

PAIN ASSESSMENT WITH PEOPLE RECEIVING PALLIATIVE CARE

INTRODUCTION

The purpose of this article is to report the research findings of a project conducted to establish an evidence based approach to pain assessment in palliative care. The project was initiated by the palliative care team at Royal District Nursing Service (RDNS) and was conducted in 2008. The aim of the project was to gain an understanding of the palliative care pain experience in order to determine triggers to various types of pain through the experiences of clients, carers and nurses.

The project was conducted in six phases which involved:

1. A comprehensive literature review to identify and synthesise evidence relating to the assessment of pain in palliative care for people living in the community. A review of relevant existing pain assessment tools was also undertaken.
2. Interviews with district nurses to explore their perceptions and experiences in conducting pain assessment with people receiving palliative care in their homes.
3. Interviews with clients and carers receiving palliative care in their homes to explore their experiences and perceptions of what is important in pain assessment.
4. Analysis and synthesis of data to inform the development of an evidence based pain assessment tool.
5. Consultation with healthcare pain specialists who provided feedback on the pain assessment pathway.
6. Trialling of the pain assessment pathway in practice with people receiving palliative care in their homes. The aim of this trial was to establish how the tool would translate into district nursing practice.

Ethics approval was obtained prior to data collection.

WHAT IS THE MEANING OF PAIN FOR PEOPLE RECEIVING PALLIATIVE CARE?

Pain is a complex, subjective experience which has meanings and implications that are unique to the individual. For people receiving palliative care, pain is foremost in their concerns in terms of fearing pain and wanting pain relief to be available when needed. Uncontrolled pain adversely impacts physical, psychological, spiritual and emotional wellbeing, and impairs quality of life. It is well accepted that people receiving palliative care have the right to effective management of their pain. Effective pain assessment is critical to pain management. Schofield and Black (2005) highlight that assessing pain is complex and involves more than using a simple pain scale. Assessment needs to be inclusive of a holistic understanding of all factors influencing the person's experience of pain.

WHAT ARE DISTRICT NURSES'S PERCEPTIONS OF PAIN ASSESSMENT?

A person centred approach is important when working with people in pain at end of life. Managing pain is a fundamental palliative care skill. RDNS nurses identify three salient issues as key to effective pain assessment. They express a prioritising of the person's description of pain as being a key source of information, emphasise the important role of observation during pain assessment and they regard all aspects of effective pain management as requiring a multidisciplinary approach.

Pain assessment in palliative care is perceived by district nurses as being different to assessing pain in other clinical situations and requires specific knowledge and the confidence to be creative.

I think you need to be a bit creative...trial and error is the best way, never be afraid to try something new. You would be amazed what makes people feel better, nice smells, music, a back rub or fresh sheets.

Not all nurses however, were confident in their knowledge and experiences of managing pain. Being confronted with a client in pain was described by some nurses as challenging and anxiety provoking. One nurse said:

[A priority is] that you can find relief for them. That's the first thing I want to attend to. I feel I want to get that sorted before anything else. I mean it's what you are there for. I feel sort of nervous until I can relieve it. I don't want to think of any client having to put up with ongoing pain.

Nurses reported feeling pressured to provide an effective pain relief option as quickly as possible. This was particularly the case for newer or less experienced district nurses and when clients and/or family members were distressed. Ultimately this pressure can have the effect of influencing the nurse's thinking about the assessment process.

Pain assessment is recognised in the literature as complex (refs). There are several barriers which may obstruct effective pain assessment including the difficulties people have in describing pain, language and cultural barriers, hesitation to report pain, and the lack of a common understanding about pain between individuals. Pain assessment is perceived by nurses as a complex task requiring special expertise. Nurses participating in this research recognised they were at different stages of confidence and competence with pain assessment in palliative care, this difference appearing to be associated with years of experience as a district nurse or having had previous palliative care experience. Nurses with less experience reported feeling 'a sense of urgency' when confronted with a client in pain until they have found an effective pain relief option. Even when nurses have knowledge of the process of pain assessment they report that their mind is focused on making the person comfortable as quickly as possible. Consequently there is a level of anxiety or nervousness associated with assessing pain.

