloproliferative disorders- Psychological aspects.

Myeloproliferative disorders include Primary Thrombocythaemia, Polycythaemia Vera, and Myelofibrosis. In these chronic conditions patients may experience a variety of stresses caused by dealing with uncertainty about the future, life threatening issues, unpleasant symptoms, loss of control, changes in self image, potentially difficult pregnancies and possible inability to have children, difficult treatment options and maintaining relationships.

People vary widely in how their MPD affects them. Many people find that having an MPD has little impact on their lives and they cope well. For others, having an MPD can cause them to experience various problems. Ability to cope with chronic conditions can change over time depending on various things like changes in the condition, treatment and other changes in the person's life.

On diagnosis, individuals and their families must deal with the shock of the news, assimilate information about the disorder and its treatment and learn how to manage the illness alongside daily life tasks of family and work. The individual must integrate treatment demands with work and social activities remain hopeful and define limits to behaviour/lifestyle, which takes account of the need to achieve personal goals whilst at the same time balancing the constraints of the illness. The physical demands and psychological challenges imposed as a consequence place some individuals under greater stress.

Emotional reactions

Patients with chronic life threatening illness can sometimes fluctuate in & out of depression primarily as they are coping with huge and increasing set of potential losses. Examples may include loss of autonomy, loss of physical control and emotional loss. For some, living with the threat of premature death is a major source of anxiety that can cause people to behave in strange and irrational ways.

The invisible nature of chronic illness

Myeloproliferative disorders are very loud at the cellular level but in communicating at the social level it can be relatively silent/invisible. This can mean that onlookers are not as sympathetic which adds to the person's distress. This is not surprising when family and friends, work colleague's and employers all seem to question the legitimacy of the illness.

A young man with a myeloproliferative disorder who found it very hard to cope exemplifies this distress:

"Everyone keeps telling me that I look fine and when I tell them I am not fine; they are not interested. This makes me upset and fed up. What's the point in trying to explain anything?"

In some patients feelings like these can cause social withdrawal and increased depression, which are compounded by the side effects of medications. Many patients may undertake a cost/benefit analysis around treatment options. In other words, if the treatment is going to make me feel worse than the illness itself, is it worth taking the medication? If the medication has to be administered via injection then fear of needles can be a major hindrance to effective treatment.

Causes/ stress induced illness?

There is quite a lot in the media/ press and on TV about the ways in which stress can cause illness. We have learnt to expect that people who are under a lot of stress can become unwell, just as we expect those who are chronically ill to feel stressed. There is significant amount of research that suggest that stress can cause illness by undermining the immune system however it's the amount and type of stress that is the problem not

stress per se. We all need a certain amount of stress to function optimally i.e. good stress (Eustress). In the good stress situations we feel challenged. Challenged people are more likely to have better morale, because to be challenged means feeling positively about demanding situations as reflected in the pleasurable emotions accompanying challenge. In these situations we function better because we feel more confident. In fact some people with MPD see it as a personal challenge, something to overcome and to fight. Research has shown that this kind of "fighting spirit" is strongly related to positive well-being in people with a wide range of chronic illnesses. Many patients see MPD as an opportunity to look after self, and to concentrate on the areas of their life that they consider to be more important.

Bad stress (Distress) generally involves strong negative emotions and negative thoughts and it's this stress that psychologist can help to control. A Health Psychology service was made officially available to MPD patients at the beginning of 2004.

Thoughts feelings & behavior

Thoughts, feelings and actions interlink with each other: what we do influences thoughts and feelings, and equally, the way we think can affect actions and feelings. With the unpredictability and uncontrollability of blood clots, bleeding, long term uncertainty, medicinal side effects and other complicating factors, it is not surprising that at times people find themselves feeling demoralised, helpless or pessimistic and these are evident in our thoughts. For example, thoughts like "I won't be able to do this properly" make it hard to even start anything. Equally, you may find yourself feeling worried, frustrated or helpless before or during an activity. These feelings are often linked to thoughts that may be running through your mind at the time. For example, thoughts along the lines of; "I can't imagine getting over this" or "I might make myself worse" are very likely to contribute to feelings of fearfulness or helplessness that are not only distressing but also hold you back. These types of thoughts are quite common in long-term illness, and because of the way they make people feel and their impact on behaviour. Fortunately something can be done to change these thoughts.

Coping with chronic illness/Taking control

In my work as a psychologist I work with patients to concentrate on the effects of their thoughts and thinking patterns. This is achieved by a technique called cognitive behaviour therapy (CBT). CBT can be thought of as a type of problem solving that involves managing difficult feelings like depression and fear. Tackling negative thoughts is thus a means to an end, not an end in itself: the goal of therapy is to find solutions to the patient's problems, using CBT strategies, not merely to help the patient to think more 'rationally' but to help people to recognize and change negative pessimistic thoughts. This strategy offers relief simply because it puts the person in control as the negative stress is being reduced.

In the longer term, the same strategies are used to solve life-problems (such as situational or relationship difficulties) and to prevent, or at least extend the periods between depression. Other strategies that you can use to take control include:

- Redefining goals to be more realistic/achievable
- Relaxation strategies
- Alternative/holistic therapy, (e.g. reflexology, aromatherapy massage)

Finally MPD Group support- is useful in reducing stress and negative thoughts because they can:

- Link people suffering from MPD and to share pertinent issues, ideas, information, experiences, struggles and hope.
- Give and receive support.
- Reduce anxiety, fears and any feelings of isolation.

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