

Reconceptualising the decision making process for the assessment and management of pain in patients with dementia in acute hospital settings: case study analysis

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What is already known about the topic

- The recognition, assessment and management of pain in patients with dementia in acute care settings is currently suboptimal
- Existing clinical and decision processes assume that clinicians follow a sequential linear approach to decision making
- Patients with dementia have problems communicating their pain to clinical staff

What this paper adds

- Pain assessment and management of patients with dementia is not a linear process, but can be characterized as a naturalistic decision process, where sense making of a patient's pain is key
- Pain assessment and management is a distributed activity over time and across individuals
- A revised model of pain recognition, assessment and management for patients with dementia in acute care settings that reflects theoretical literature and the findings from our study

*Author Checklist

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Part 2 identifies recognized guidelines for scientific reporting, which you should use to prepare your manuscript (required for systematic reviews and original research)

PART 1 Basic requirements		Author response or further detail – please complete the boxes below
Word count		6780
Was ethical approval given and by whom? (give any reference number)		NRES committee Yorkshire & the Humber – Leeds West Ref: 12/YH/0363 Scotland A REC. Ref: 13/SS/0006
Please state any conflicts of interest		There are no conflicts of interest
Please state sources of funding and the role of funders in the conduct of the research		The study is funded by the National Institute for Health Research HS&DR Programme (HS&DR - 11/2000/05)
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For the items below, please tick in the right hand column to confirm you have included/addressed the items:		Tick
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Abstract	A structured abstract appropriate to the design of the study is included (see guidelines for authors).	X
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Abbreviations	No abbreviations are used in the title / abstract. Use of abbreviations /acronyms in the paper is minimised and restricted to those that are likely to be universally recognized (e.g. USA)	X
References	All citations in the paper have a complete and accurate reference in the reference list (see Guide for Authors)	X
Other Published accounts	All published and in press accounts of the study from which data in this paper originate are referred to in the paper and the relationship between this and other publications from the same study is made clear (see Guide for Authors) (Please upload copies of all previous, current and under review publications from this study and / or give full details below)	X

	Please provide references of ANY other papers using data from the study that this paper is based on) below.	
	The study is referred to by a distinctive name which will be used in any future publications to identify that it is the same study (e.g. RN4Cast)	
Authorship	All authors and contributors sufficiently acknowledged as per Guide for Authors.	X

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Quasi experimental / non-randomized evaluations	TREND - Transparent Reporting of Evaluations with Non-randomized Designs http://www.equator-network.org/index.aspx?o=1032	
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Study of Diagnostic accuracy / assessment scale	STARD Standards for the Reporting of Diagnostic Accuracy studies http://www.equator-network.org/index.aspx?o=1032	
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Other (please give source)		
Not applicable (please elaborate)	The study uses a qualitative ethnographic case studies, with the majority of the data being observation and interview based – we have used the COREQ checklist, but some of the questions are not relevant for our study.	X

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COREQ Checklist

Domain 1: Research team and reflexivity

Personal Characteristics

- 1. Interviewer/facilitator Which author/s conducted the interview or focus group?
Details of individuals who collected the data are provided in the acknowledgements
- 2. Credentials What were the researcher's credentials? E.g. PhD, MD
This is not provided in the paper – IJNS does not ask for credentials when submitting the paper – all researchers were skilled in qualitative research
- 3. Occupation What was their occupation at the time of the study?
Not provided
- 4. Gender Was the researcher male or female?
Not provided
- 5. Experience and training What experience or training did the researcher have?
Not provided

Relationship with participants

- 6. Relationship established Was a relationship established prior to study commencement?
This is covered in data collection

Participant knowledge of the interviewer

What did the participants know about the researcher? e.g. personal goals, reasons for doing the Research

This is covered in consent

- 7. Interviewer characteristics What characteristics were reported about the interviewer/facilitator?
e.g. Bias, assumptions, reasons and interests in the research topic
This is not relevant for our study

Domain 2: study design

Theoretical framework

9. Methodological orientation and Theory

What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis

This is covered in study design

Participant selection

- 10. Sampling How were participants selected? e.g. purposive, convenience, consecutive, snowball

This is detailed in sample/methods

- 11. Method of approach How were participants approached? e.g. face-to-face, telephone, mail, email

This is discussed in methods

- 12. Sample size How many participants were in the study?

This data is provided in the results

- 13. Non-participation How many people refused to participate or dropped out? Reasons?

This is not relevant for our study

Setting

- 14. Setting of data collection Where was the data collected? e.g. home, clinic, workplace

This is described in the methods

- 15. Presence of non-participants Was anyone else present besides the participants and researchers?

This is described in the methods

- 16. Description of sample What are the important characteristics of the sample? e.g. demographic data, date

This is provided in methods and results

Data collection

17. Interview guide Were questions, prompts, guides provided by the authors? Was it pilot tested?

Interviews were based on observational data – not reported in the text

18. Repeat interviews Were repeat interviews carried out? If yes, how many?

N/A

19. Audio/visual recording Did the research use audio or visual recording to collect the data?

We report audio recording of interview data

20. Field notes Were field notes made during and/or after the interview or focus group?

Field notes made during observation – reported in the methods

21. Duration What was the duration of the interviews or focus group?

N/A

22. Data saturation Was data saturation discussed?

We report our methods of analysis in the methods section

23. Transcripts returned Were transcripts returned to participants for comment and/or correction?

N/A

Domain 3: analysis and findings

Data analysis

24. Number of data coders How many data coders coded the data?

Not explicitly mentioned – this was a team approach to coding

25. Description of the coding tree Did authors provide a description of the coding tree?

No description provided

26. Derivation of themes Were themes identified in advance or derived from the data?

We report in the analysis – a mixture

27. Software What software, if applicable, was used to manage the data?

NVivo – reported in the methods

28. Participant checking Did participants provide feedback on the findings?

N/A

Reporting

29. Quotations presented Were participant quotations presented to illustrate the themes / findings? Was each

quotation identified? e.g. participant number

We have provided quotations and excerpts from field notes with identification details

