CONTENTS

PREFACE vii
CONTRIBUTORS viii
REVIEWERS xiii

SECTION 1: FRAMEWORKS FOR CHRONIC ILLNESS AND DISABILITY 1

1 Chronic illness and disability: an overview 1
   Amanda Johnson, Esther Chang

2 Role of the interdisciplinary/multidisciplinary team 16

3 Models of care 38
   Vicki Drury, Samar Aoun

4 Spirituality and the nurse: engaging in human suffering, hope and meaning 60
   John Rolley, Esther Chang, Amanda Johnson

5 Psychosocial care 81
   Alan Merritt, Marina Boogaerts

6 Stigmatisation of people living with a chronic illness or disability 101
   Lynne S. Giddings, Dianne E. Roy

7 Sexuality in chronic illness and disability 115
   Tinashe Dune

8 Developmental and intellectual disability 133
   Jennifer Evans, Susan Gallagher

9 Management of chronic pain 153
   Clint Douglas

10 Rehabilitation for the individual and family 183
    Julie Pryor, Kate O’Reilly, Melissa Bonser, Gillian Garrett

11 Impact of obesity on chronic illness and disability 211
    Annette James, Gilbert de Chalain

12 Palliation in chronic illness 232
    Christine Haley, James Daley

SECTION 2: PRINCIPLES OF PRACTICE FOR SUPPORTIVE CARE 252

13 Schizophrenia 252
   Louise O’Brien, Scott Fanker

14 Depression 269
   Scott Fanker, Louise O’Brien

15 Advanced dementia 294
   Esther Chang, Amanda Johnson, Karen Hancock

16 Stroke (cerebrovascular accident) 314
   Andrew Scanlon
17 Parkinson's disease, multiple sclerosis and motor neuron disease
Robin Ray, Anne Kavanagh, (with contributions from Laraine McAnally) 329

18 Chronic asthma
Philip Stumbles, Prue Andrus, Christophe von Garnier 351

19 Chronic obstructive pulmonary disease
Colleen Doyle, Rebecca Howard, Sandy Ward, Maree Daly 371

20 Coronary heart disease
Angela M. Kucia, Elizabeth Birchmore 393

21 Chronic heart failure
Patricia M. Davidson, Phillip J. Newton, Peter S. Macdonald 409

22 Chronic kidney disease
Ann Bonner, Bettina Douglas 424

23 Chronic diseases of the bowel
Michelle Woods 445

24 Non-melanocytic skin cancers and melanoma
Isabelle Ellis, Keryln Carville 465

25 Ageing and disability (osteoarthritis and osteoporosis)
Tiffany Northall 478

26 Principles of practice for supportive care: diabetes
Rhonda Griffiths 492

27 HIV/AIDS
Stephen Neville, Mark Henrickson 514

28 Cancer
Patsy Yates 531

INDEX 546
This book is developed for undergraduate nursing students, students in the TAFE sector, newly registered nurses and other health professionals who share our commitment to providing quality of care to people with chronic illness and disability. This book is based on principles for practice supported by evidence from Australian and international literature to enhance the understanding of some of the issues and challenges of caring for a person with chronic illness and disability. Across all chapters, the text illustrates a holistic approach highlighting quality of life in all aspects of care for chronic illnesses and disability. Concepts essential for underpinning best practice in self-management of chronic illness and disability are included, such as spirituality, individual education strategies, valuing the person's expertise, resources, culture, minimising socially stigmatising processes and social isolation. Issues affecting carers and family are also addressed. Attention to these concepts recognises the important shift nurses and other health professionals are making towards working in partnership with individuals, their family and carers. Through education and empowerment, individuals, their family and carers are supported in their adjustment and adaptation to chronic illness and disability to achieve optimal outcomes.

This second edition provides new case studies and reflective questions on chronic illness and disability for discussion. Where relevant, the text is supported by current statistics to illustrate key aspects of the discussion. Acquiring the knowledge and skills for people with a chronic illness and/or disability is vital in giving competent care. The reader will find viewpoints that are challenging but at the same time motivating and thought-provoking. The exercises and learning activities that are presented throughout the text offer the reader a range of helpful suggestions in understanding the context. This edition also includes one new chapter in models of management. In addition, each chapter has recommended readings for further exploration.

Nurses and other health professionals in clinical practice and academic roles have been involved in producing this text resource. We hope that readers will find the text scholarly, accessible, reality-based and practically useful. It is a resource intended for every student, practising nurse, educator and administrator in understanding the issues of caring for people with chronic illness and disability. By reading the text, reflecting on the issues and posing possible answers, the reader should be able to gain a comprehensive view of the issues, challenges and opportunities ahead of them in their practice.

We want to acknowledge a number of key people who contributed and assisted us in preparing this 2nd edition for publication. We wish to extend our sincere thanks and appreciation to the contributors for their shared interest and concern with the issues and challenges of caring for people and their families in nursing. This book would not be possible without them. We would like to extend our special appreciation to members of the Elsevier team: Libby Houston, Elizabeth Coady, Vicky Spichopoulos, Natalie Hamad and Nayagi Athmanathan. Elsevier Australia joins us in thanking all the reviewers who were involved in providing invaluable feedback during the development process (listed on page xiii). We would also like to thank our families for their endless support and encouragement through the years. Finally, we’d like to dedicate this important text to our past, present and future students.

Esther Chang
Amanda Johnson
Learning objectives

When you have completed this chapter you will be able to:

- recognise the scope and impact of chronic pain in Australia
- discuss the relevance of a biopsychosocial model of chronic pain for persons with chronic illness and disability
- identify key components of pain assessment
- acknowledge the central role the person with chronic pain takes in the management of their health
- identify a range of therapies available for the management of chronic pain.

Key words

chronic pain, disability-related pain, biopsychosocial model, pain assessment, pain management

INTRODUCTION

Pain is a common and often under-recognised problem among people with chronic illness and disability. For example, accumulating evidence demonstrates that pain is a prominent component of most of the specific chronic diseases discussed in this volume. Recent surveys have found pain is prevalent among people with stroke (Klit, Finnerup, Overvad, Andersen, & Jensen, 2011), multiple sclerosis (Douglas, Wollin, & Windsor, 2008a), chronic obstructive pulmonary disease (Bentsen, Rustoen, & Miaskowski, 2011), chronic heart failure (Evangelista, Sackett, & Dracup, 2009), chronic kidney disease (Davidson, 2003),...
inflammatory bowel disease (Schirbel et al., 2010), diabetes (Bair et al., 2010), HIV/AIDS (Namisango et al., 2012) and cancer (van den Beuken-van Everdingen et al., 2007). A consistent finding across these studies is that individuals often report multiple types of pain and a significant subset experience moderate-to-severe pain intensity on a daily basis. Once pain develops, it often becomes a chronic problem across the illness trajectory. For example, a comprehensive review of symptom prevalence in end-stage cancer, AIDS, heart disease, COPD and renal disease revealed pain was found among more than 50% of people for all five conditions (Solano, Gomes, & Higginson, 2006). As the life expectancy of individuals with chronic illness has increased, observations of the prevalence of pain problems over the entire disease course without reversible causes suggests disability-related pain is often best conceptualised as a chronic pain condition (e.g., Marcus, Kerns, Rosenfeld, & Breitbart, 2000).

The clinical significance of chronic pain in the context of a disabling disease is underscored by the negative impact of pain on functioning. Chronic pain can cause severe physical, emotional, social and economic problems for affected individuals and their significant others. The general pain literature has documented the profound effects that chronic pain has on mood, personality and social relationships, as well as the concomitant experiences of depression, sleep disturbance and decrease in overall function (e.g. Turk et al., 2008). Much less is known about the specific impact of pain on physical and psychosocial functioning among people who already have a physical disability. Although there are significant gaps in the literature, the available evidence indicates that chronic disability-related pain is associated with poorer adjustment and reduced quality of life, independent of the effects of the disease itself (e.g. Douglas et al., 2009; also see reviews by Ehde et al., 2003; Ehde & Hanley, 2006). Taken together, these findings suggest chronic disability-related pain warrants further research and clinical attention as a significant problem in its own right.

This chapter is written for nurses and other health professionals as a broad overview of a complex topic. It briefly reviews the scope and nature of chronic pain with a particular focus on chronic pain secondary to chronic illness and disability. It argues the relevance of a biopsychosocial model of chronic disability-related pain and discusses the important role of some key psychosocial factors in shaping the pain experience. Key components of pain assessment and the array of therapies that are available are also briefly outlined.

**CHRONIC PAIN DEFINED**

The most oft-cited definition of pain in the literature and that accepted by the International Association for the Study of Pain (Merskey, 1986, p. 51) is:

Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage.

