PRELIMINARY COMMUNICATION

The experience and expression of pain in Alzheimer patients

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Abstract

Objectives: to establish whether there is a sub-group of patients suffering from senile dementia, Alzheimer-type (SDAT), who have ceased to undergo normal experience of pain.

Methods: two single case studies are briefly described and a small-scale national survey by questionnaire is reported.

Results: combining the original two cases with those garnered from the survey yielded 49 cases of SDAT patients who failed to exhibit normal experience of pain. In none of the cases does there seem to have been any particular problem of emotional expression or of verbal communication, but pain reactions to accidents, surgical procedures, infections and pre-existing conditions seem to have been extinguished.

Conclusions: such patients may form a theoretically interesting sub-group with particular neuroanatomical pathology. Recognition of the existence of such a group has important legal and ethical implications for those treating or caring for patients of this kind.

Keywords: Alzheimer patients, experience and expression of pain

Introduction

We are currently involved in research into cognitive responses to pain in patients suffering from senile dementia, Alzheimer-type (SDAT). Over recent years one of us (M.F.-M.) has been actively involved with these SDAT patients and has observed a marked decrease in pain responses in certain individuals. Subsequent enquiries, both formal and informal, indicate that similar observations are not uncommon amongst those caring for SDAT patients. Yet despite this 'folk knowledge' we have been unable to find any reports of abnormal sensitivity in either the literature on SDAT or that on pain. There is little awareness of the phenomenon amongst either medical practitioners or pain researchers, and no published data to indicate its prevalence.

In this paper we report observations of two patients diagnosed as having SDAT who had experienced physical trauma of various kinds. Neither of these patients exhibited normal pain behaviour or gave verbal reports of pain commensurate with the tissue damage they had incurred. We then report the results of a survey of pain behaviour in SDAT patients. Finally we consider some practical, theoretical and legal implications of these observations and findings.

Case studies

Case I

D.H. was a 90-year-old woman with SDAT of 5 years' standing. She presented as a mobile, cheerful woman who admitted to being 'forgetful' but was capable of coping with daily living if provided with support. On admission to the nursing home, she was assessed (by M.F.-M.) as being at stage 4 on the Functional Assessment Staging of Dementia [1]. D.H. also had an advanced fungating carcinoma of the breast for which she had received a course of radiotherapy 3 years previously, but on admission she was not on any medication or treatment. She was prescribed tamoxifen 20 mg daily. The lesion—a fungating cauliflower growth, 95 x 75 mm with a cavity 70 x 50 mm—had ulcerated through the skin, invading and destroying the left breast and chest wall. There were also two secondary raised masses above the primary lesion adherent to the chest wall, which were ready to...
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ulcerate through the skin. The central sloughy cavity required irrigation and packing each day, sometimes more frequently, and the tissue around the lesion remained very fragile and bled on touch.

Throughout the 18 months D.H. was observed in the nursing home, her pain responses to these lesions were notably diminished or absent. During daily dressings she did not complain of pain, nor indeed did she demonstrate any physiological evidence of physical discomfort; her pulse remained stable and regular, there was no perspiring or changes in skin colour, blood pressure remained stable and she maintained a calm level of conversation. D.H. was fully aware of the dressing procedure as the lesion was so visible. She watched the sloughy dead tissue being excised and the packing being inserted, yet to direct questioning, 'Does that hurt?' or 'Can you feel this?', she would positively affirm that she could feel it but that it was not painful.

Her non-dementing brother was resident in the same home and repeatedly confirmed that she never complained of any pain or discomfort from the lesion. D.M. was nevertheless prescribed morphine sulphate sustained-release tablets (MST) as it was expected that she would be experiencing some pain from such an advanced lesion. Another non-dementing patient who was also suffering from an advanced carcinoma of the breast, albeit not as advanced as D.H.’s, was being cared for and required 200 mg MST twice daily to maintain pain control. It was feared that D.H. might have been having pain but been unable to verbalize such feelings [2, 3], but administering MST (10–30 mg) to D.H. served only to slow her down and make her rather lethargic. When medication was discontinued, she responded well, her appetite increased and mobility improved. On the discontinuation of MST there was no evidence, verbal or non-verbal, of onset of pain from the lesion.

D.H. also experienced a severe bout of herpes zoster radiating around her lower spine, sides and abdomen. Despite extensive blistering, she appeared to experience minimal or no pain. She became lethargic and drowsy and co-operated with suggestions of remaining in bed but, whilst the blisters were being treated and in response to direct questioning regarding the shingles, she reported no pain. She was mobile with help and taking full diet up to the day prior to her death, despite the advanced carcinoma and numerous secondary deposits.