30. Data and findings consistent Was there consistency between the data presented and the findings?

Reported in results and analysis

31. Clarity of major themes Were major themes clearly presented in the findings?

Reported in findings

32. Clarity of minor themes Is there a description of diverse cases or discussion of minor themes?

Where there are deviations we have reported them in the findings

Using sense-making theories of decision making to aid understanding of the recognition, assessment and management of pain in patients with dementia in acute hospital settings: a UK multi-site study

Abstract

Background: The recognition, assessment and management of pain in hospital settings is suboptimal, and is a particular challenge in patients with dementia. The existing process guiding pain assessment and management in clinical settings is based on the assumption that nurses follow a sequential linear approach to decision making. In this paper we re-evaluate this theoretical assumption drawing on findings from a study of pain recognition, assessment and management in patients with dementia.

Aim: To provide a revised conceptual model of pain recognition, assessment and management based on sense-making theories of decision making.

Methods: The research we refer to is an exploratory ethnographic study using nested case sites. Patients with dementia (n= 31) were the unit of data collection, nested in 11 wards (vascular, continuing care, stroke rehabilitation, orthopaedic, acute medicine, care of the elderly, elective and emergency surgery), located in four NHS hospital organizations in the UK. Data consisted of observations of patients at bedside (170 hours in total); observations of the context of care; audits of patient hospital records; documentary analysis of artefacts; semi-structured interviews (n=56) and informal open conversations with staff and carers (family members).

Findings: Existing conceptualizations of pain recognition, assessment and management do not fully explain how the decision process occurs in clinical practice. Our research indicates that pain recognition, assessment and management is not an individual cognitive activity;

rather it is carried out by groups of individuals over time and within a specific organizational culture or climate, which influences both health care professional and patient behavior.

Conclusions: We propose a revised theoretical model of decision making related to pain assessment and management for patients with dementia based on theories of sense-making, which is reflective of the reality of clinical decision making in acute hospital wards. The revised model recognizes the salience of individual cognition as well as acknowledging that decisions are constructed through social interaction and organizational context. The model will be used in further research to develop decision support interventions to assist with the assessment and management of patients with dementia in acute hospital settings.

Keywords: Decision Theory, Pain Measurement, Pain Management, Dementia, Decision Making, Qualitative Research

Background

It has been estimated that approximately 50% of people with dementia regularly experience pain and a concomitant decrease in quality of life (van Kooten et al., 2015). A number of studies internationally have identified that pain is often substantially undertreated or untreated in geriatric patients (Daoust et al., 2014, Lukas et al., 2013, Morrison and Siu, 2000, Niruban et al., 2010), and that people with dementia are significantly less likely to receive analgesia than their cognitively intact counterparts (Closs et al., 2004, Hoffman et al., 2014, Morrison and Siu, 2000). There are particular issues with the management of pain for older patients in acute hospital settings (Atkinson and Almahdi, 2014, Carr et al., 2014, Chang et al., 2010, Lin et al., 2014, Niruban et al., 2010). Poor management of pain may lead to slower rehabilitation and a decrease in physical function with hospitals stays longer for a person with dementia than for others admitted for the same procedure (Alzheimer's Society, 2009).

There are particular challenges for clinical staff when caring for patients in acute settings who have dementia; for example, they may not be able to report their pain experiences verbally and are therefore at increased risk of having their pain inadequately assessed and managed (Sampson et al., 2015). In addition, behavioral symptoms associated with dementia, such as agitation, aggression and shouting, often arise as a result of underlying pain that, if misidentified, may lead to the inappropriate prescription of antipsychotic medications (Ballard et al., 2011). A number of studies have highlighted particular issues faced by clinical staff when assessing and managing pain in older adults and those with dementia; communication with patients may be problematic if they are unable to express their pain experiences clearly (Coker et al., 2010, Manias, 2012), organizational issues may impact on when older adults receive pain relief (Manias, 2012, Manias et al., 2002), and trying to balance effectively

1 treating pain whilst simultaneously minimizing the side effects of analgesics has been
2 reported as challenging (Manias, 2012). Nurses have been both observed and reported as not
3 using validated tools for the assessment of pain when caring for patients with dementia in the
4 acute hospital, preferring instead to rely on simple questioning and observation of non-verbal
5 cues (Coker et al., 2010, Manias, 2012). This means that there is ‘the risk of inaccurate
6 judgements being made about patients’ pain intensity’ (Manias, 2012) [p.1252].
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17 Existing models of pain recognition, assessment and management assume a clinical process
18 which is sequential in nature and could be compared to a linear cognitive or judgment and
19 decision making process (Figure 1), where the nurse accurately interprets the patient’s pain
20 experience (i.e. makes an *assessment or judgment* about their pain), and takes appropriate
21 actions to decrease their pain (i.e. makes a *decision* about the most appropriate treatment to
22 achieve this goal). This paper uses data from an ongoing study to examine these
23 assumptions, highlighting the limitations of a theoretical approach which assumes a linear
24 process to understanding the process of pain assessment and management in acute care
25 settings. The aim of the paper is to re-evaluate the process of pain recognition, assessment
26 and management, providing an alternative theoretical framework.
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50 *Pain assessment as a judgement process*