This definition underscores the inherent subjectivity of pain and acknowledges the importance of emotional as well as sensory factors in the pain experience. It also highlights that although pain is usually considered as a warning signal of actual or potential tissue damage, pain can occur in the absence of tissue damage, even though the experience may be described as if the damage has occurred.

The most widely accepted and clinically useful definition of pain, however, was developed by a leading nursing expert on pain, Margo McCaffery (1968), who wrote (p. 95):

Pain is whatever the experiencing person says it is, existing whenever he says it does.

In evolutionary terms, *acute pain* can be understood as an important biological protective mechanism to warn the body of injury or disease. It directs immediate attention to the
situations, promotes reflexive withdrawal and fosters other actions that prevent further damage and enhance healing. Acute pain usually stops long before healing has occurred, which may take days or a few weeks.

In contrast, chronic pain persists constantly or intermittently past the normal time of healing and serves no biological purpose. It refers to pain that persists for extended periods of time (i.e. months or years), that accompanies a disease process, or that is associated with an injury that has not resolved within an expected time (Turk & Melzack, 2011). The mechanisms underlying the transition from acute to chronic pain include a complex interaction of physiological, emotional, cognitive, social and environmental factors. One of the most salient contributors to the pathophysiology of chronic pain is the neuroplasticity of the nervous system which refers to the ability of neurons throughout the peripheral and central nervous systems to change their structure and function because of nociceptive input. Recognising that chronic pain is perpetuated by factors that are both pathogenetically and physically remote from the originating cause, Siddall and Cousins (2004) have argued that chronic pain should be recognised as a disease entity in its own right.

Although pain problems are often classified by duration, another approach is to categorise pain problems based on underlying mechanisms. Nociceptive (physiological) pain is sustained by ongoing activation of the sensory system that subserves the perception of noxious stimuli. It implies the existence of damage to somatic or visceral tissues sufficient to activate the nociceptive system (Pasero & McCaffery, 2011). Neuropathic (pathophysiological) pain is sustained by a set of mechanisms that is driven by damage to, or dysfunction of, the peripheral or central nervous systems (Pasero & McCaffery, 2011). Neuropathic pain problems are common in diseases affecting the nervous system such as multiple sclerosis, diabetes mellitus and herpes zoster. It may also result from surgery or trauma to nervous tissue.

THE SCOPE AND IMPACT OF CHRONIC PAIN

Chronic pain is a major health problem in our communities that exacts a substantial social and economic burden on both the affected individual and society. Blyth and colleagues’ (2001) seminal Australian prevalence study \( n = 17,543 \) found that approximately one in five people experience chronic pain (defined as pain experienced every day for 3 months in the 6 months prior to interview), with an overall prevalence of 17.1% for men and 20% for women. These findings are consistent with international data. For example, a World Health Organization (WHO) survey of primary care patients in 15 countries reported that 22% of patients reported persistent pain (Gureje, 1998).

The MBF Foundation report The High Price of Pain, conducted by Access Economics (2007) using epidemiological data from the University of Sydney Pain Management Research Institute, estimated that around 3.2 million Australians (1.4 million men and 1.7 million women) experience chronic pain (not including children or adolescents). This is projected to increase to 5 million by 2050 as Australia’s population ages. The economic impact of chronic pain on the Australian community is also significant — costing approximately $34.3 billion annually, or $10,847 per person with chronic pain — making it the nation’s third most costly health problem (Access Economics, 2007).

For most of those affected, the presence of chronic pain compromises all aspects of their lives and the lives of their significant others. It is a major cause of physical and psychosocial disability, leading to loss of employment, interference with daily activities, emotional distress and depression and social isolation from family and friends (Dworkin & Breitbart, 2004). Enduring pain can create a sense of hopelessness and helplessness, increasing the
risk of suicide (Tang & Crane, 2006). Wallis’s (2005) words capture the pervasive impact of chronic pain (p. 46):

Chronic pain is a thief. It breaks into your body and robs you blind. With lightning fingers, it can take away your livelihood, your marriage, your friends, your favourite pastimes and big chunks of your personality. Left unapprehended, it will steal your days and your nights until the world has collapsed into a cramped cell of suffering.

The increasing burden of pain and resources devoted to its treatment, as well as the growing insight by clinicians that pain affects the person as a whole, has seen the rapid development of a large body of literature on pain and quality of life (QOL). Niv and Kreitler’s (2001) comprehensive review of this broad area of research draws several key conclusions about the impact of pain on QOL. The first and major conclusion supported by a great number of studies is that pain has a significant adverse effect on QOL. This effect is very strong and exists despite different kinds of pain, diseases, cultures and individuals. Second, the effect is pervasive and is manifested in many domains of life. The domains most affected are the physical, followed by the emotional, social and cognitive functioning. Third, the degree and kind of impact on QOL was shown to depend on features of pain such as its duration, intensity, present activation and salience of affective and evaluative components, as well as on the disease that contributes to modulating the meaning of the pain and on characteristics of the patients themselves, demographic and psychological.

Given the evidence cited here about the scope and impact of chronic pain, it might be expected that pain would be well treated. Unfortunately, this is not the case. In the Australian context, Cousins (2012) provides evidence that pain has long been underestimated by health professionals and sufferers poorly served and stigmatised by previous healthcare approaches which have lagged behind the advances and recommendations of the time. Part of the problem, Cousins suggests, has been the absence of data on the prevalence of pain and the associated costs of treatment which have conspired to make pain almost invisible as a national health priority.

It is also particularly difficult for people with chronic pain to obtain effective care and support because chronic pain is poorly understood by the general community, including many health professionals. The growing evidence base and theoretical insights into chronic pain have been translated into practice with limited success across the healthcare system. The next section deals with these important conceptual issues.

UNDERSTANDING CHRONIC PAIN SECONDARY TO DISABILITY

Over the past half-century researchers have developed several theoretical perspectives of chronic pain (see e.g. Novy, Nelson, Francis, & Turk, 1995) and there is an extensive literature examining the utility of these models. Much of this work, however, has focused on individuals suffering from chronic non-malignant pain as a primary condition (e.g. chronic low back pain, headaches). In contrast, very little has been written about the experience of chronic pain secondary to a disabling disease, despite pain being a prominent characteristic of many chronic diseases and its potential to compound distress and disability (Ehde et al., 2003). This is particularly the case for rehabilitation populations such as people with multiple sclerosis, spinal cord injury and cerebral palsy. Little is known, for example, about how pain contributes to disability, distress and QOL in these populations. Few studies have examined the psychosocial aspects of pain in these groups. Only relatively recently have researchers begun to explore the utility of psychological approaches to chronic pain.
conditions related to chronic diseases such as arthritis, cancer and sickle cell disease (Keefe, Abernethy, & Campbell, 2005).

A major contributor to the current state is the failure of the prevailing biomedical model of pain to provide an adequate conceptualisation of chronic pain complicating disability. Although the dominant theoretical model in the chronic pain literature is a biopsychosocial model, most health professionals and lay persons continue to view disability-related pain from a traditional biomedical model (Keefe et al., 2005). According to this view, chronic pain is a symptom of underlying disease activity that can be treated only by identifying and correcting underlying tissue pathology. Psychological and social factors are viewed as reactions to pain such that once the underlying disease is successfully treated, the associated psychosocial complications will disappear. While this model has proved useful in producing a number of important insights into pathophysiological mechanisms and the development of pharmacological treatments for clinical pain, it falls short when faced with the complexity of chronic pain (Turk & Flor, 1999).

Investigators’ loyalty to the biomedical model can in part be attributed to the prevalent assumption that chronic pain secondary to chronic illness and disability is uniquely different to chronic pain as a primary condition. The putative distinction between these conditions implies that, since they are unique, the principles that are important to each differ and thus they should be viewed and treated differently. This distinction is based primarily on the belief that disability-related pain is closely tied to disease activity or tissue damage, whereas the association between reports of pain and tissue damage in people with chronic pain as a primary condition is of lower magnitude and, in some cases, largely nonexistent. Thus, researchers concerned with disability-related pain have attempted to explain it in terms of disease activity and pathological pain mechanisms. Conversely, in the literature on chronic pain as a primary condition, greater attention is given to the role of psychosocial and environmental contributors to pain. These divergent literatures reflect the theoretical perspectives of researchers based on the presumed aetiology of chronic pain.

Consistent with this view, Campbell and colleagues (2003, p. 400) point to the fundamentally different assumptions relating to pain based on its putative aetiology. They maintain that, in disease-related pain:

… persistent pain is believed to be more strongly linked to peripheral factors, psychosocial factors are considered to be less important and treatments that primarily alter peripheral, nociceptive input are often effective.

Yet where chronic pain is the primary condition, they assert that (p. 401):

… persistent pain is believed to be more strongly linked to changes in the central nervous system, psychosocial factors are considered to play a major role and psychopharmacological treatments that alter depression are often effective in pain management.

