

Making sense of chronic illness

—a therapeutic approach

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ABSTRACT

INTRODUCTION: A diagnosis of any chronic progressive illness can be a traumatic experience. People wonder how they will be able to cope and health care professionals wonder how they can help those so affected. The aim of the study was to discover how people find meaning when they are diagnosed with chronic illness. The research question asked is: How do people make sense of living with chronic progressive illness?

METHOD: This is a qualitative study using a phenomenological approach to apply what is learned to developing therapeutic strategies in order to help those so diagnosed to find the meaning they need in order to live with resilience. Semi-structured interviews with seven people were held in order to determine how they cope with living with chronic progressive illness. The results were then used to develop some suggestions for health professionals as they seek to assist people with chronic progressive illness.

FINDINGS: All participants displayed much resilience and determination which was found to emerge from three main themes: memory, hope and meaning. Memory was seen to be the link between all the themes. These are described and, arising out of the results of this study, some suggestions are made in order to assist in management.

CONCLUSION: It is possible for health care professionals to assist patients to make sense of chronic illness by helping them to view their illness as part of life, and therefore a challenge to be faced rather than seeing life as dominated by illness.

KEYWORDS: Chronic disease; resilience, psychological; narration; psychology, existential

Introduction

The origins of this article are to be found in a thesis submitted in 2009 for the degree of Master of Health Sciences.¹ The research question originates in the experience of the corresponding author who has multiple sclerosis.

When cure is not possible, the relief of suffering is the cardinal role of medicine.² Caring for people with chronic illness involves more than relieving physical symptoms. Making sense of life is important to everyone, not simply to people with chronic progressive illness. However, when people become ill, and especially if their

life ambitions are conflicted because of that, then making sense of the situation becomes urgent. Roos and Neimeyer³ make the point that chronic loss can hamper the reconstruction of meaning. If we are to help patients with chronic illness find meaning, then we need to ensure that their grief is assessed and that they are helped to deal with it.

Telling one's story is at the heart of a narrative approach and the story is used to imagine different endings and reflect how the story might change. Not only is narrative a useful therapeutic tool, but it can be invaluable in terms of research.⁴ By analysing the stories of patients and

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making use of the collected stories of illness, researchers can learn about the ways in which suffering affects the self. It teaches professionals about suffering from people who are the experts (i.e. those who are suffering). Suffering is more than of the body and more than a psychological response. It involves more than coping. Therefore, narrative medicine has the potential to keep practitioners more focused on what much of medicine is about—caring for patients.⁵

In a study focusing on people with multiple sclerosis, Eeltink and Duffy⁶ suggest that the experience of illness as well as the experience of caring for, and living with, an ill family member represents a set of unique cultural experiences. Identity is too often blurred by the merging of the experience of being a person with the experience of being a person who is ill—this is a life-limiting situation. Health professionals can help patients see their life events in terms which are different—by helping them look at new ways of being in the world.

Finding a ‘good outcome’ in rehabilitation is no easy task. ‘Quality of life’, which is easily and

WHAT GAP THIS FILLS

What we already know: A diagnosis of chronic progressive illness can cause patients distress as they struggle with not only physical symptoms but also with existential questions. Such questions can undermine the patient's ability to cope with the diagnosis.

What this study adds: Various types of therapeutic approaches, including the use of narrative-type interventions, can aid the patient in their struggle for meaning. This study includes suggestions which may provide a way for patients to make sense of what is happening.

‘Taking charge’ does not necessarily mean disposing of caregivers. It means that emotionally the patient remains as the author of his or her own story. Suffering from chronic, progressive illness does not mean simply opting out of life with all its ambitions, although it may mean reframing ambitions and making some significant emotional as well as physical changes. Thorne et al. investigate this concept by focusing on a group of people suffering from Type 2 diabetes, HIV/AIDS and multiple sclerosis.⁸ The question they asked was, “How do persons with chronic illness

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naturally assumed to be the outcome of rehabilitation, is difficult to determine and generally poorly defined. Personality plays an important part in the ways in which people respond to their disability. McPherson et al. introduce the concept of ‘taking charge’—which stresses the importance of those who are suffering ‘taking charge’ of aspects of their lives which in the past have been taken charge of by other people.⁷ In the words of the authors:

“The term embraces the overall philosophy of living with arthritis rather than relating just to disease control.”

describe self-care decision-making?” All participants reflected the outcome of an unconscious decision to gain control of the management of their disease and their subsequent efforts to do that. They understood that their illness was going to be part of their lives for the foreseeable future and that being in control meant that they could live as normally as possible, therefore knowledge about their disease was important.

Carter et al. bring the concept of ‘taking charge’ to the fore in a study of people living with a terminal illness⁹. These authors demonstrate that preparation for dying is of far less importance

than living life to the full, within the constraints of their illness.