51 One of the most influential models of decision making is that of hypothetico-deductive
52 reasoning (Dowding and Thompson, 2004, Elstein, 1978). Hypothetico-deductive reasoning
53 suggests that individuals go through a series of stages when processing information to make a
54 *judgment*, defined as ‘an assessment between alternatives’ (Dowie, 1993) or diagnosis. The
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1 first stage, known as cue acquisition, is the gathering of clinical information about the patient.
2 Following the collection of information, hypotheses are generated which provide a possible
3 explanation for the information; the information collected is then interpreted in the light of
4 the hypotheses, before a hypothesis is chosen that is favoured by the majority of the evidence
5 or information. At this point the decision maker may choose to collect more information, if
6 they feel that none of the original hypotheses fit the data.
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17 The assessment of a patient's pain could be interpreted as a process of hypothetico-deductive
18 reasoning; during the assessment of pain nurses collect information (cue acquisition) to
19 determine the presence, nature and intensity of a patient's pain (hypothesis generation and
20 evaluation). In order to assist with the assessment process a number of assessment tools
21 have been developed. These include simple rating scales for self-reporting of pain as well as
22 tools to structure the observation of behavioural cues as a method for identifying the presence
23 of (and changes in) pain in patients with dementia and other cognitive impairments (Corbett
24 et al., 2012, Lichtner et al., 2014). Despite the abundance of such tools (Lichtner et al.,
25 2014), many studies have highlighted that nurses do not use them in practice, preferring to
26 rely on simple questioning (Manias, 2012) and their "intuition" (Parke, 1998) or 'feelings'
27 that a patient may be experiencing pain (Parke, 1998)[p26].
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46 *Pain Management as a decision process*

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48 Once it has been ascertained that a patient is in pain, and the type and level of pain (they have
49 made a judgment), the clinician then needs to make a *decision* ('a choice between
50 alternatives') (Dowie, 1993) regarding what to do to manage that pain. The goal, relief of a
51 patient's pain, is normally achieved through the prescription and administration of analgesia,
52 on the basis of frameworks such as national guidance (American Geriatrics Society Panel on
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1 the Pharmacological Management of Persistent Pain in Older persons, 2009, British
2 Geriatrics Society, 2013) or the WHO analgesic pain ladder (Kapur et al., 2014, Vargas-
3 Schaffer, 2010). Although not explicitly stated, an underlying rationale is that choices
4 between different analgesic or other treatment options are based on both a) their probability
5 of effectiveness and b) the utility or value associated with their effectiveness; a normative
6 model of decision making known as subjective expected utility theory (SEUT) (Bell et al.,
7 1988, Dowding and Thompson, 2009, Thompson and Dowding, 2009). There are very few
8 studies that have explored nurses' decision making around the use of interventions for pain
9 management in dementia; those that have been carried out highlight how the uncertainty of
10 whether or not a patient is experiencing pain often leads to lower use of analgesia and a
11 reluctance to use opioids (Gilmore-Bykovskyi and Bowers, 2013, Kaasalainen et al., 2007).
12 Rather than the formal approach outlined by SEUT, nurses have been found to use a 'trial and
13 error' approach to interventions, often with a focus on a patient's behavior to try and bring it
14 back to some form of baseline, rather than targeting pain specifically (Gilmore-Bykovskyi
15 and Bowers, 2013). This means it is difficult to identify whether specific interventions have
16 been successful or not at relieving pain or distress.

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41 In contrast to hypothetico-deductive and SEUT approaches to judgement and decision making,
42 dual process theory (Table 1) suggests that individuals use both analytical and intuitive
43 strategies when faced with a decision problem. System 1 processing which is experience
44 based, unconscious and automatic (akin to intuition) is the default approach to thinking which
45 doesn't require the use of working memory and can process large amounts of information
46 rapidly (Evans, 2011). System 2 processing (conscious, controlled, rule based) provides a
47 supervisory role, involving the use of working memory, and is characterized by slow,
48 sequential processing, which appears to be conscious (Evans, 2011). What dual process
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theory suggests is that *individual* decision makers are likely to use *both* intuitive, subconscious, and fast, and more deliberative, slow approaches to pain recognition, assessment and management.

INSERT TABLE 1 ABOUT HERE

One possible explanation for why pain assessment tools have produced a mixed picture in terms of improving pain recognition, assessment and management (Ang and Chow, 2010, Haller et al., 2011, Idvall and Ehrenberg, 2002, Purser et al., 2014, Rockett, 2010), particularly in patients with dementia, may be because they have been developed with a view that the process can be characterized in a sequential, linear fashion (system 2 processing) rather than acknowledging the prevalence of more intuitive subconscious approaches to judgment and decision making (system 1), characteristic of nurses' preferred mode of decision making (Parke, 1998). Additionally, assessment tools also only focus on one part of the pain recognition, assessment and management process (the assessment) assuming that once pain has been identified decisions regarding interventions and subsequent actions will be taken 'automatically'.

The aim of the wider study related to this paper is to develop a decision support intervention for the recognition, assessment and management of pain in patients with dementia in acute hospital settings. Initially, the study proposed to use the model outlined in Figure 1 as the theoretical framework for data analysis, anticipating that it would identify points in the judgment and decision process where the provision of decision support (beyond that provided by existing assessment tools, and tailored to the realities of how nurses actually make judgements and decisions), would enable nurses to process information more effectively,

1 linking it to better pain management decisions. However, after initial analysis, it was
2 apparent that the theoretical conceptualization was not sufficient to explain the actual process
3 of pain recognition, assessment and management in clinical practice. This paper reports the
4 initial analysis and then discusses how the data have been used to reformulate the theoretical
5 framework.
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11 **Research Aim**

12 To provide a revised conceptual model of decision making for the recognition, assessment
13 and management of pain in patients with dementia in acute care settings.
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22 **Methods**

23 An exploratory study using ethnography was carried out using a nested case study design,
24 where patients with dementia were considered as cases, nested in wards in four National
25 Health Service (NHS) hospital organisations in England and Scotland, UK. Ethnographic
26 non-participant observations were centred on the patients - their experience and expression of
27 pain, their interaction with healthcare professionals and the care they received.
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38 *Setting and participants*

39 Four case sites (hospitals) were sampled to provide varying settings for acute care: one in the
40 south of England, two in the north of England and one in Scotland. In each site, a minimum
41 of two wards were selected purposively to ensure the sample was a representation of a variety
42 of clinical settings where patients with dementia were cared for.
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53 Patients were eligible for inclusion in the study if they were over the age of 65 and had a
54 diagnosis of dementia recorded in their notes. Participants for staff for interviews included all
55 members of staff caring for patients in the study wards, together with the managers of those
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wards and specialists from relevant hospital services. The families of patients participating in the study were approached to participate in interviews as carers.