Clinical approaches to the treatment of disability-related pain also reflect the dominance of a biomedical paradigm. The literature demonstrates that health professionals have tended to focus on physical modalities of treatment to the exclusion of psychosocial interventions (Ehde & Jensen, 2004; Keefe et al., 2005). Conventional methods of pain management consist of empirically-based pharmacological, surgical and other physical interventions aimed at eliminating the cause of the pain. Medical interventions alone, however, often fail to effectively treat individuals with chronic pain and carry with them the potential for iatrogenic complications (Turk, Wilson, & Cahana, 2011).

Recognising that chronic pain and disability are not only influenced by tissue pathology but also by psychological and social factors, multidisciplinary interventions for chronic pain have become more accepted with various comprehensive approaches and have rapidly
increased in number over the last few decades. There is strong evidence that multidisciplinary pain programs which attend to the role of psychosocial contributors to pain are effective in populations where chronic pain is the primary condition (Gatchel & Okifuji, 2006). What has not been argued so cogently, however, is that even when a disease process is identifiable and treatable, psychosocial factors remain central to the development and perpetuation of chronic pain and may provide fruitful targets for intervention. There is a notable absence of research examining the effectiveness of multidisciplinary pain programs for chronic disability-related pain.

It could be argued, therefore, that although over the past few decades a major paradigm shift has occurred in the conceptualisation of chronic pain from a biopsychosocial perspective, pain experienced by individuals with a disability continues to be understood largely from a traditional biomedical model, despite its inherent limitations. Instead, an integrative model of chronic pain which attends to the multiple physical, psychosocial and behavioural factors involved is a more useful perspective to guide the study, assessment and treatment of disability-related pain.

**TOWARDS A BIOPSYCHOSOCIAL MODEL OF CHRONIC DISABILITY-RELATED PAIN**

Despite the intuitive appeal of a biomedical conceptualisation of disability-related pain, the assumption that there exists a simple one-to-one relationship between tissue pathology and pain has been convincingly refuted in the general pain literature. Pain — regardless of its presumed aetiology — is always more than a simple sensation. It is a subjective, perceptual experience that involves the person as a whole. Disease or tissue injury is only one, albeit a significant, contributor to the experience of pain. Over time, it is far more likely that psychosocial and behavioural factors interact with tissue damage to influence adjustment to pain (Turk, 1996). Thus it is argued here that disability-related pain may best be viewed from a biopsychosocial perspective which seeks to incorporate the interrelationships among physical, psychological and social factors and the changes that occur among these relationships over time.

Biopsychosocial theorists draw attention to the distinction between disease and illness in understanding chronic pain (Gatchel, Peng, Peters, Fuchs, & Turk, 2007). Whereas the biomedical model has focused on disease, an objective, disruptive biological event caused by pathological, anatomic or physiological changes, the biopsychosocial model instead emphasises illness (Engel, 1977). Illness is defined as the human experience of symptoms and suffering, resulting in physical discomfort, emotional distress, functional limitations and psychosocial disruption (Larsen, 2013). It refers to how the individual, family members and the social network around them receive and respond to the consequences of the symptoms.

The distinction between disease and illness is analogous to that of nociception and pain (Gatchel et al., 2007). Nociception is a physiological phenomenon that involves activation of sensory transduction in nerves by thermal, mechanical or chemical energy impinging on specialised nerve endings. The nerves involved convey information about tissue damage to the CNS, but such sensations are not yet considered pain until they are subjected to higher order psychological and cognitive processing that involves appraisals. Hence, nociception is a sensory process with nociceptive stimuli capable of producing pain. Pain, however, is a subjective, perceptual experience that results from the nociceptive input and is modulated on a number of different levels in the CNS (Turk & Monarch, 2002). This conception of pain is consistent with the IASP definition of pain discussed earlier which
highlights that nociception may be necessary for pain to occur, but it is not sufficient to account for pain as a clinical phenomenon, which is always a perceptual experience.

The biopsychosocial model thus focuses on the illness experience, attending to the multiple factors that both contribute to and are affected by pain. It builds on Melzack and Wall’s (1965) gate-control theory of pain perception which focused primarily on the neurophysiology of pain by emphasising the influence of psychosocial and behavioural components of chronic pain. The conceptual view of the biopsychosocial model is presented in Figure 9.1. This nested circles model demonstrates the interdependent relationships among processes that culminate in the person’s perception of pain and overt pain behaviours. For example, biological factors may initiate and maintain nociceptive input, psychological factors influence the appraisal and perception of pain and social factors shape the person’s behavioural responses.

Several key assumptions characterise the biopsychosocial model of pain, as championed by Turk and colleagues (Turk, 1996; Turk & Flor, 1999). A central premise of the model is the multidimensional nature of chronic pain. From this perspective, pain is never solely somatically or psychologically based. Instead, the model posits that neurobiological, psychological and sociocultural factors interact to contribute to the development and perpetuation of pain. According to the model it is this dynamic and reciprocal interplay among biomedical, psychosocial and behavioural factors that produces the individual’s subjective experience of, and responses to, pain. Nociceptive stimulation, for example, can cause biological, psychological and social changes that, in turn, affect future responses to pain. Moreover, psychological and social mechanisms can modulate nociceptive input and the response to treatment (Turk, 1996). The model also explicitly acknowledges that during the evolution of a pain problem, the relative weighting of physical, psychological and social factors may shift. Thus, although biomedical contributors may initiate the report of pain and predominate during the acute phase, over time psychosocial factors play an increasingly important role in the maintenance of and adjustment to pain (Turk, 1996).
In brief, the biopsychosocial conceptualisation of pain comprises three major elements: (1) integrated action; (2) reciprocal determinism; and (3) development and evolution (Turk, 1996). It holds that pain (Turk, 1996, p. 24):

... is a complex amalgam maintained by an interdependent set of biomedical, psychosocial, and behavioural factors, whose relationships are not static but evolve and change over time.

This can be contrasted with the dominant biomedical model of disability-related pain, whose emphasis on underlying disease activity and tissue damage alone is too narrow in scope to accommodate the complexity of chronic pain.

**PSYCHOSOCIAL FACTORS AND CHRONIC PAIN**

The biopsychosocial model identifies several psychosocial variables, in particular, as having a prominent role in the experience of and adjustment to chronic pain including attitudes and beliefs about pain as well as pain-specific coping strategies (Turk, 1996; Turk & Flor, 1999). Research on these variables, in turn, has provided empirical support for the model.

As active processors of information, people with chronic pain develop underlying beliefs, attitudes and assumptions in an attempt to make sense of their pain condition. These include attributions about the cause, meaning, appropriate treatment of pain, as well as perceptions of control over pain and personal coping efficacy (Thorn, 2004). Although certain beliefs may be adaptive and promote positive adjustment, others are likely to contribute to heightened pain, distress and disability. A large and growing body of research shows that pain-related beliefs are strongly associated with various measures of pain severity, physical and psychosocial functioning (Douglas, Wollin, & Windsor, 2008b; DeGood & Cook, 2011), as well as response and adherence to multidisciplinary pain treatments (Jensen, Turner, & Romano, 2007). For example, beliefs that one does not have control over pain, that pain signifies harm and that one is disabled by pain are particularly problematic for people with chronic pain; increases in self-efficacy beliefs for managing pain appear beneficial (Ehde & Jensen, 2010). These beliefs, appraisals and expectancies held by individuals regarding the possible consequences of pain and their abilities to deal with them are hypothesised to affect functioning directly by influencing mood as well as indirectly by influencing coping efforts (Jensen, Turner, Romano, & Karoly, 1991).

Faced with ongoing pain, individuals also learn and utilise a variety of strategies to help them cope or deal with their pain (Keefe, Rumble, Scipio, Giordano, & Perri, 2004). Pain coping is defined as purposeful cognitive and behavioural efforts to manage or negate the negative impact of pain (Jensen et al., 1991). Much of the pain literature broadly classifies coping strategies as active or passive. In general, studies have found active coping strategies (efforts to function in spite of pain or to distract oneself from pain, such as activity or ignoring pain) to be associated with adaptive functioning and passive coping strategies (withdrawal or surrendering control to an external source, such as resting or medication use) to be related to greater pain and depression (Boothby, Thorn, Stroud, & Jensen, 1999). Interestingly, although maladaptive strategies are strongly associated with negative outcomes, adaptive strategies generally show only modest correlations with positive outcomes (Geisser, Robinson, & Riley, 1999).