Suffering is more than physical and a whole range of issues needs to be addressed if holistic care is to be offered to people with chronic illness.¹⁰ A variety of influences in a patient's life may affect their perception and experience of pain. Speck reminds us of the growing evidence for the importance of spirituality and the importance of addressing and responding to this.¹¹ This view is supported by many patients, some of whom view relationships especially with family and friends as forming the basis of spirituality.¹² Speck suggests that spirituality is often described as a search for meaning and, in fact, many people link spirituality and meaning. He calls this "existential meaning". The aim of this study is to look at the components which contribute to finding meaning in the midst of chronic progressive illness.

Method

This is a qualitative study and a phenomenological approach was used. Seven people (six with chronic progressive disease and one with severe irritable bowel syndrome and food intolerances) aged between 36 and 78 were interviewed in order to discover if they made sense of their illness and, if they did, then what strategies they used. Three of the participants were retired, one worked as a volunteer and three were professionals in full-time employment. All were European.

Approval for the research and the ways of approaching potential participants was given by the Northern X Regional Ethics Committee of the Ministry of Health. (NTX/08/105). Participants were recruited in two ways: initially, letters were sent to 25 general practitioners and others were recruited by word of mouth. Willing participants were sent information sheets and consent forms, contacted and arrangements made for interviews. Each interview lasted under an hour and was audio taped and transcribed. The interviews were semi-structured in order to provide similar questions for each interviewee. Questions were asked about the history of the illness, the significance of diagnosis, changes to life because of it, the role of spirituality (if any), support, disruption to life and the construction of meaning. Field notes were also kept.

Transcripts were re-read several times, paying attention to what was said by the participant, as well as to become familiar with the participant's situation. When all the interviews were completed, the transcripts were analysed and themes identified. Transcripts were compared with each other and that was followed by a comparison between this research and that of other researchers.

Findings

It became apparent that all participants demonstrated a large degree of determination and resilience. This led to questioning from whence that theme derived. It became clear that the emerging themes could be categorised under the headings of memory, hope and meaning.

Participants were asked to speak about their illness and the effect it had on their lives. Memory was found to play an important role. As they reviewed their lives and the ways in which illness had impacted them, it became clear that they were all proud of their achievements and proud too of the ways in which they had coped with challenges. A participant with Huntington's disease said:

"You know I had a lovely job with teaching... I was a very successful teacher."

She also looked back with pride on the fact that in the past she was able to cook beautiful meals for people.

Table 1 Characteristics of participants

Participant	Age	Gender	Diagnosis	Duration of illness
A	65	Female	Huntington's	11 years
B	69	Female	Rheumatoid arthritis	15 years
C	78	Female	RA, diabetes 1, osteoarthritis, coeliac disease	40 years
D	36	Female	Crohn's	13 years
E	67	Female	Atrial fibrillation, diabetes 1, lymphoma	25 years
F	53	Male	Renal failure, cancer, stroke	31 years
X	46	Female	Irritable bowel syndrome and food intolerances	30 years

Another, who has chronic renal failure, speaks of his experience following a stroke which left him severely incapacitated and having to learn to walk again. He had been physically very fit and describes how his wife “stole” him out of hospital one day and took him to the river basin where he used to run:

“It [used to take me] 17 minutes to run around... and I wandered around that track... and it took me two and a half hours to get around... it was a long trip so um... yes it was a good benchmark—two-and-a-half hours. I’d get back to 17 minutes one day.”

While receiving a diagnosis can end a period of uncertainty, it can also bring pain and distress; but it also appears that having a diagnosis can allow people to ‘move on’ to living with the symptoms. Most of the participants had lived for some time with the symptoms before receiving a diagnosis.

One participant felt devastated by her diagnosis after she had had a blood test to find out whether she had Huntington’s disease, but arising out of the shattering experience of receiving the diagnosis came her conclusion:

“I decided I could live or just become a couch potato.”

It became apparent that reflecting on past successes and reviewing how they coped with challenges, disappointments and difficulties became a significant part of enabling the participants to see their illness as part of their life narrative rather than seeing life in terms of the illness.

All participants demonstrated a considerable amount of hope, despite their diagnosis, and, for some, serious incapacity. While this hope was fed by the memories they have of the past, both in terms of pride in achievement and also in conquering problems, there was also an appreciation of the fact that they had support in a variety of ways, including family and friends. Some spoke of their faith. One says:

“I couldn’t live without my faith. And I couldn’t manage without it... I thank God every day for the gift because it is a gift.”

Another says:

Table 2. Themes

Memory	Hope	Meaning	Outcome
Pride in achievements	Wider support—family, friends, Church	Making sense	Resilience and determination
Diagnosis	Spirituality—role of Church and /or personal faith		
Illness as a journey			
Acceptance			
Grief			
Frustrations, changes and challenges			

“Well... I ’as a chat with him every night... But I can’t hear him saying anything but I’m sure he does.”

All participants were asked how they made sense of their condition. One spoke of genetics—her mother, two sisters and some of her children have the same disease:

“This is something awful—this has teeth which are vicious.”

Others spoke of their faith and pointed out that because of their experience with illness they were able to contribute more to the community. Another initially stated that she thought meaning was not an appropriate category:

“Well... to me it seems everybody gets something... we all are going to suffer... and to die... well maybe not to suffer but we’re going to die. Why do we need to find a meaning? This is God’s will for us... this is our cross... that’s my meaning.”