A SENSE OF URGENCY

Some researchers have closely examined the nurse-client relationship in palliative care and have identified that nurses experience 'a sense of urgency' to make the client comfortable. Mok and Chui (2004) found that this was associated with nurses having certain expectations of their roles, involvement in the client's care and reciprocity between nurse and client. Mok and Chui (2004) suggest that both nurse and client had their own preconceptions about their roles and the meaning of the palliative care situation. Nurses were designated with specific responsibilities and were dedicated to relieving the suffering experienced by the person. Bignold, Cribb & Ball, (2007) found

that pain was often accompanied by family distress in palliative care and this could place increased demand for emotional labour from nurses. Nurses felt a pressure to serve the client and family and to restore comfort. The findings of these authors may describe similar responses to palliative care clients and families as those experienced by RDNS nurses.

HOW DO EXPERIENCED NURSES ASSESS PAIN?

Nurses with more experience as a district nurse or previous experience in palliative care demonstrated increased confidence with the pain assessment process. Through experience, these nurses had developed a series of key questions and observations about different aspects of the pain, involving the person and/or their family members/carers. They articulated a deeper understanding about different aspects of pain that needed to be taken into consideration during assessment such as individual style of expression. They approached the task of pain assessment with more ease however they had also established a supportive network of professionals who they accessed when uncertain about the optimal course of action. This was an important strategy for nurses working in palliative care.

WHAT IS IMPORTANT TO CLIENTS ABOUT PAIN ASSESSMENT?

Pain is all consuming for both the client and their family. Severe and uncontrolled pain is feared. Client's shared that fundamental to a 'good' death was keeping pain controlled. Partners become emotionally invested in regulating the home environment and managing regimes in order to minimise their partner's pain. Any episodes of uncontrolled pain are experienced as distressing and chaotic. Partners will go to extraordinary lengths to be there for the person in pain at these times.

Clients acknowledge a hesitancy to report pain, difficulties in describing pain and the fickle, shifting nature of their pain. The changeable nature of pain and the importance of capturing this across the day was highlighted by clients, therefore it has been accommodated in the development of our pain tool. Responsiveness is identified as being essential for effective pain management by clients. Their experiences with the acute healthcare system demonstrates that often it is not effective in supporting clients with pain. RDNS district nurses operating from a primary health care approach are highly valued by clients for the support they provide and as a key link in their pain management network.

HOW DOES EVIDENCE INFORM PAIN ASSESSMENT?

Expert opinion informs the following key components of pain assessment:

1. Self report of pain by the person experiencing is the most reliable source of information. "Pain is whatever the person says it is, existing when the person says it does" (McCaffery, 1979, p.8)
2. Pain assessment needs to be inclusive of all the dimensions in which the pain is experienced e.g. social, emotional, physical, spiritual, psychological, cultural.
3. Establish what the meaning of pain is to the person and to recognise potential cultural influences as part of pain assessment.
4. Common dimensions of pain assessment include:
 - Location of the pain in the body
 - Intensity or severity
 - Type or quality of pain
 - Duration: constant, intermittent or at specific times of the day
 - Factors that relieve or aggravate pain
 - Effect of pain on function
5. The type and experience of pain changes over the course of 24 hours. It is important to identify the patterns of pain.
6. Spiritual meaning of pain.
7. Knowing the type of pain the person experiences is important to finding effective pain relief. Different types of pain are linked to different pain management strategies.
8. Behaviour observation methods are used with people with cognitive impairment, impaired consciousness or unconscious and communication difficulties who are unable to give a self report of pain. However obtaining a self report should be attempted in the first instance.
9. Evaluation of pain assessment and management outcomes is essential to continuous improvement of the response to pain.
10. A multidisciplinary approach to pain assessment and management can increase effectiveness of response. Pain is multidimensional and must be addressed from various perspectives.
11. Communication of the assessment results and treatment decisions to the person, family members or carer and other healthcare professionals is fundamental.

AN EVIDENCE BASED TOOL TO SUPPORT NURSES IN PAIN ASSESSMENT

The pain assessment pathway was developed to

guide nurses through the various aspects of pain assessment and support clinical decision making about what occurs next. Client choice and involvement in decision making is prioritized throughout the pathway therefore it fits with a primary health care approach and a person-centred model of district nursing care. RDNS nurses have had significant input into the format and content of the pathway. The pathway is a flow chart of questions or prompts that step through the process of assessment. Five nurses trialled the pathway in practice and provided feedback which further influenced the format and content of the pathway. Consultation with expert pain specialists regarding their view of the pain assessment pathway also informed further modification. Characteristics of the pathway include:

1. **Assessment prompts:** a series of questions or prompts to elicit information about different aspects of pain assessment
2. **Communication tasks:** There are two sections. (1) Names and words for different types of pain to assist communication with the client's doctor (2) A list of prompts to support the nurse in taking relevant communication actions following assessment
3. **Evaluation prompts:** A list of questions to ask in evaluating the effectiveness of assessment and interventions
4. **Describing Pain tool:** for clients and RDNS nurses (on reverse side of pathway)

The Pain Assessment Pathway and Describing Pain tool are inserted in this newsletter and a coloured version is available from the Palliative Care Team.

DESCRIBING PAIN – A TOOL FOR NURSES AND CLIENTS

The 'Describing Pain' tool is intended for use by both nurses and clients when assessing and describing pain. The intention is that nurses use the tool in conjunction with the pathway during assessment. The tool is on the reverse side of the pain assessment pathway and provides strategies to assist clients to describe pain during assessment i.e. a pain scale, body maps, descriptive words for pain. During a client visit nurses can flip the sheet to access strategies to assist both client and nurse in the assessment process.

The tool also aims to provide clients with some strategies to understand and describe pain. e.g. it offers the client a range of words to describe pain, a scale to rate pain intensity, body maps for identifying pain location and asks a number of questions on temporal issues, impact on functioning and aggravating/relieving factors. Having considered these aspects of pain assessment it is intended that clients will be able to communicate more effectively about the pain they

are experiencing to healthcare professionals. The tool also offers a range of first line pharmacological and non-pharmacological strategies for the client to try to relieve pain in the first instance. It is intended that assisting clients to describe their pain and to take some initial steps in managing it will empower them with a sense of having some control over pain.

HOW DOES THE PAIN ASSESSMENT PATHWAY TRANSLATE INTO PRACTICE?

The feedback from nurses indicated that the pathway has the potential to allay the anxiety experienced by some nurses when faced with a person experiencing pain in palliative care. All nurses found the tool beneficial to their nursing practice around pain assessment with one nurse stating that it had broadened her knowledge about pain. Nurses were positive about their experience of using the pain assessment pathway in practice with comments such as "great prompts", "good guide for pain assessment" and "easy to follow". Their responses identify that the pathway acts as a prompt and a guide through the process of pain assessment. Nurses had used the tool in different ways:

- as a resource to refer to when asking clients questions about pain
- in collaboration with the symptom assessment chart
- to prompt clients to elaborate their descriptions of pain
- in assessment and planning care.

Optimal times for using the pathway were considered to be for new clients and new reports of pain. Two nurses preferred its use to be ongoing and for all visits involving pain.

WHAT CAN BE CONCLUDED FROM THIS PROJECT?

This research has affirmed that pain is a complex, subjective and multi dimensional experience which is unique to each individual. In palliative care the pain experience is further complicated by the persons other symptoms and experiences associated with being at end of life, including the heightened emotions associated with impending death. It is an emotionally charged situation that district nurses enter when responding to a palliative care client reporting pain.

RDNS round nurses vary in their confidence regarding conducting an assessment of pain in this situation. Both real and self imposed pressure (a sense of urgency) to find effective pain relief quickly can undermine clear thinking and cause the nurse to feel anxious when faced with a client in pain. Nurses view the introduction of a pathway to guide them through the process of pain assessment as supportive in assisting them to conduct pain assessment despite the tension that may be present. The favourable responses of nurses to the pathway after trialling it in practice suggests that it is considered to add value to their clinical practice in pain assessment for people receiving palliative care.

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