Ethical approval was obtained for both English (REC reference: 12/YH/0363) and Scottish (REC Reference 13/SS/0006) sites. Patient recruitment was informed by the Mental Capacity Act 2005 and the Mental Health (Care and Treatment) (Scotland) Act 2003. Patients' consent to participate was subject to capacity assessment to consent, consultation with staff and agreement of a carer consultee where appropriate (Monroe et al., 2013). All interviewees were asked for their written consent. All data were anonymised at the point of data collection.

Data Collection

Data included non-participant observation of patients at the bedside, observations of the context of care (recorded in field notes), audits of patient hospital records, documentary analysis of artefacts, semi-structured interviews and informal open conversations with staff and carers.

Non-participant observation of health care professionals (HCPs) and health care assistants (HCAs) interacting with patients who had dementia was carried out using an observational protocol derived from the theoretical framework (Figure 1). Observations focused on identifying how information appeared to be identified and elicited in order to detect and manage pain and the care processes that are currently used to manage pain. Semi-structured interviews were carried out with staff (HCAs, nurses, doctors, other members of the MDT) and carers. Interviews lasted approximately 15 – 60 minutes, were recorded and transcribed verbatim (by a professional transcribing service), with the exception of those conducted in Case Site 3 which were recorded using handwritten notes.

Copies of existing policies and procedures for the assessment and management of pain that were in place in the ward and/or organization were also obtained. Patient notes were audited for information on the documentation of pain assessment, pain management interventions, pain reassessment and records of prescribed analgesia. Data collection at each site continued until the research team assessed that saturation had been achieved.

Data Analysis

Data were qualitative in nature and consisted of transcripts of observations and interviews, data from medical and nursing notes and field notes. Data were organized using specialist software (NVivo v10) and analyzed both inductively and deductively using a thematic approach. Dimensions of decision making, including information/pain cues used, pain assessment records and decisions/pain management interventions were used as initial categories for coding the data. Other themes emerged from the data during analysis.

The process of analysis was carried out across the research team; transcripts were read and re-read to identify initial themes, with the lead research fellow developing an initial coding structure. This structure was verified by 2 other research team members, and then used to code data by all three researchers. A sample of each subset of data was checked across researchers to verify consistency in coding and analysis. Analytic processes included the identification of negative cases or contradictory findings, with emerging themes compared and contrasted with the wider project team at team meetings. Repeated readings of field notes, interview transcripts and audit reports and contrasted throughout the analytic process across the research team.

Findings

Participant Characteristics

An overview of the data collected and participant characteristics are provided in Table 2. The patients included in the study had a mean age of 88 years (range 75 - 99), and had diagnoses of dementia with varying degrees of severity. The hospital wards (n=11) covered a variety of specialities including acute admissions, surgical wards (vascular and general surgery/orthopaedic), elderly medicine, rehabilitation and continuing care.

INSERT TABLE 2 ABOUT HERE

Data consisted of a total of 170 hours of direct observations with 31 patients, with field notes from 480 hours in the field. Interviews were conducted with 52 staff (including physicians, staff nurses, charge nurses, ward managers, support workers and specialist nurses) from all 4 sites and 4 carers from 2 sites.

Themes arising from the Data

In this paper three main themes arising from the data related to the clinical and decision processes for pain recognition, assessment and management in patients are reported.

The nature of pain and pain assessment in patients with dementia

The patient's pain experience was seen to be *complex and dynamic*. Participants discussed how pain may be intermittent and fluctuate, often only being present when patients are engaged in certain activities.

"often the doctors will go round and they'll ask the patient in their bed or in their chair, "Oh, are you alright? Any pain anywhere?", "No, I'm fine". As soon as we [physiotherapists] come, get them up on it, "Oh, oh, that really hurts"." [H1, physiotherapist]

1 They also highlighted how pain may depend on, or be associated with distress and anxiety,
2 from which it may be impossible to differentiate, and is often affected by the person's
3 relations and surroundings.
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7 *"... [pain and anxiety] are very closely associated and it was both, she [the*
8 *patient] did have pain but her pain perception was much worse and much*
9 *heightened because she was so anxious"* [H1, nurse specialist/tissue viability]
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12 As with other patients, one of the challenges faced by clinicians is the initial recognition of
13 whether or not a patient may be in pain at all; for a variety of reasons patients (including
14 those with cognitive impairment) may not be able to verbally express they have pain, and
15 clinicians often find it challenging to interpret behavioural signals which may be 'atypical' in
16 nature.
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24 *"he's like nervous or screaming or like with anxiety, we need to be there, maybe*
25 *he's in pain. It depends also on the surgery he had, you know. But yes with the*
26 *facial reactions and if you touch around the wound and he's like, you know,*
27 *with a screaming reaction or...[....] and if he can't mobilise himself really well*
28 *and normally he does, you know, it's kind of signs that you can see, the*
29 *indications are telling you. The blood pressure as well, if it's high, it kind of*
30 *seems like he's in pain. So everything together is like an assessment"* [H4, staff
31 nurse]
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37 Interviewees referred to the need to rely on their 'total assessment skills' to try and interpret
38 whether either complaints of pain or alternately denials of pain could be taken 'literally'. In
39 this context nurses often reported relying on non-verbal or behavioural assessment skills,
40 their intuition and comparisons to what is usual or different to interpret patient signs to
41 recognize them as pain. They also highlighted that they draw on a variety of sources
42 including their own knowledge and experience to identify whether or not a patient has pain or
43 what kind of pain. Once the possibility of pain has been established, then they embark on a
44 process of 'trial and error' to test out whether or not they are correct, trying out different
45 approaches to pain management.
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1 *"...It really is a common sense approach. If a patient is sat stable and content, but*
2 *then starts to flap and make noises and are not themselves, then that would indicate*
3 *that they are in pain. [...]... You need to identify the source and if it's a new thing."*
4 [H3, notes from interviews]

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6
7 *"...But if we went to turn them, they would maybe react to the pain as we're turning*
8 *on to the bad hip or if we was going to move them. So we would read the body*
9 *language and the signs that they'd give off if they wasn't able to actually*
10 *communicate"* [H4, staff nurse]

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16 One of the key factors in assessing and managing pain is the ability to build a 'picture' or
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18 narrative of the patient case; which is used as the basis for the interpretation of cues, to try
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20 and 'make sense' of a situation. Participants highlighted the importance of building patterns
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22 of information cues and patient behaviour, to help inform their decision making. This
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24 narrative occurred over time (an issue which arose in other themes from the data), trying to
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26 link different events over the trajectory of a patient stay, to help test 'guesses' and form the
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28 basis of trial and error approaches to management.
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33 *"...then you're looking at your drug chart and you're linking it, you know,*
34 *you're creating a picture ... we're like [...] trying to find out what's going*
35 *on, you know, why the patient's here, why have they got this pain or where's*
36 *it, what's going on here? You know, we're trying to build a picture, ..." [H1,*
37 *staff nurse]*
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41 Overall nurses tended not to use pain assessment tools to aid their decision making, although
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43 one nurse reported using assessment tools as a way of ensuring that they '*don't rule out*
44 *anything*' and consider pain as a possible explanation for the behaviour they are observing.
45
46 In general, they appeared to distrust the scores given by a tool, preferring to rely on 'common
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48 sense' and their own experience to make assessments of patient pain.
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53 *"...if a patient's got dementia then it's not really much use asking the patient*
54 *what their pain scale is. [...] I don't tend to go by it."* [H1, doctor in training]
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57 *"I could assess a patient using my observation skills without looking at a score*
58 *to know they were at a higher risk of something. So I think, in some way, we*
59 *need to ensure that there's professional judgement, there's observation as well*
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1 *as a bit of calculation and prompt but certainly linking to other documentation*
2 *and getting people to make these connections, to help them make the*
3 *connections.” [H2, nurse manager]*
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5 *The role of context in recognizing, assessing and managing pain*
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7 The nature of the ward and hospital context also appeared to have an impact on how nurses
8
9 recognized, assessed and managed pain. The different wards catered for different patient
10 populations or ‘patient types’ with an associated expectation for the likelihood that certain
11 types of pain will be present or absent. In most of the surgical wards, for example, there
12 appeared to be an expectation that individuals would be experiencing pain as a result of their
13 surgical intervention, but that this pain would be acute in nature and for a limited time. As a
14 result it appeared from the observation data that patients in surgical wards were often (but not
15 always) routinely asked about pain and given pain relief medication.
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17

18 *“Anyway they have always painkillers prescribed at every six hours. So even if*
19 *they don’t tell anything, they will have those painkillers” [H4, staff nurse]*
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21

22 However, in some medical wards there appeared to be less focus on considering pain as a
23 possible cause of patient distress. Across some of the wards where we collected data patients
24 did not appear to be routinely asked about their pain, and the documentation of pain scores
25 was rarely completed. This was explained by one medical consultant in terms of the
26 expectation that elderly patients would have some degree of aches and pains (presumably due
27 to their age), so that the routine charting of such pain would not be ‘helpful’ in terms of
28 informing actions.
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30

31 *“And I particularly ask those people who, you know, you might expect to*
32 *have pain so people who have got osteoarthritis or had fractures recently,*
33 *that sort of thing than I’m likely to ask about any pain. [...] Somebody who’s*
34 *on a HDU, we might be worried about their pancreatic masses can cause*
35 *lots of pain and so they might be charted for that reason. So for elderly*
36 *medicine patients I think it’s less useful to just routinely chart it, it’s not very*
37 *helpful really, it doesn’t really tell us anything.” [H1, Consultant]*
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2 The process of pain recognition, assessment and management appeared to be governed by the
3
4 routine of the specific ward where the patient was located. The recognition of pain requires
5
6 that the patient is able to communicate their pain, and that there is someone available to
7
8 receive it. Patients were often asked if they had pain on wards where healthcare assistants
9
10 carried out 'comfort rounds'. However, in other wards patient interactions with nursing staff
11
12 were limited and often related to routine tasks (such as drug rounds, doctors' rounds). In all
13
14 cases, given the fluctuating nature of pain, and the challenges of assessing pain in patients
15
16 with dementia, the points in time when clinicians were available to listen to the patient may
17
18 not have corresponded to the points when they were experiencing pain, which was
19
20 problematic for those patients with dementia who were able only to report on 'here and now'
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22 experiences.
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31 *Pain recognition, assessment and management as a process distributed across individuals*
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33 *and over time*
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36 From the observations it appeared that pain recognition, assessment and management was
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38 carried out over time, by many individuals. Rather than being under the control of one
39
40 specific nurse or other health care professional, it could be characterized more as a process of
41
42 distributed work, which is time dependent. This is reflected in the comments in interviews,
43
44 which highlight how there is a division of labour in the hospital ward; there numerous people
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46 with different professional roles who are all involved in the care of each patient, each with
47
48 specific duties, responsibilities and powers. In turn, these roles often governed which part of
49
50 the pain recognition, assessment and management process they participated in, and how they
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52 communicated their findings.
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57 *"I mean the student, the patient can tell the student they are in pain. And we will go*
58 *and assess the patient with the pain, you know, and speak to them and get them to tell*
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1 *us how severe the pain is, because we are the ones who will have to administer the*
2 *medication.*

3 *[...] But we all kind of assess patients' pain, you know. But it's then, it's normally*
4 *left to the trained staff to manage the pain. And then if we can't, then we'll go to the*
5 *next one and then ask the pain team to come in and see the patient"* [H4, deputy ward
6 manager]
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10 *"What I would then do is I would go to staff nurse, and I would say, "The lady that I was*
11 *at is in pain," and then probably get assessed from there, find out where the pain's*
12 *coming from and then the doctor would probably have to come and examine and find out*
13 *initially where the pain's actually coming from"* [H2, healthcare assistant]
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17 The work of a hospital ward is organized in shifts; during each shift on the wards in this study
18 a nurse had responsibility for the care of between 8 and 14 patients. Therefore often those
19 individuals who assessed a patient are not necessarily those who reassessed them, and those
20 who decided on a care plan or medication were not those who administered it.
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27 The ability to build a picture of the patient, and the interpretation of whether they have pain,
28 the nature of the pain and the best way to manage it occurs over time. It is both in the nature
29 of the pain (which may be transient, fluctuating) and in the nature of the distributed
30 information gathering process. As care of the patient is shared among people and
31 professions, gathering this information for 'building a picture of the patient's pain' relies on
32 effective communication and documentation. It was apparent from our interviews, that in
33 general, clinicians found existing paper documentation tools, including the scores provided
34 by pain assessment tools, was fragmented and therefore failed to provide the information they
35 needed in order to carry out effective pain assessment and management.
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52 *"... [in a pain assessment form, with pain scores] you only know at ten past*
53 *twelve when they did that, the person said they had some pain, doesn't tell*
54 *you what it is, doesn't tell what somebody's doing about it, doesn't tell you*
55 *whether that intervention has been beneficial or not. [...] there's no link to*
56 *the management..."* [H1, staff nurse]
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Discussion

The findings of this study suggest that the process of pain recognition, assessment and management for patients who have dementia in hospital settings (and potentially for all hospital patients) does not appear to be a sequential linear process carried out by one individual nurse or clinician. Instead, conceptual frameworks for pain recognition, assessment and management need to acknowledge that pain assessment is carried out by a range of individuals over time and socially embedded within a specific organizational culture or climate (Lauzon Clabo, 2008, Manias, 2012). In this study health care staff (nurses, health care assistants, physicians) reported using intuition, experience and their ability to ‘build a picture’ of the patient to identify whether or not they were experiencing pain. This supports findings of previous studies exploring the process of pain management across settings (Manias, 2012, Parke, 1998). The management of pain was often also described as ‘trial and error’ (‘guesswork’) – with the use of pain medication as a way of seeing if symptoms or distress improved. Again this is similar to findings from studies exploring nurses’ decision making strategies for pain management in nursing homes and long term care facilities internationally (Gilmore-Bykovskyi and Bowers, 2013, Kaasalainen et al., 2007). The process of pain assessment and management took place in a context which is reliant on effective communication; where the patient needs to be able to communicate their pain and where there is a nurse available to receive that communication. This provides particular difficulties for patients with dementia; depending on their level of impairment they may not be able to verbalise their pain, or communicate distress if it is not in the ‘here and now’ of experience. In this context, pain assessment tools by themselves, did not appear to provide the type of information nurses used to enable effective pain recognition and assessment. Organizational context was therefore a mediating factor in the recognition, assessment and management of pain (Lauzon Clabo, 2008, Manias et al., 2002). Particular ‘types’ of patient

(depending on the ward) were more likely to have their pain recognized and different ward routines provided varying opportunities for communication of that pain.

The need for a different conceptual framework

The conceptual model described in Figure 1, whilst potentially providing some explanatory power for aspects of individual cognition, is not supported by the findings of this study. In particular:

- Nurses use a mixture of type 1 (more subconscious, automatic processing) as well as type 2 thinking. This thinking is characterized by the process of building patterns or mental models of the patient (narratives over time), which are then used as the basis of recognizing if pain exists. These patterns or mental models are framed by the specialty of the ward where patients are located, and for dementia patients are reliant on nurses' ability to identify individual behavioural characteristics that may indicate pain is present.
- The process of decision taking is often based on an approach that could be characterized as 'guess-work' and 'trial and error' – a process where knowledge, and experience about the specific patient ('knowing the patient') provide potential solutions to a patients problem (their pain and/or distress), and nurses try different solutions until one appears to be successful.
- The 'work' of pain recognition, assessment and management is distributed across individuals and over time; it is less an individual cognitive activity, but more a collection of individuals carrying out components of that activity between them in a dynamic fashion.

Many of these characteristics of the process of decision making have been found in other areas of research; for example the Recognition-Primed Decision (RPD) Model (Klein, 2008)

suggests that individuals use their experience in the form of patterns, which “highlight relevant cues, provide expectancies, identify plausible goals, and suggest typical types of reactions in that type of situation” [p.457]. Using this model it could be hypothesized that nurses who work with surgical patients will have different patterns (or mental models) based on their experience in relation to pain, which means that they may focus on different cues, have different expectancies about a patient having pain, and will have different reactions to those cues than nurses who work on other wards. The RPD model also suggests that individuals use mental simulation to imagine how an action might be effective in a particular situation (Klein, 2008), akin to the ‘trial and error’ approach to pain management reported by the participants in this study. Klein suggests that the RPD model is a blend of intuition (type 1) and analysis (type 2) processing, with pattern matching being intuitive and mental simulation the deliberate analytic part. The RPD model may therefore be more representative of the pain recognition, assessment and management decision processes used by nurses when caring for patients with dementia in acute settings than the original framework outlined in Figure 1. However, it still fails to acknowledge the broader role of context and organization (beyond the role of experience in framing the patterns used to recognize pain in the first place), which was also a key issue in the study findings.