However, later in the interview she shared a somewhat different opinion:

“I strictly believe this... it’s very flaky but I believe that I gave the disease to myself... Because... nobody in my family’s got it... there’s no history of it... just me and why I did it is that for three weeks I put my body under enormous stress, trying to be Mrs Perfect... doing about 15 jobs when I could really seriously only manage three... I was doing exam supervision... um... I was looking after a lady... I had to do her shopping... I was working... I had an hour or so just between finishing work and getting to the university... I pushed, pushed, pushed myself...

After three weeks—blow me down... I had a stiff knee... a very painful wrist... the nodules which are another key symptom... I was finished... so I truly believe that and no medical people would accept that but that's what I believe and yes I grieved over that but I didn't have to do all that I was just trying to be too blooming perfect! And now I can't change it... it's non-returnable... you see what I mean? The symptoms are distressing... but I knew I'd brought it on myself... I had no one to blame... so there you go."

Someone else simply said: "Maybe people like us inspire people who have nothing wrong with them."

All displayed high levels of resilience and determination. Despite all that seemed to be going wrong in their lives, they seem to have risen above it and become stronger.

to find meaning in the midst of chronic illness. Memory forms the heart of such narrative.

Chochinov,¹³ in writing about people who are dying, encourages the treatment of patients in ways which help them feel valued as human beings. People who are dying are invited to share their memories with a biographer who will write up parts of their life story and then edit it so that it may be bequeathed to loved ones. Being able to relate their story to someone else enables patients to find a sense of hope in that they can hand on to the next generation something of value which they themselves have learned and would like to pass on. The important point, in terms of this research, is the fact that it appears to be the telling of the story and handing it on which gives the patient a sense of hope.

Memory plays a central role in our sense of being. Nouwen writes that emotions—such as pain and joy and sorrow and feelings of grief and satisfaction—are not simply dependent on events in life, but on the ways in which they are remembered. Memories provide a lens through which to see life.

Discussion

Making sense of what is happening, asking why and seeking answers to that question seems to be part of the human condition. The participants in this study make sense of what is happening to them in terms of their situation as well as in their wider belief structure. It is of significance that the majority see their illness as an opportunity to reach out and continue to contribute to the wider community. All were able to make sense of their illness and find meaning in life. A wider study may well include people for whom the process of meaning-making is impossible. Six out of the seven participants spoke about the importance of spirituality.

This study has shown the importance of paying attention to the entire life narrative in order

Memory plays a central role in our sense of being. Nouwen writes that emotions—such as pain and joy and sorrow and feelings of grief and satisfaction—are not simply dependent on events in life, but on the ways in which they are remembered.¹⁴ Memories provide a lens through which to see life. The past can become an important teacher. In this study, all the participants shared painful memories and times of frustration, but dealing with those times gave them the strength to face and to deal with what was happening in the present in terms of their illness. Nouwen reflects on the French expression 'reculer pour mieux sauter', meaning 'to step back in order to jump farther'. Certainly, the participants in this study demonstrated in many ways that they were able to do that.

While this study deals only with a small group of participants, this finding could influence the

ways in which health professionals and others assist people diagnosed with chronic progressive illness to cope with both their diagnosis and with leading a fulfilled lifestyle. Chronic progressive illness is, by its nature, about change and helping people to cope with those changes is part of a holistic approach to health care. Change sometimes comes dramatically but, more frequently, it is a much slower process. Living with such illness may involve constantly readjusting to changes in life which are brought about by the illness.

Arising out of this research, some suggestions are offered which may assist the health professional help people who are struggling with chronic progressive illness. There are no 'quick-fixes' or 'magical cures' when it comes to chronic progressive illness, and this approach certainly does not offer them. However, it does suggest that respectful listening to the patient's story may reveal some strengths (often hitherto unrecognised) that may become triggers for new ways of looking at the situation.

The participants in this study were able to use the experience of being successful in the past in order to assist them to deal with issues in the present. In working with a patient who feels 'stuck' in the diagnosis, it is necessary to begin with the presenting issue and take that seriously before proceeding to help the person find strength from past achievements which may in fact be times of coping with failure. Open-ended questions need to be asked concerning the present issue before focusing on successful coping strategies from the past.

It may involve careful analysis of the past and an ability to 'reframe' some events which, to the patient, have appeared to be negative. Such an approach needs to be seen in terms of assisting people to develop life skills rather than assisting them to face past trauma. Crises may occur more than once in a person's life as he or she seeks to deal with new situations and symptoms which may arise. When a person receives a diagnosis of chronic progressive illness it may feel as though life is falling apart. Likewise, when illness deteriorates to the point where changes have to be made, it can feel like a threatening blow and a disruption of security. Many people feel 'stuck'

and alone and may find it impossible to believe that they have a future—or any future which will bring happiness and fulfilment. Looking at past successes and affirming them may enable the patient to apply what he or she has learned in the past to the present situation.

When people are encouraged to tell their stories, it becomes possible to help them identify strengths and coping strategies which they may not realise they had.

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COMPETING INTERESTS

None declared.