Case 2

E.A. also had a history of angina and on admission to the nursing home was frequently (one to two times weekly) in need of his nitrolingual spray. As the dementia progressed, his signs and symptoms of angina decreased and the condition appeared to resolve itself. He is now in the terminal stage of SDAT with the last recorded angina attack some 2 years ago.

Survey: methods and results

In order to follow up on these informal observations, one of us (M.F.-M.) conducted a small-scale national survey of abnormal pain experience in SDAT sufferers. An initial request for reports of such cases was printed in the Alzheimer Disease Society newsletter under the heading ‘Forgotten pain’. A total of 54 responses were obtained from carers. Each was sent a questionnaire containing open-ended questions (see Appendix), of which 47 were returned, although not all fully completed. Twenty-three of these 47 had been or were caring for a parent, 21 for a spouse and only three were professional carers, a sample which doubtless reflects the readership of the newsletter. Of the 47 patients reported, 35 were female and 12 male; suggesting a somewhat biased sample relative to the estimated SDAT population as a whole [4, 5]. Of these, 16 women and five men were still alive at the time. Diagnosis of the women was reported to have been by hospital consultant in 16 cases, by general practitioner in four cases, and was unreported or unknown in 15 cases. For men the respective figures were four, one and seven. Age of onset was reported for 28 women; the sample mean was 73.6 years, with standard deviation of 9.3 years. The same information was given for only six men, whose onset age ranged from 50 to 89 years.

All 47 cases were judged by their carers to have been capable of effective and unprompted verbal communication. Many of the patients were reported to have expressed feelings of one sort or another in response to the incidents reported but these were of the nature of shock and dismay at falls, surprise when engagement in self-injurious behaviour was brought to their attention, surprise or irritation at hospitalization and so on. Expression of feelings of pain were notable only for their absence. In no case did carers witness non-verbal behaviours which were clearly in contradiction to spoken utterances; the absence of wincing, rubbing,
rocking and so on seeming to have been as striking as the absence of verbal expressions of pain.

The completed questionnaire data sheets were assigned to four main categories (15 patients being assigned to more than one category), according to whether they reported incidents of:

1. Acute accidents (28): these included fractures, burns, and lacerations that were seen either as admissions or at outpatient visits, as well as multiple episodes of bumps and bruises and of bizarre behaviours. One patient was reported to pull up stinging nettles with her bare hands, to dip her fingers into boiling water and to pick up red-hot coals in her fingers. Another sustained a compound fracture of tibia and fibula and, if not supervised, repeatedly attempted to walk normally prior to hospitalization. Other patients fell over, sustaining severe facial lacerations and fractures, and were helped up only to attempt to carry on as if uninjured. Another patient sustained a fractured radius but refused to go to hospital, denying anything was wrong. She continued to use the arm normally for 24 h without complaint. Subsequently she removed two plaster casts within 24 h and partially removed a bent full arm plaster with a carving knife and scissors, insisting there was nothing wrong with her.

2. Acute surgical conditions (18): this group included a leaking aortic aneurysm, which finally ruptured. The patient's family visited him at home and noticed signs of shock but he denied any feelings of pain or discomfort before or after admission to hospital. One 57-year-old man suffered a perforated gastric ulcer without any complaints of pain. As an emergency admission, he was examined by five doctors in hospital but consistently denied any vomiting or pain. Surgical intervention occurred only following signs of clinical shock. Another 77-year-old man underwent surgical repair of an inguinal hernia under general anaesthetic. Within 3 h of surgery he had dressed himself and, despite medical advice, insisted on wandering around the ward. He was discharged back to the nursing home that day, and insisted on resuming his normal place in the dining room, consuming a full three-course meal without ill effect. He did not complain of any pain or acknowledge that he had undergone surgery.

3. Infections and chronic conditions (seven): cases were cited of shingles, pressure sores, carcinomas, cellulitis and skin conditions, all diagnosed by general practitioner or consultant. In all of the recorded cases, the carers reported either a complete absence of overt discomfort and pain whilst the signs of the disease were evident, or only mild scratching or prodding, consistent with the patient's reporting of slight sensation when intense sensation would have been expected.

4. Disappearance of symptoms from diagnosed medical conditions (nine): these included cases of osteoporosis, arthritis, frozen shoulder of many years' standing, migraine, Meniere's syndrome, Raynaud's disease and glaucoma. As their dementia increased, patients who had been 'crippled' with back problems and sciatic complaints became more mobile than they had been for years. In all nine cases either the patients themselves discontinued medication or the carer and general practitioner slowly withdrew analgesia.