One specific maladaptive coping response that has consistently demonstrated robust associations with virtually all pain outcomes investigated is termed catastrophising. It refers to ‘a method of cognitively coping with pain characterised by negative self-statements and overly negative thoughts and ideas about the future’ (Keefe, Brown, Wallston, & Caldwell, 1989, p. 51). Greater endorsement of catastrophic thinking when in pain has been consistently associated with higher levels of pain, distress and disability among diverse
populations (Ehde & Jensen, 2010; Keefe et al., 2004). Research findings concerning the relationship between other specific pain coping strategies and adjustment to chronic pain have been somewhat more inconsistent (Boothby et al., 1999). When significant associations are found, greater use of coping self-statements is generally related to positive adjustment, whereas hoping, pain-contingent rest and wishful thinking are frequently associated with greater dysfunction. Ignoring pain, reinterpreting pain and distraction/diverting attention in contrast, rarely predict functioning among people with chronic pain (Boothby et al., 1999).

Attention to the social environment is another important component of the biopsychosocial model, particularly perceived social support and the role of solicitous responses of significant others to pain. It draws on operant conditioning principles that emphasise the role that pain-contingent social responses such as solicitous responses to demonstrations of pain and disability (e.g. offers to take over tasks or encouragement to become less active) may play in the perpetuation of chronic pain. While perceived general social support has found to be associated with positive functioning among persons with chronic pain, solicitous responses to pain behaviours from spouses and family members tend to be associated with greater pain and disability (Kerns, Rosenberg, & Otis, 2002; Schwartz, Jensen & Romano, 2005).

Although there is a large body of evidence to support a biopsychosocial model in understanding and treating chronic pain as a primary condition, only recently have researchers begun to examine its utility among persons with disability-related pain. Jensen and colleagues’ (2011) recent systematic review of psychosocial factors and adjustment to chronic disability-related pain identified 29 studies investigating these variables among people with spinal cord injury, acquired amputation, cerebral palsy, multiple sclerosis and muscular dystrophy. Strong and consistent associations between psychosocial factors and adjustment to pain were observed in all disability groups including: (1) catastrophising cognitions; (2) task persistence, guarding and resting coping responses; and (3) perceived social support and solicitous responding social factors. Pain-related beliefs were significantly associated with adjustment for all groups, except persons with acquired amputation. Consistent with the general pain literature, the belief that one can control pain and its effects was found to be associated with positive outcomes, whereas the beliefs that one is necessarily disabled by pain, others should be solicitous (and take care of the patient) when in pain and that pain is an indication of physical damage were associated with poorer adjustment. Taken together, these findings support the importance of psychosocial factors as significant predictors of pain and functioning in persons with physical disabilities. They also suggest the possibility that interventions targeting these variables would reduce the negative impact of chronic disability-related pain.

STIGMA AND CHRONIC PAIN

The broader social context of the individual also profoundly shapes the chronic pain experience. This is an understudied area of chronic pain, with few Australian studies on this topic (Nielsen, Foster, Henman & Strong, 2012; Tollefson, Usher & Foster, 2011). One of the most important social aspects from the perspective of people with chronic pain is the stigmatisation of chronic pain. Frequently the person with chronic pain faces not only the negative personal impact of pain, but also the potent social dilemma of not being believed or having their experience delegitimised by others. Indeed, it is the very nature of chronic pain — its invisibility, its subjectivity, its challenge to the biomedical paradigm — that is deeply problematic for the sufferer (Heshusius, 2009). Pain simply cannot be proved or disproved. In contrast to the visible manifestations of disease, pain is privately
experienced, demonstrable to others only through the individual’s self-report or other non-verbal pain behaviour. As one author with chronic pain explains so well (Heshusius, 2009, p. 14):

We appear normal. That is our liability. One can wince and moan only for so long. There comes a point where giving expression to one’s pain takes energy one no longer has. One becomes quiet and pain becomes internalised ... Also, wincing and moaning when in acute pain are instinctive behaviours to which others respond with sympathy. When it becomes clear the pain will not go away, others may feel helpless. They may start to think you are exaggerating. They may be overwhelmed. They change the subject. The person in pain withdraws. You try to keep your composure, to stay coherent, not fall apart. Others will see exhaustion and depression in your face before they see pain.

The invisibility and often lack of known physical basis for chronic pain frequently invites speculation and judgments from others about its legitimacy. In the past this has led to labelling of individuals as fraudulent when they claim pain over time for which there is no medical explanation. This stigma, attached to those who report pain without an identifiable pathological basis, occurs in part because their illness falls outside of the socially sanctioned biomedical model of healthcare (Jackson, 2005). If medicine is unable to identify and treat the pain, either the person may be seen to be exaggerating for secondary gain, or the pain is attributed to psychogenic causes. Cohen, Quintner, Buchanan, Nielsen and Guy (2011) call for health professionals to critically reflect on their own, often inadvertent, potential to contribute to the stigmatisation of people with chronic pain when they adopt this dualistic thinking inherent in the biomedical model of pain.

Interestingly, despite their known medical diagnosis, the stigma of chronic pain has also been found to be central to the pain experience of people with physical disabilities (Douglas, Windsor, & Wollin, 2008). In contrast to visible impairments, pain problems may be dismissed or discredited by friends, family, co-workers and others. People with physical disabilities are often particularly aware of the contested nature of their pain experience during encounters with healthcare providers (Douglas et al., 2008; Yorkston, Johnson, Boesflug, Skala, & Amtmann, 2010). From their perspective, pain is often trivialised by healthcare providers as a natural or expected part of their disease, or dismissed altogether. Over time, people with disabilities tend to keep pain hidden from others to avoid negative responses and the threat of stigma (Douglas et al., 2008; Dudgeon, Gerrard, Jensen, Rhodes, & Tyler, 2002).

In the clinical setting, pain problems may be overlooked among people with chronic illness and disability given the myriad of other symptoms experienced. However, clinicians should not discount the problem of pain in persons with other, more obvious impairments. It is important that clinicians acknowledge and validate the person’s report of pain and allow enough time during interactions to discuss pain and pain-related concerns. Health professionals should also be cognisant that people with chronic disabling conditions may be reluctant to disclose or discuss their pain problems. Dudgeon and colleagues (2002) recommend that it may help some clients if the practitioner normalises pain by stressing that it is a common problem in people with physical disabilities. Chapter 5 also provides some excellent strategies to prevent stigma when working with people with chronic illness and disability.

Case Study 9.1 is a story of Paul’s experience with chronic back pain taken from a phenomenological study of the experience of chronic illness in rural Australia (Tollefson et al., 2011). His was a long story of struggle for recognition and compensation. The story deals with trust, belief, self-stigma and emotions of fear and anger associated with chronic back pain.
CASE STUDY 9.1

Paul was on sickness benefits and had ceased work. He lived outside a regional city in Victoria and was booked in to have an operation in Melbourne. Before he was due to go to Melbourne the Department of Social Security sent him a letter, requiring him to present at the local office of the Department of Social Security on 9 April, which was a Friday. So, wanting everything to be right for the family while he was away, he went into the Department on the preceding Monday.

He was in the queue and recognised another man in the queue, whom he knew to be a ‘bludger’. He wanted to appear different from this man but how could he? — his back pain was not obvious to those around him. Paul resigned himself to the fact that he and the man looked remarkably similar. ‘I am here because I am sick,’ he cried inwardly, with enough passion to make his heart race and his back ache.

He shuffled from side to side, trying to ease the pain. There were no chairs anywhere; he could not take a walk around because he would lose his place and have to start queuing all over again.

After over half an hour, which seemed an eternity, his turn came. He held his letter out to the clerk behind the glass-fronted counter and before he could open his mouth to give the prepared apology for presenting earlier than the day stipulated in the letter, it was snatched from his outstretched hand. It disappeared under the hole in the glass screen. The clerk glanced at the letter and with a resigned look on his face said in a singsong tone, ‘This says to bring it in on Friday’.

‘I know,’ Paul replied mirroring his tone, ‘but Friday is Good Friday. There won’t be anyone here.’ Paul knew he had irritated the man.

‘Well, you can’t bring it in today.’

‘That is okay,’ Paul said, ‘when shall I bring it in?’

The clerk thought about this and said, ‘Tuesday after.’

Now the frustration was beginning to well up inside Paul. He described it, ‘The pain in my back was like two hard bricks pressing down, my stomach ached and my teeth were clenched.’ He really wanted to cry but that was unthinkable — that, or reach through the glass hole and throttle his tormentor. People were shifting in the queue behind Paul. He explained that he was going away to Melbourne on Sunday.

‘Well, take it to an office in Melbourne,’ the clerk responded.

‘I will be in hospital,’ Paul replied. ‘Gotcha!’ he thought. ‘Can I bring it here on Thursday?’ he asked.

‘No,’ was the clerk’s belligerent reply.

Paul asked for the manager but there was not one. He tried asking for the clerk’s name but he would not give it to him. Paul felt that the people in the queue were enjoying the scene; he had to give up but before he did so he clenched his fist tightly and shot it towards the clerk’s jaw. Stopping just at the glass, he opened both hands and placed them flat on the glass which divided them. The man looked scared and Paul was ashamed, defeated, disgusted and so angry. His hands slipped slowly down the glass and dejectedly he walked to his rickety old ute for the 20 km jolting journey through the bush with nothing to offer his family.
The concept of legitimation is bound up with trust. Challenges in patient-provider interactions in the management of chronic pain in primary care have been identified, including insufficient knowledge of pain management, time constraints, differing goals and attitudes concerning treatment, and debate surrounding the use of opioids for chronic pain (Frantsve & Kerns, 2007; Matthias et al., 2010). Specialist multidisciplinary pain management services have arisen over the past four decades to support general practitioners (GPs) in the care of individuals with chronic pain. Yet Hogg and colleagues’ (2012) Australian survey found there are long waiting times for an initial appointment at many publicly funded pain management services, with a median wait of 150 days, and several services reported a waiting time of over a year. By comparison, of the 20% of the population reporting chronic pain, less than 0.2% will gain access to a specialist service in any given year. For Australians living outside capital cities, the proportion who gain access is even lower (Hogg, Gibson, Helou, DeGabriele, & Farrel, 2012).

Indeed, it was many years after Paul first sought medical attention for his chronic back pain that a diagnosis was eventually made and surgery offered as a last resort. However, to retain the person’s trust, health professionals need to be seen to be exploring all options to find a diagnosis and treatment. This eventually adds to the financial burden of chronic pain and demoralisation as a diagnosis and cure remains elusive. If a cure or full explanation of the pain is unavailable, people search through their own lives to come up with some sort of explanation for the pain. Accidents, hereditary weaknesses, childhood illnesses and normal ageing are used to give meaning to the pain within the person’s life (Richardson, Ong, & Sim, 2006).

Much of the care of those who live with chronic pain falls onto the person with pain and their family. Community nurses, GPs and, where available, the health professionals in specialised pain clinics are increasingly recognising the need for supportive and educative models of care for people with chronic pain in the community so that they do not feel they are reliant on services that are not readily available or do not exist. People who live in rural and remote areas often have to rely on the very limited resources of the healthcare system in their area, as travel is often too traumatic and expensive to contemplate (Tollefson & Usher, 2006). People who live with chronic pain are also occasionally admitted to hospital or will present at community health centres or general practices for conditions other than their chronic pain. Chronic pain will complicate their treatment requiring all health professionals to have an understanding of chronic pain.

**CULTURAL DETERMINANTS OF THE EXPERIENCE OF CHRONIC PAIN**

Culture is significant in shaping beliefs about pain, in dictating acceptable pain behaviour and giving meaning to the pain experience. Thus culture affects the individual’s perception, report and expression of pain. Pain assessment and management strategies put in place can easily fail if cultural considerations are not addressed between the individual and health professional. For example, some important pain cues for central Australian Aboriginal people that may be misinterpreted by non-Indigenous health professionals during pain assessment include: silence, physically lying on their side with eyes averted, feigning sleep (using ‘centring’ to control the pain experience), head turned away or hiding their head/body under a blanket on questioning, a slight upward nod of the head with downcast eyes when asked if in pain and the whispered response ‘paining, Sister’ (Fenwick, 2006; Fenwick & Stevens, 2004).

There is a paucity of research examining the pain experience of Australian Aboriginal and Torres Strait Islander people. McGrath’s (2006) qualitative study in Australia’s
Northern Territory explored issues associated with pain management for rural and remote Aboriginal peoples. A key finding was the importance of those involved in pain management being aware of the complexity of cultural relationship rules that determine who should and should not be directly involved in providing physical care. It also found that Aboriginal peoples may have a higher threshold of pain and are less likely to report pain, especially the men, who do not wish to appear weak. Pain management is influenced by the cultural concerns of ‘pay back’ and ‘blame’. There is also a mistrust of mainstream medicine, stemming from a lack of understanding of clinical notions of pain relief, fear of the administration, side effects and ramifications of medications, and fear that Western pain medications will speed up the dying process and inhibit the passing on of traditional knowledge and secrets that occurs during end-of-life. Developing relationships built on trust between health professionals and Aboriginal peoples is reported as the most important strategy for overcoming such fears.

Davidhizar and Giger’s (2004) review of the literature on caring for people in pain from diverse cultural backgrounds recommends several key strategies to assist in culturally appropriate assessment and management, namely: (1) utilising assessment tools to assist in measuring pain; (2) appreciating variations in affective response to pain; (3) being sensitive to variations in communication styles; (4) recognising that communication of pain may not be acceptable within a culture; (5) appreciating that the meaning of pain varies between cultures; (6) utilising the knowledge of biological variations; and (7) developing a personal awareness of values and beliefs that may affect responses to pain. This last recommendation is particularly important. Fenwick (2006) suggests that non-Indigenous nurses working within rich cultural environments need to listen to Indigenous people and respect the differences that exist. Health professionals need to adopt culturally safe pain assessment strategies and wherever possible defer to the person with chronic pain or their family and friends for cultural interpretations. Wherever possible, help should be sought from professionals with inside understanding of cultural norms; an obvious example is Indigenous health workers in Australia.

ASSESSMENT OF CHRONIC PAIN

A biopsychosocial assessment of chronic pain is the key to developing an effective management plan. Assessment begins with a comprehensive pain history (using the PQRST mnemonic) including provoking/palliative factors, quality, region (location) and radiation, severity and temporal pattern (onset, duration, pattern) for each individual pain problem. Evaluation of psychosocial factors such as pain beliefs and coping strategies, mood and social interactions is undertaken. Assessment of the impact of pain on functioning and QOL is also an essential component to direct treatment. Finally, a physical assessment should be completed focusing on neurological and musculoskeletal body systems.

This section provides only a brief introduction to some key pain assessment tools. For a comprehensive review of chronic pain assessment please refer to Turk and Melzack’s (2011) excellent text.

Pain rating scales

Pain intensity — a quantitative estimate of the severity or magnitude of perceived pain — is without a doubt the most salient dimension of pain and a variety of pain rating scales have been developed to measure it. Most of these tools are highly correlated with each other and therefore they can be used in most situations (Jensen & Karoly, 2011). What is important is that the assessment tool is selected based on the individual’s needs (e.g.
developmental, cognitive, language and cultural factors) with consideration of the particular strengths and weaknesses of each tool.

The numerical rating scale (NRS) is the most widely used measure of pain intensity in clinical practice. A NRS asks the client to rate their pain from 0 to 10 (an 11-point scale) or 0 to 100 (a 101-point scale), with the understanding that the 0 represents one end of the pain intensity continuum (‘no pain’) and the 10 or 100 represents the other extreme of pain intensity (‘pain as bad as it can be’). Clients simply state or circle the number on written versions of the scale that best represents their pain intensity by asking: ‘On a scale of 0 to 10, with 0 being no pain and 10 being the worst possible pain you could imagine, where would you rate the pain you are experiencing right now?’ The reliability and validity of the NRS is well established (Jensen & Karoly, 2011) and is easily administered. Based on their review of measures, Pasero and McCaffery (2011) recommend a combined NRS and faces scale as the preferred pain rating scale in most clinical settings.

A verbal descriptor scale (VDS) simply consists of a list of adjectives describing different levels of pain intensity. Clients are asked to read over the list of descriptors and choose the word that best describes their pain intensity on the scale. A simple and clinically useful example is no pain, mild, moderate and severe pain (scored numerically from 0 to 3).

The visual analogue scale (VAS) consists of a 10 cm horizontal line, representing a continuum of pain intensity, with verbal descriptors at each end (e.g. ‘no pain’ to ‘pain as bad as it can be’ or ‘worst possible pain’). The client is asked to indicate which point along the line best represents their pain intensity. The distance measured from the ‘no pain’ end to the mark made by the client is the pain intensity score. The VAS is commonly used in research as a measure of pain intensity.

The faces pain scale is another tool that was originally developed for children but has been found to be useful and popular among adults, especially those with cognitive or communication difficulties. Facial pain scales include cartoon faces (e.g. Wong-Baker FACES Pain Rating Scale; Wong & Baker, 1988), hand-drawn realistic depictions (e.g. The Faces Pain Scale — Revised; Hicks, von Baeyer, Spafford, van Korlaar & Goodenough, 2001) and photographs of actual children in distress (e.g. Oucher Scale; Beyer, Denyes, & Villarruel, 1992). The Wong-Baker FACES pain rating scale, for example, contains 6 cartoon faces (from ‘smiling’ to ‘crying’) and is recommended for persons aged 3 years and older. An explanation is given to the client that each face is a person who feels happy because he has no pain (hurt) or sad because he has some or a lot of pain. Instructions are read to the client and they are asked to choose the face that best describes their pain intensity.

Quality

Unidimensional measures of pain intensity alone do not capture the other qualitative aspects of pain. Asking the client to describe the quality of their pain using their own words is important. Providing a list of possible descriptors can sometimes be helpful if clients find it difficult to do this.

Although used more for research than clinical practice, the McGill Pain Questionnaire (MPQ) (Melzack, 1975) provides a measure of the sensory, affective and evaluative aspects of the pain experience, based on the gate-control theory. It consists of 78 pain descriptors which are categorised into 20 groups evaluating the major dimensions of pain quality. Clients are read each list of descriptors and may select one word from each group if applicable to their pain. Each of the 78 words has been assigned a rank value within its group. From this data, it is possible to derive a Pain Rating Index (PRI) for the sensory, affective,
evaluative and miscellaneous subscales, as well as a total PRI (Melzack, 1975). The psychometric properties of the MPQ have been well established and the MPQ is often utilised as a gold standard against which to validate pain measures (Katz & Melzack, 2011).

The types of words chosen can also provide valuable information about the underlying pain mechanisms. For example, it has been demonstrated clinically that individuals with neuropathic pain are significantly more likely to use particular sensory adjectives (e.g. electric-shock, burning, tingling, cold, pricking and itching) to describe their pain. A Short-Form MPQ (Melzack, 1987) has been developed and recently expanded and revised as the Short-Form MPQ–2 (Dworkin et al., 2009), capable of discriminating neuropathic and non-neuropathic pain. Other specifically designed measures such as the Neuropathic Pain Scale (Galer & Jensen, 1997) can be useful when a neuropathic component is suspected.

**Onset and duration**

Information should be elicited about the onset, duration and pattern of pain. When did the pain begin? How long has it lasted? Does it occur at the same time each day? How often does it recur? Is it intermittent or constant?

**Location**

To assess pain location, the client is asked to describe or point to all areas of discomfort. Pain sites can be documented on a body diagram. A pain drawing consists of outline drawings of the human body, front and back, on which the participant indicates the location of pain by shading the painful area (see Case Study 9.2).

**Exacerbating/relieving factors**

The client is asked to describe provoking factors, such as physical movement or position, certain activities or environmental factors. For example, with a ruptured intervertebral disc, the low back pain and radiation down the leg is usually aggravated by bending over or lifting objects. When exacerbating factors are identified, it is easier to plan interventions to prevent pain from occurring or worsening.

People with chronic pain have usually tried a number of pain management techniques so it is informative to know whether the client has found effective ways of relieving pain, including drug and non-drug pain management techniques. These strategies can then be incorporated into the management plan if appropriate.

**Impact of pain**

An assessment of the impact of pain on QOL domains is particularly useful to determine treatment priorities. Several pain assessment instruments incorporate most of the relevant questions and can help standardise pain assessment. The Brief Pain Inventory (BPI; Cleeland, 1989), for example, is a widely used measure of pain severity and interference for clinical and research purposes (see Figure 9.2). It is relatively short, easy for patients to complete and is sensitive to changes in pain over time or in response to treatment. The BPI scale assesses the extent to which pain interferes with mood, walking, general activity, work, relations with other people, sleep and enjoyment of life. Using validated, brief screening tools such as the BPI is useful for identifying problems which can then be more comprehensively assessed by the nurse and/or referred for specialist assessment and management.
**FIGURE 9.2** Brief Pain Inventory. *Note: From: Pasero & McCaffery (2011, Form 3-2, p. 53).*

**Brief Pain Inventory**

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Name:  

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<td>1</td>
<td>Yes</td>
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</tbody>
</table>

1. Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains and toothaches). Have you had pain other than these everyday kinds of pain today?
   1. Yes  2. No

2. On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.

3. Please rate your pain by circling the one number that best describes your pain at its worst in the past 24 hours.
   0 1 2 3 4 5 6 7 8 9 10
   No pain  Pain as bad as you can imagine

4. Please rate your pain by circling the one number that best describes your pain at its least in the past 24 hours.
   0 1 2 3 4 5 6 7 8 9 10
   No pain  Pain as bad as you can imagine

5. Please rate your pain by circling the one number that best describes your pain on the average.
   0 1 2 3 4 5 6 7 8 9 10
   No pain  Pain as bad as you can imagine

6. Please rate your pain by circling the one number that tells how much pain you have right now.
   0 1 2 3 4 5 6 7 8 9 10
   No pain  Pain as bad as you can imagine

7. What treatments or medications are you receiving for your pain?

8. In the past 24 hours, how much relief have pain treatments or medications provided? Please circle the one percentage that most shows how much relief you have received.
   0% 10 20 30 40 50 60 70 80 90 100% Complete relief

9. Circle the one number that describes how, during the past 24 hours, pain has interfered with your:
   - A. General activity
     0 1 2 3 4 5 6 7 8 9 10
     Does not interfere  Completely interferes
   - B. Mood
     0 1 2 3 4 5 6 7 8 9 10
     Does not interfere  Completely interferes
   - C. Walking ability
     0 1 2 3 4 5 6 7 8 9 10
     Does not interfere  Completely interferes
   - D. Normal work (includes both work outside the home and housework)
     0 1 2 3 4 5 6 7 8 9 10
     Does not interfere  Completely interferes
   - E. Relations with other people
     0 1 2 3 4 5 6 7 8 9 10
     Does not interfere  Completely interferes
   - F. Sleep
     0 1 2 3 4 5 6 7 8 9 10
     Does not interfere  Completely interferes
   - G. Enjoyment of life
     0 1 2 3 4 5 6 7 8 9 10
     Does not interfere  Completely interferes
Pain diaries

Pain diaries are also effective tools to assess the peaks and troughs of pain, identify triggers and to determine the effectiveness of treatments (see Figure 9.3). A common problem is that people fail to fill them out or complete them just before an appointment ‘for the nurse’. The client and family should receive explanations of the purpose of using the pain diary, along with information about how and when to complete the diary. The discussion also helps the nurse to establish the degree to which the person is committed to collecting the information.

There is increasing clinical and research interest in the use of electronic pain diaries (e.g. digital pens, palmtop computers, mobile phones) to improve compliance and satisfaction. Research thus far suggests electronic pain assessment measures are preferable compared with traditional paper and pencil measures, yet there are some notable barriers such as cost, hardware and software requirements, concerns about confidentiality, respondent burden and modifying the behaviour of clients and providers (Marceau, Smith, & Jamison, 2011). Further research is needed to examine the effectiveness of electronic pain assessment over and above standard practices.

MANAGEMENT OF CHRONIC PAIN

People with chronic pain generally refer themselves to GPs who now act as agents for a broad range of conventional and complementary specialists to manage chronic pain. The majority of nurses become involved in the care of people with chronic pain when it affects function or psychological wellbeing to such an extent that independence in activities of living or self-care needs are adversely affected. These nurses take a supportive and educative role to enable people with chronic pain to adopt positive self-management strategies that maximise their independence.

There are nurse practitioners who specifically work with people who are referred to pain clinics and there are specialist nurses who work with people with conditions that are particularly associated with chronic pain, for example people with cancer and specialists in oncology nursing, or people with long-term angina and specialists in cardiac rehabilitation nursing. These nurses work in multidisciplinary teams and have extended knowledge of chronic pain and skills in the assessment, therapy and evaluation of pain management. While nurses play a critical role, the management of chronic pain is essentially in the hands of individuals and support for them comes from a range of health professionals whose roles can overlap to a large degree in the offering and delivery of a person-centred philosophy of healthcare service. People with chronic pain and their families are the primary managers of chronic pain — including that caused by cancer — as treatment has shifted from the hospital to the outpatient department or GP surgery to the home.

While many of the specific treatment options for chronic pain are outlined below, there are some important generic principles of practice that are relevant to all health professionals working with people with chronic pain. Unruh and Harman (2002) provide an excellent discussion of these guiding principles which are summarised in Box 9.1. The reader is encouraged to reflect on their past experience of working with clients with chronic pain as a health professional or student — or perhaps personal experience of pain and interaction with health professionals — and consider how these principles might facilitate therapeutic intervention.

Effective communication and a trusting relationship are fundamental to helping the person in pain to achieve their goals. It is vital for nurses to give opportunities for people to talk about their pain and pain-related concerns, validate their experiences and provide
## Pain Control Diary: Patient Example

This is a record of how your pain medicines are working. Please keep this record until you and your nurse/doctor find the dose and frequency of medicine that provides satisfactory pain relief for you most of the time. After that, you only need to keep this record when you have problems related to your pain medicines.

### Name: Martin

### Date: Friday

**GOALS** Satisfactory pain rating: 3

**Activities:** sleep through the night, walk around the house

**Analgesics:**
- ibuprofen 400 mg 8 am, 2 pm, 8 pm
- duloxetine 30 mg 8 am, 8 pm
- MS Contin 100 mg 8 am, 8 pm
- MSIR 30 mg every 2 hours if needed

My pain rating scale:

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
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<tbody>
<tr>
<td>No pain</td>
<td>Moderate pain</td>
<td>Worst possible pain</td>
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</table>

### Directions:
Rate your pain before you take pain medicine and 1 to 2 hours later.

<table>
<thead>
<tr>
<th>Time</th>
<th>Pain Rating</th>
<th>Pain Medicine I Took</th>
<th>Side Effects (drowsy? upset stomach?)</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>12:15 am</td>
<td>6</td>
<td>30 MSIR</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>6</td>
<td>30 MSIR</td>
<td>can't sleep</td>
<td></td>
</tr>
<tr>
<td>5:15</td>
<td>6</td>
<td>30 MSIR</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>6</td>
<td>30 MSIR + ibuprofen + MS Contin 100 mg + duloxetine</td>
<td>staging in bed</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>5</td>
<td>45 mg</td>
<td></td>
<td>talk with nurse</td>
</tr>
<tr>
<td>10:30</td>
<td>6</td>
<td>MS Contin 30 mg</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12:30 pm</td>
<td>3</td>
<td></td>
<td>planning to nap</td>
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If pain is greater than 5, or if you have other problems with your pain medicine, call:

**Nurse: Name/phone**
- C. Adams 555-1234

**Doctor: Name/phone**
- Jancs 555-4321

**FIGURE 9.3** Pain diary. *Note: From Pasero & McCaffery (2011, Form 3-11, pp. 116–17).*
CASE STUDY 9.2

The following case study is an example of a nursing assessment of an individual with chronic disability-related pain drawn from research on the impact of pain on the quality of life of people with multiple sclerosis (Douglas et al., 2009).

History

Mrs L is a 41-year-old married woman living in south-east Queensland, who presents with worsening pain in her hands. She has secondary progressive multiple sclerosis diagnosed 2 years ago. Mrs L was employed as an office worker, but was unable to continue working because of increasing pain and fatigue.

Mrs L reports pain and fatigue as her worst MS-related problems. She has minor difficulties with memory and speech. There is some upper extremity involvement with difficulty with zips, handling small coins and washing her hair. She also reports bladder incontinence and sexual dysfunction.

Current medications for pain include Avonex® (interferon beta-1a), Zoloft® (sertraline) and Neurontin® (gabapentin).

Pain characteristics

- Using a 0–10 numerical rating scale Mrs L reported her pain was 2/10 on assessment. Over the past 2 weeks Mrs L rates her pain as 10/10 at its worst, 2/10 at its least and 8/10 on average.
- Mrs L indicated she experiences pain in both hands and right leg, shown on the pain drawings below.
- She completed the McGill Pain Questionnaire and endorsed the following: sensory descriptors were flickering, shooting, lancinating, cramping, searing, hurting and taut; affective descriptors were exhausting, terrifying, punishing and wretched; evaluative descriptor chosen was unbearable; miscellaneous descriptors chosen were radiating, numb, freezing and torturing.
- She describes the pain as constant over the past year and a half.
- Provoking factors identified were heat, stress and friction. She manages her pain best by controlling the temperature (keeping cool) and avoiding stress.

Psychosocial responses to pain

- On the Pain Beliefs and Perceptions Inventory, Mrs L endorses beliefs about pain constancy and pain permanence, but scores low on beliefs about self-blame or that pain is a mystery.
- The Coping Strategies Questionnaire was administered and scores demonstrate frequent use of catastrophising, praying/hoping and ignoring pain, low scores for coping self-statements or increasing behavioural activities and no use of reinterpreting pain or diverting attention.
- Her perceived self-efficacy was low with perceived control over pain scored as 1/6 and ability to decrease pain 2/6 on the CSQ.

Impact of pain

- Mrs L completed the Brief Pain Inventory pain interference scales (0 = does not interfere, 10 = completely interferes) indicating: mood 5/10, walking 0/10, general activity 8/10, work 10/10, relations with other people 3/10, sleep 3/10 and enjoyment of life 5/10.
BOX 9.1
Generic principles of practice  Note: From Unruh & Harman (2002), Box 8.2, p. 152.

- Believe the client’s description of her or his pain and suffering.
- Treat acute pain aggressively.
- Always assess the client’s pain and its impact on daily life before planning intervention.
- Avoid ‘leaps to the head’ to explain the client’s pain.
- Determine whether the primary goal of intervention is pain reduction or improvement in function.
- Incorporate evidence-based decision-making into practice.
- Combine medical, pharmacological, cognitive behavioural, occupational and physical strategies.
- Understand and correct misconceptions about the use of pain medication and addiction risks.
- Recognise that a positive response to a cognitive behavioural intervention does not mean that the client’s pain has a psychological cause.
- Help the client to make long-term lifestyle changes.
- Involve the client’s family whenever possible.
- Recognise dual responsibilities and obligations.
- Create a positive therapeutic milieu.
- Conduct an ethical practice.
- Participate in research, education and professional pain associations.
interventions that enable self-management. Good communication with the multidisciplinary team and mutual respect for their specialist contributions is also essential. Developing a trusting, therapeutic relationship with the person involves accepting the person’s report of pain, actively listening, displaying empathy and using effective verbal and non-verbal communication skills.

Education about the illness, its manifestations, diagnostic studies and the treatment regimen can assist to diminish anxiety, reduce stress and assist the person to cope with ongoing pain, self-manage the pain, enhance feelings of control and adhere to the treatment plan (Richardson, Adams, & Poole, 2006). As always, it is important to evaluate the person’s knowledge levels before starting. Partners, friends and lay carers are important players in the management of chronic pain and can assist the person with chronic pain by supporting their coping strategies and not undermining their skills. This support is encouraged when the partners are included in the pain management education and they are supported to learn the principles of self-management. Close communication about the pain experience between partners is supportive (Newton-John & Williams, 2006). Negative impacts on the relationship include friction between the partners, resentment, decrease in intimacy and ultimately erosion of the relationship, which can end in separation and divorce (Sofaer-Bennett, Holloway et al., 2007). Sofaer-Bennett, Walker et al. (2007) also found that personal friendships wane as pain interferes with visiting, social outings and movement. Holidays become a pleasure of the past, and planned activities are frequently cancelled due to pain.

Management should be directed towards addressing the impact of pain on QOL domains affected, particularly mood and sleep. People with chronic pain are often depressed and there is evidence that treatment with antidepressants and psychological therapies can be effective (Holmes, Christelis, & Arnold, 2012). Sleep disturbance is also frequently a problem, contributing to irritability and difficulty with relationships (Call-Schmidt & Richardson, 2003). Sleep promotion interventions such as teaching the individual and partner about the need for stimulus control, progressive muscle relaxation and sleep hygiene measures are the first-line management strategies. Sleep hygiene measures include establishing a sleep routine, environmental control, limiting caffeine and alcohol (and, for some, fluids) during the evening, establishing the bedroom as a sleep room (not for reading, working or hobbies), physical comfort (temperature, perhaps a warm bath just prior to bedtime, planning analgesia so the effects are peaking at the time of falling asleep) and promoting relaxation. If these are ineffective, the assistance of the multidisciplinary team must be sought for such additional measures as hypnotic medication, biofeedback and cognitive behavioural therapy (Zelman, Brandenberg, & Gore, 2006).

**TREATMENT OPTIONS**

Treatment options for chronic pain broadly include: pharmacological approaches; interventional techniques including nerve blocks, surgery, implantable drug-delivery systems and spinal-cord stimulators; exercise and physical rehabilitation; psychological treatments; interdisciplinary treatment; and complementary and alternative treatments. It is beyond the scope of this chapter to provide a detailed discussion of each of these treatments and the reader should consult recent reviews by Turk, Wilson and Cahana (2011) and Portenoy (2011) on the management of chronic non-cancer and cancer pain. Based on their comprehensive review, Turk and others draw the sobering conclusion that overall, present treatment options for chronic non-cancer pain result in modest improvements at best. Given these findings management should include dialogue with the client about realistic expectations of pain relief and a need to bring the focus to improvement of function.
Management often necessitates use of a blend of different approaches based on the individual’s response to treatment.