Theories of sense making recognize both the cognition of individuals and the interaction of those individuals within an organization or social culture, as being important for impacting on action or behaviour (Weick et al., 2005). During the process of sense making individuals identify certain cues or pieces of information, a process called noticing and bracketing (Weick et al., 2005) where noticing is paying attention to a signal among a noise of many, and bracketing is the singling out of this signal for interpretation. This process is guided by mental models based on experience (which is akin to the process of pattern matching described by the RPD model). Where theories of sense making differ is in their focus on how

1 individuals develop their mental models, which is seen to be through the continual, iteratively
2 developed, shared understandings between individuals within a particular organizational or
3 social culture. It is these shared understandings (such as the ‘narratives’ surrounding
4 patients, the organizational culture within which actions occur) that provide a framework to
5 inform the interpretation of information, and which form the basis of actions. Pain
6 assessment is about gathering/seeking information and attributing meaning to this
7 information. It is a process of sense-making where both the actions undertaken (e.g. to gather
8 information, to perceive cues) and the process of interpretation are not only person but also
9 context dependent
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23 Organizational routines and boundaries of professional roles provide a framework within
24 which sense making occurs. As Greenhalgh (2008) states, "Organisational members are
25 active framers, *cognitively making sense of the events, processes, objects, and issues* that
26 make up organisational life in a way that links with their personal and professional identity"
27 [p.1271]. Routines provide guidance in clinical practice relieving individuals of the need to
28 deliberate over every decision they take (Goodwin, 2014). Rules and routines are then a kind
29 of decision support system. Routines are "generative systems that produce repetitive,
30 recognizable patterns of interdependent action carried out by multiple participants" (Pentland
31 and Feldman, 2008)[p.236]. Rules and routines reduce uncertainty and shape the behavior of
32 people, they enable and/or constrain actions (Greenhalgh, 2008). In this way, routines enable
33 individuals to make decisions subconsciously, without thought, enabling them to focus on the
34 non-routine activities or events which require more cognitive power (Greenhalgh, 2008).
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54 Through the lens of sense making, decision making is seen as the result of a complex
55 interplay between individual cognition and social/organizational context, where decisions
56 emerge over time, through multiple interactions across a number of individuals (Goodwin,
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2014). In this approach, whether or not an individual patient is even identified as being in pain depends on the expectations and previous experiences of health care professionals (through the development of patterns or mental models) and the social/organizational context of the environment (with a specific organizational culture and patterns of behaviour, recognized routines for when and how pain assessment occurs, and the strategies used to manage that pain). The findings of this study, alongside other research, highlight the difficulties nurses' often have in attributing meaning to the information or behaviours they observe in patients with dementia (Gilmore-Bykovskyi and Bowers, 2013). In wards like the surgical ones, where the nurses' have developed 'mental models' to identify patients with (post-op, acute) pain, patients with dementia were identified as being asked if they had pain and provided with pain relief. However, without the development of such mental models, and with an organizational culture and routine that did not recognize pain as an issue, patients with dementia on other wards were less likely to have their pain either recognized or managed. In both types of ward overall, the organizational culture and routines for when and how pain assessment occurs were detrimental to patients with dementia being able to communicate their pain.

Figure 2 presents a revised conceptual model of pain recognition, assessment and management based on RPD and theories of sense making, which reflects the findings of this study. In this framework the patient situation (the patient experiencing pain) triggers cues (such as behaviours, vocalizations of pain, scores on formal assessment tools), that may or may not trigger mental models or patterns in individual clinicians to identify the experience as one of pain. This then feeds into mental simulations (what to do or actions to take) to affect the patient situation. All of these processes will be influenced by individual nurse, organizational and social processes.

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INSERT FIGURE 2 ABOUT HERE

It should be highlighted that to conceptualize pain assessment and management in this way is not to say that this is always effective in producing the best outcomes for the patient. Indeed some of the reasons why there are cases of suboptimal pain management for patients with dementia in hospital can be found in individual inherent, inevitable biases used to make sense of patterns (intuition/system 1 modes of thinking), or in routines unfavourable to the gathering of the necessary information for accurately putting together a patient's picture (and patterns), rather than in problems with 'cue acquisition' or in the application of rules as in the traditional model. The use of pain assessment tools is only one of a number of ways that cues could be noticed, bracketed and interpreted about the patient, and they may not trigger a mental model or pattern in the individual using them; meaning that subsequent parts of the decision process (the triggering of mental simulations and actions) also do not occur, especially if the information they generate is not 'cumulative' – compared to previous points in time to build 'accurate pictures'.

Future research should focus on developing tools that enable nurses and other clinicians to develop patient specific patterns for patients with dementia, that mean they recognize patient behaviour and information cues from others (such as patients' carers) as being representative of pain, and that they have appropriate mental models (based on formal guidelines for pain management) to guide their mental simulations and subsequent actions. Organizational routines and culture will also need to be considered, to promote the development of this knowledge, and to enable the communication of narratives or patient stories between individuals over time, so that there is a 'shared sense-making' of a patient and their pain.

Conclusion

The theoretical lens of the RPD model and sense making provide a more expansive and comprehensive conceptual framework for exploring the nature of pain recognition, assessment and management, which is supported by previous research (Klein, 2008, Parke, 1998, Weick et al., 2005, Weick, 1995, Weick et al., 1999). The revised model recognizes the salience of individual cognition, as well as acknowledging that the knowledge and experience that guides that cognition is constructed through social interaction and organizational context. It moves beyond a model of pain recognition, assessment and management as being located within a sequential linear decision making framework, recognizing the importance of collaborative, co-constructed knowledge which develops over time. Future decision tools need to recognize the nature of the broader context in which such decisions are taken, the importance of shared understandings and communication, and the temporal nature of such decision taking. The assessment and management of pain is not only an individual cognitive activity; it is the product of a collaborative process between many individuals which occur over time and within a particular organizational culture.

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Figure 1: Correspondence between cognitive and clinical process for the recognition, assessment and management of pain

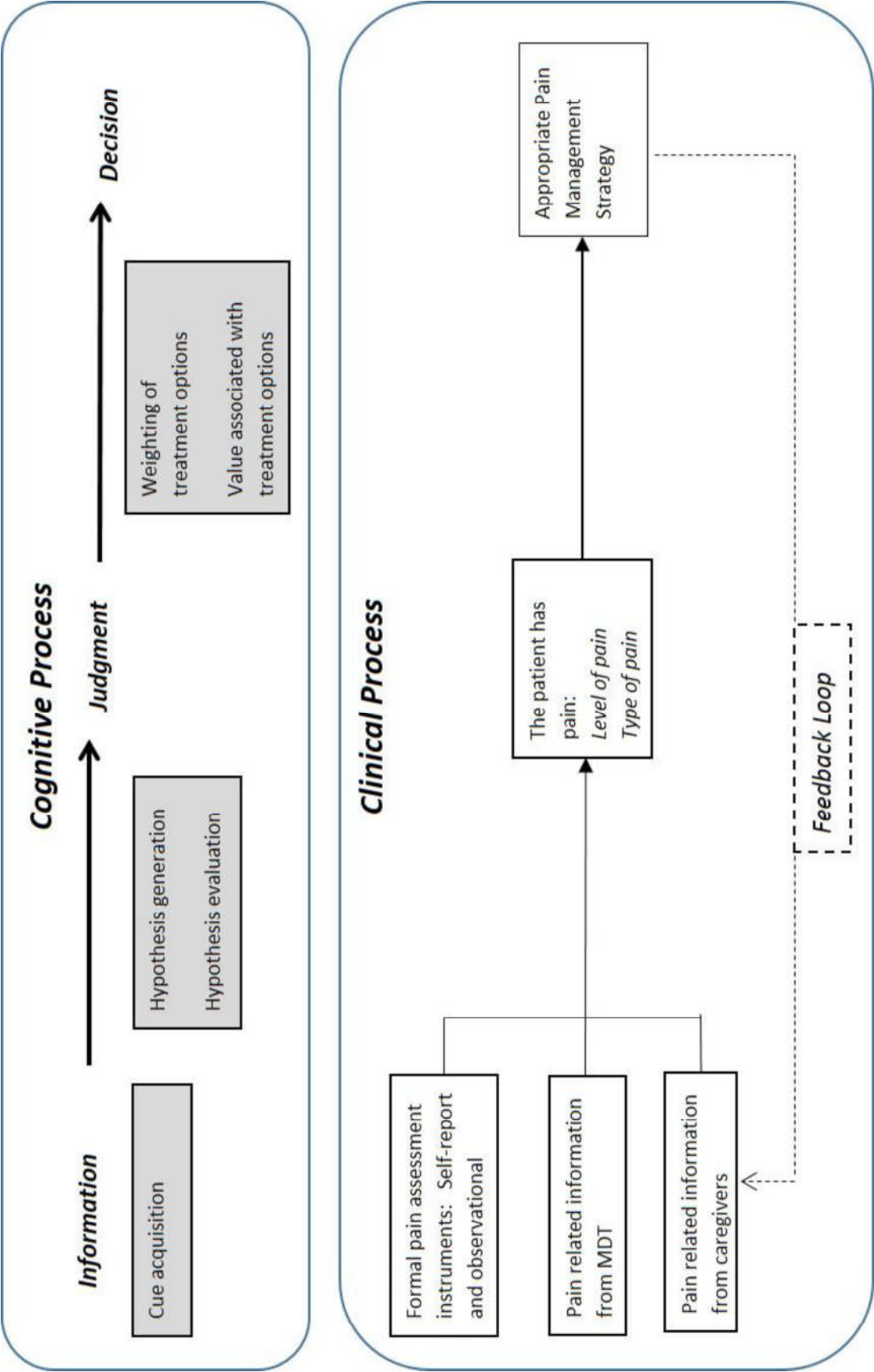


Table 1: Characteristics of Type 1 and Type 2 processing (adapted from (Evans, 2011))

Type 1 process (intuitive)	Type 2 process (reflective)
Fast	Slow
High capacity	Capacity limited
Parallel	Serial
Nonconscious	Conscious
Biased responses	Normative responses
Contextualized	Abstract
Automatic	Controlled
Associative	Rule-based
Experience based decision making	Consequential decision making
Independent of cognitive ability	Correlated with cognitive ability

Table 2: Overview of data collected and patient characteristics

	Hospital 1	Hospital 2	Hospital 3	Hospital 4	Total
Ward Speciality (N)	Vascular (1) Elderly Medicine (1)	Elderly Medicine (1) Continuing Care (1)	Stroke Rehabilitation (1) Elderly Medicine (3) Surgical (1)	Surgical/orthopaedic (1) Acute admissions unit (1)	
Patients Observed (N)	8	7	9	7	31
Interviews with staff (N)	24	13	7	8	52
Interviews with carers	1	3	0	0	4
Total time spent observing patients (hh:mm)	71	45	22	32	170
Total time in the field (hh:mm)	161	167	73	85	480
Mean patient age (range)	83 (77-87)	84 (75-93)	88 (79-99)	85 (75-94)	88 (75-99)
Patient Gender	Male = 1 Female = 7	Male = 2 Female = 5	Male = 4 Female = 5	Male = 4 Female = 3	Male = 11 Female=20

Figure 2: Reconceptualized model of decision making in relation to pain recognition, assessment and management (adapted from (Karrer, 2009)).