Discussion

It is of the greatest importance that carers should perpetually be alert to the danger of under-recognition of pain experienced by SDAT patients. Previous research suggests that some SDAT patients perhaps mismanage communication of their pain experience, or that some carers in turn misinterpret their communications [3]. However, this does not seem to have been the case with the members of our sample. None of the 47 patients was reported as lacking in ability to make themselves understood or to answer questions appropriately. Whilst our survey suffers from methodological shortcomings—there is no way to verify the accuracy of the reports or to estimate the prevalence of the condition—nevertheless the findings are indicative of the existence of a sub-set of SDAT patients who do not experience pain.

In the cases cited above, various types of physical trauma have been observed occurring in patients—burns, fractures, invasive tumours, herpes zoster—all capable of creating different types of pain and involving a variety of different types of structures (nerves, soft tissue, bone, superficial skin, deep tissues and so on). Yet in the patients involved the pain signals appeared to be overridden by the psychological and physiological complexities involved in SDAT, as has also been noted in certain other groups of demented or brain-insulted individuals [6]. If such patients do form a 'pain-blind' sub-group, then at least three sets of implications can be identified:

1. From the perspective of the study of pain experience and pain behaviour it would be of great interest to know what, if any, common abnormality of neuroanatomy is to be found among the different patients of this putative group. Involvement of the amygdala or pre-tectal nuclei is a possibility, and neuro-imaging techniques might well throw light on this issue. In addition it would be helpful to know if other bodily sensations are affected, for example touch and heat thresholds.

2. There are practical implications for carers, as identified by Marzinski [2]. How are carers to identify SDAT patients who may have injuries which require medical
intervention but which the patients are unable to report on account of reduced verbal ability and/or impaired pain sensitivity? It may be that appropriate procedures will vary with individual cases.

3. Following on from this are potential legal implications. With current guidelines emphasizing freedom of individual choice, care of SDAT patients within an institutional setting needs reassessment and re-definition. If patients are unaware that by 'normal' daily interactions they are putting themselves and others physically at risk, whom are guidelines attempting to protect? In response to the survey described above, one care-home manager reported that he had been severely criticised by a coroner at an inquest into the death of an elderly female patient in his care. She had sustained a fractured femur which had not been diagnosed, primarily because she had not complained of any pain and had continued to ambulate without any apparent discomfort. Following her death, and despite statements to the contrary from care staff, the coroner's enquiry stated that she must have died an "agonising death". The suggestion that this demented female did not in fact experience any pain was dismissed as "unbelievable" on the grounds that "as the man in the street feels pain, so should an elderly demented lady with a fracture". The legal implications of this are considerable and need investigation. If some SDAT patients do not experience pain or exhibit pain behaviour, how can carers and physicians be held responsible or labelled as negligent if and when trauma/accidents occur and are undiagnosed and untreated? Unfortunately, the current study does not indicate the likely size of the pain anomalous subgroup within the general SDAT population, and obtaining a proper estimate of it must be one aim of future research.

**Key points**

- There appears to be a sub-group of patients with senile dementia, Alzheimer-type, who do not experience pain in the normal way.
- The prevalence of the condition is presently unknown.
- The existence of such a group of patients raises serious legal and ethical issues for those treating or caring for such patients.

**References**


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**Appendix. Confidental questionnaire**

**Patient details**

Sex (male/female):
Current age:
Age at onset of Alzheimer symptoms:
Diagnosis made by hospital consultant/GP/other:

**Carer details**

Name of carer:
Relationship:

**Pains**

Did patient ever complain of pains which they now no longer appear to suffer, or which appear to have become less severe? Yes/no

If yes, please give details

**Accidents, illnesses and injuries**

Has the patient ever had an accident or illness which you would have expected to cause her/him pain, but which she/he did not complain of? Yes/no

Please complete a data sheet for each accident/incident/illness, noting as much information as possible

**Data sheet**

1. Description of illness/injuries/incidents
   Please give approximate dates and times and indicate whether the patient was:
   (a) admitted to hospital
   (b) seen in outpatients
   (c) seen by GP
   (d) Other—please explain

2. Conversation at time of events
   Did the patient make themselves understood easily and answer questions appropriately? Yes/no
   Comments:
   Did they describe their feelings in words? Yes/no
   Comments:
   Did they exhibit any other physical signs of discomfort—wincing, rubbing etc.? Yes/no
   Comments: