

Chapter 26

Patients with a Spinal Cord Injury Inform and Co-Construct Services at a Spinal Cord Rehabilitation Unit

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ABSTRACT

This chapter reports on a qualitative research project which explored patients' experiences of counseling and which provided the impetus for changes to be incorporated in the rehabilitation and health care provided at a spinal cord rehabilitation unit in Auckland, New Zealand. Navigating different landscapes of meaning, philosophies, ideas and practices from approaches such as the relationship-centred model and narrative medicine developed into a collaborative meaning-making partnership between the patient team and the multidisciplinary team that further shaped practices of doing reasonable hope together.

INTRODUCTION

Different models of medical health care to patients and their families have been developed in the quest for optimal and successful provision of service, care and patient satisfaction. There have been a number of shifts in medicine with regard to the models used to shape practitioners' relationships and interactions with their patients. These medical and biomedical practices and approaches regarding what is in the best interests of patients were

initially informed by a philosophy that patients should not be burdened with making decisions about their care. The aim was to ease the burden for patients by letting the doctor, who was believed to have exclusive specialist knowledge in this field, make the decisions. However, in recent years, doctors have increasingly been invited to discuss treatment options, including benefits and risks, with patients and their families. These models include the medical model, the bio-psychosocial model (McDaniel, Hepworth, & Doherty, 1992), the integrated care model (World Health Organisa-

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tion, 2001), the relationship-centred model (Beach, Inui, & the Relationship-Centered Care Research Network, 2006; Frankel & Quill, 2005), a narrative approach to health psychology (Murray, 2009) and narrative medicine (Charon, 2006). All these models offer varying positions and responsibilities to health practitioners, the multi-disciplinary team, the patient and his/her family.

This chapter draws on a qualitative research study carried out at the Auckland Spinal Rehabilitation Unit in New Zealand (hereafter called the Spinal Unit). Results from the study and ongoing patient feed-back were used to shape and re-plan certain services. The chapter shows how different landscapes of meaning, philosophies, ideas and practices from approaches such as the relationship-centred model and narrative medicine developed into a collaborative meaning-making partnership between the patient team and the multidisciplinary team that further shaped practices of doing reasonable hope together. Reasonable hope directs attention to what is within reach and it softens the polarities between hope and despair. It maintains that the future is open, influentiable and influenciabile and it accommodates contradiction and despair (Weingarten, 2009).

BACKGROUND

The Spinal Unit offers services to in-patients and outpatients. The medical multi-disciplinary team consists of doctors, nurses, physiotherapists, occupational therapists, dieticians, nutritionists, pharmacists, social workers and counsellors. Patients are admitted to the Spinal Unit once they are medically stable and ready for active rehabilitation, usually about four to eight weeks after they were injured, depending on the waiting list at the unit.

The Spinal Unit aims to work in a partnership relationship with patients. This partnership relationship was informed and co-constructed by the findings from the research study and patient feed-back. Negotiating a partnership that speaks

of respect for multiple perspectives and collaboration as described in this chapter will draw on positioning theory and post structuralist definitions of agency.

Providing health care services poses different challenges for both the multidisciplinary team and the patient team (members of a patient's support team can include caregivers, friends and family). The health professionals' purpose at the Spinal Unit is to enable patients to be as independent in their activities for daily living as possible and live a quality life. Quality of life depends on a person's subjective evaluation of the degree to which his/her most important needs, goals and wishes are fulfilled (Frisch, 2006). Independence may be gained through equipment, for example, a wheelchair, or through learning about personal care so that patients can direct others to assist them. Independence can also be gained through education about aspects of the patient's body that may have changed and/or through managing the psychological and emotional adjustments that result from a spinal cord injury. The discourse of what "independence" might look like in the lives of patients with spinal cord injuries becomes a site of deconstruction, questioning and is being held up for review. The process of negotiating new meaning of "independent" may open the possibility of a spectrum of dependencies, independence and interdependence. Health care professionals of the Spinal Unit are committed to working alongside patients to provide the best possible spectrum of service to patients in assisting them with this challenge.

The medical team and the patient team are differently positioned in this: while health care professionals are committed to using their knowledge and skills in the service of patient care, they exercise a choice about whether or not to work at the unit. Patients and families are committed to a healing rehabilitation journey frequently filled with uncertainty, challenges and possible disappointments, and do not experience a similar sense of agency. Agency is defined as participating in

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