**Analgesics**

There are three classes of analgesics: non-opioids (paracetamol, non-steroidal anti-inflammatory drugs [NSAIDs]), opioids and adjuvant drugs. The WHO analgesic pain ladder is a well-known treatment model developed for people with cancer pain, but broadly relevant to other acute and chronic pain problems (WHO, 2007). The three steps of the analgesic ladder address different pain intensities beginning with a non-opioid analgesic such as paracetamol or an NSAID and possibly an adjuvant, then adding so-called ‘mild’ opioids such as codeine and eventually ‘strong’ opioids such as morphine. Administration of analgesics should be orally whenever possible and around the clock rather than as needed. Adjuvant analgesics are drugs that have a primary indication other than pain but are analgesic for some painful conditions. They include drugs such as anticonvulsants, antidepressants, sodium channel blockers or muscle relaxants. Older people taking these adjuvants, even in small doses, should be carefully monitored for their effect and side effects.

Pharmacological management of chronic pain is a complex area and beyond the remit of this chapter. The reader is referred to Pasero and McCaffery’s (2011) classic pain management text for a comprehensive review of pharmacological management. Nurses are required to understand the actions and side effects of all analgesics in a medication regimen and to help the recipient and carers obtain and use this information in the safe and efficient administration and storage of the medicine. Contemporary technology is moving at a fast pace and it is now possible, as illustrated in Case study 9.3, to have ‘state of the art’ administration technology at home and beyond to ensure continuous administration of opioids.

The greatest barriers to adequate and timely pain management for people with chronic pain remain those fears and misconceptions that have been reported for decades, such as the side effects of opioids, fear of addiction and the belief that pain indicates disease progression (Pasero & McCaffery, 2011). Family caregivers who have good pain management knowledge are less influenced by these beliefs and are better able to manage pain levels (Vallerand, Collins-Bohler, Templin, & Hasenau, 2007). Discussing each aspect of their pain management with the person and their significant others, and ensuring a good understanding of the basics of self-care, prepares the person to better manage their chronic pain.

**Non-drug interventions**

Non-pharmaceutical interventions can bring relief from chronic pain and give people a sense of control. Relaxation therapy, cutaneous stimulation such as heat and cold, massage, guided imagery, music therapy, self-hypnosis and biofeedback are some examples.

Kerns, Sellinger and Goodin (2011) provide a critical review of the broad domain of psychological interventions for chronic pain including self-regulatory, behavioural, cognitive behavioural and acceptance and commitment therapy. Cognitive behavioural therapy is an effective approach for assisting people to manage their pain. The primary aims of cognitive behavioural therapy are to help patients to alter beliefs that are detrimental to their self-management of the pain; monitor their thoughts, emotions and behaviours and link these to environmental events, pain, emotional distress and psychosocial difficulties; develop and maintain effective and adaptive ways of thinking, feeling and responding; and perform behaviours that assist them to cope with pain, emotional distress and psychosocial difficulties (Adams, Poole, & Richardson, 2006). Interventions that influence the person’s cognition, such as education, reassurance, coping strategy training, stress management,
cognitive restructuring, distraction, problem solving, changing pain behaviours, increasing physical activity, goal setting and pacing are all part of cognitive behavioural therapy (Richardson, Adams, & Poole, 2006).

People living with chronic pain often fear that they will increase the pain and cause further damage by movement and exercise; or that there is an underlying pathology that has not yet been discovered. Reassurance and education can assist the person to understand the fallacy of these beliefs and develop more realistic strategies, such as exercise and pacing to prevent further deterioration in their physical capabilities. Acceptance that chronic pain is not curable or not even explainable is difficult and the individual with chronic pain needs professional as well as personal support to come to this acceptance.

### Complementary therapies

People who suffer from chronic pain are increasingly turning to complementary and alternative therapies. The philosophical orientation of these therapists is opposite to the reductive stance taken by conventional Western medicine. They take a holistic perspective and treat, according to their particular tradition, the person rather than the causative pathology. The emphasis is on total wellbeing rather than the control or, some would say, masking of symptoms, in this particular case pain. Of course as the sciences of complementary therapy and Western medicine advance, their boundaries overlap. Indeed, in many general practices medical practitioners and complementary therapists work from the same centre. Some registered nurses also bring their expertise in complementary therapies to the management of chronic pain and have led research in developing an evidence base for these approaches.

Given the increasing use of complementary therapies for chronic pain, health professionals require knowledge about the use and effectiveness of these specific practices so that they can assist clients to make informed, evidence-based decisions about these therapies. The reader is referred to Tan and colleagues’ (2007) systematic review of the effectiveness of commonly used complementary therapies for chronic pain.

### CASE STUDY 9.3

This case study is used to show a typical professional approach to diagnosis and treatment of a person with chronic pain. It illustrates the importance of therapeutic communication and a holistic approach. The breakthrough in the management of this person is accurate diagnosis of the cause of the pain and pharmaceutical therapy associated with an understanding of the emotional turmoil of the person involved. The nursing role is a combination of diagnosis, support and education and continuing evaluation.

#### Social history

Mr B, a 69-year-old retired man living in north Queensland, is married with four grown children. His wife is very supportive of Mr B’s condition. He does not drink or smoke and has no significant family history.

#### Relevant medical history

Depression, anxiety, hypogonadism.
CASE STUDY 9.3 — cont’d

Presenting problem

Mr B presented to a neurologist for investigation of left arm paraesthesia and dysesthesia of left thigh — chronic radiculopathy (spinal nerve root disease). He was diagnosed at that time with multiple sclerosis following positive results on Magnetic Resonance Imaging (MRI) and lumbar puncture. Prior to diagnosis Mr B developed recurrent left upper quadrant abdominal pain. This was diagnosed as pancreatitis and led to a distal pancreatectomy for a possible lesion on the tail of the pancreas with multiple subsequent operations for removal of collections. Sepsis followed.

This pain was extensively investigated in 1994, when Mr B had CT scans and endoscopic retrograde cholangio-pancreatography as well as pancreatic biochemistry tests. All resulted in 'no abnormality detected'. Mr B was admitted to a private hospital for investigation of severe back pain a short time later.

Mr B was depressed to the point of considering suicide. His medications at this stage were:

- Baclofen 20 mg BD
- Prozac 20 mg daily
- Kapanol 50 mg BD
- Pethidine 150 mg intramuscularly PRN Q4H
- Maxalon 10 mg PRN 4/24.

An epidural catheter was inserted with an infusion of Marcain 0.25% and Fentanyl to provide pain relief. The catheter remained in situ for 7 days before it was removed. It was believed that the pain may have been the result of spinal cord lesions. Following this admission Mr B was transferred to the public hospital for implantation of an intrathecal catheter with a drug delivery pump. The overall goal was to reach a therapeutic level of drug administration where pain was kept at an acceptable level. Post-operatively some technical complications occurred while titrating the dose (an intrathecal pump will not eliminate all pain, but with it working at a therapeutic rate the pain will be decreased to a manageable level). Pain management strategies developed in conjunction with allied health staff experts in pain management were implemented. As part of the team approach to his pain management Mr B was referred to a clinical psychologist. During his consultations it was uncovered that Mr B was grieving for the ‘life’ he had lost and his altered relationship with his wife. He felt that his condition was causing his relationship to break down because his wife needed to take on more of the day-to-day running of the household. He mourned the loss of responsibility and control that he had had at work prior to the chronic pain. He felt he could no longer make a difference at work.

By 2002, the pain was no longer at a manageable level and the intrathecal pump dose per day was titrated to 3.0 mg/day of morphine with clonidine added. Clonidine has an analgesic effect mediated at the alpha2-adrenergic sites, which are located in the dorsal horn of the spinal cord (Pasero & McCaffery, 2011). Binding to these receptor sites activates the endogenous inhibitory pathway and pain is diminished.
CONCLUSION

Chronic pain is a common problem experienced among persons with chronic illness and disability. Despite significant gaps in the literature, the available evidence demonstrates the negative impact of pain on QOL, over and above the effects of the disease itself. It was argued here that the biopsychosocial model offers the most heuristic approach to chronic disability-related pain. From this perspective it is the person in pain, rather than the underlying disease process, that is the focus of assessment and management.

Chronic pain is also invisible to others. Health professionals are encouraged to routinely screen for pain problems during each interaction with persons with physical disabilities. Elicitation of a pain problem should prompt a comprehensive pain assessment as well as the need to assess its potential impact on the person’s QOL. Many of the strategies for adequately managing and adapting to chronic pain are educational — self-management, coping skills, knowledge of the condition and effective use of analgesia — and registered nurses have a significant role in this education (Tollefson et al., 2011). Timely referral to and collaboration with specialist pain management services will also enhance the care of people with chronic pain and ensure they receive the best available therapies.

Reflective questions

1. Pain is an under-recognised and under-treated problem among people with disabilities. Why do you think this is so? What are the potential barriers?

2. Revisit Case study 9.2 and determine the clinical priorities in this case. What strategies could you utilise to promote the client’s self-management of pain in this situation?

3. What are your experiences of working with people with chronic pain as a student or health professional? Did you feel adequately prepared? What knowledge gaps have you identified that require further study?
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Recommended reading


References


