

**A visit to explore issues in the history of cancer pain relief
and extend the work of the project:**
Innovations in cancer pain relief: technologies, ethics and practices

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Acknowledgements

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Introduction

This is a report of a visit made by Michelle Winslow to The University of California Los Angeles (UCLA); ALZA Corporation; and the City of Hope National Medical Centre, (Cancer Centre). The visit extended the work of the project ‘Innovations in cancer pain relief: technologies, ethics and practices’, through the opportunity to work in partnership with Marcia Meldrum, project consultant, and her colleagues at the John C. Liebeskind History of Pain Collection.

The aim of the visit was:

- To gain experience and knowledge of history of pain research.
- To work with the History of Pain Archives, focusing on the papers of John Bonica, a pioneer in post World War Two pain research.
- To conduct oral history interviews with key people in the development of transdermal fentanyl at the ALZA Corporation. This meeting was especially relevant to the project’s transdermal fentanyl case study.
- To gain knowledge of a unique study, headed by Marcia Meldrum, which is conducting video interviews with children about their pain.
- To meet local researchers in the pain field.

Relevant project in the IHT programme

‘Innovations in Cancer Pain Relief: Technologies, Ethics and Practices’.¹ 2002-2003
(Clark. D, Seymour JE, Winslow M and Noble B).

Host Organisations

**Sheffield Palliative Care Studies Group, Academic Palliative Medicine Unit,
University of Sheffield**

Michelle Winslow is a Research Associate with the Academic Palliative Medicine Unit at the University of Sheffield, and Trent Palliative Care Centre which together

¹ See appendix for details

form the Sheffield Palliative Care Studies Group (SPCSG). This group has built up an international reputation for the quality of its research, educational and clinical work in the fields of palliative and supportive care. SPCSG is responsible for a wide range of academic and clinical activities. In addition to historical and cultural studies, its multi-disciplinary research programme includes clinical trials, needs assessment and service evaluations, methodological development and information services.

UCLA Center for the Interdisciplinary Study and Treatment of Pain, University of California Los Angeles

This group of researchers have diverse academic backgrounds but share a common interest in all issues related to the study and management of pain. Their vision is to make UCLA the principal centre for pain research in the USA, and they are aiming to achieve this by stimulating intellectual discourse between scholars which transcends traditional academic domains.²

The John C. Liebeskind History of Pain Collection

The goal of the UCLA History of Pain Project is to promote and ensure the study of the history of pain research and pain therapy in the post-World War II era, in particular, the origins, growth, and development of the international, interdisciplinary pain field. Its major initiatives to achieve this goal are the creation of the John



C. Liebeskind History of Pain Collection at the Louise M. Darling Biomedical Library at UCLA, and the active dissemination of information about the Collection and the history of pain to appropriate audiences.³

² UCLA Center for the Interdisciplinary Study and Treatment of Pain: <http://www.pain.ucla.edu/>

³ The John C. Liebeskind History of Pain Collection, UCLA History of Pain Project: <http://www.library.ucla.edu/libraries/biomed/his/pain.html>

Links between the cancer pain relief project and the host organisation

Dr Marcia Meldrum is a consultant on the ‘Innovations in cancer pain relief’ project and has made key visits to the Sheffield team in this capacity. Her work at the John C Liebeskind Pain Archive at UCLA enjoys support from the International Association or the Study of Pain, and other donors. Both projects adopt an oral history approach and have a mutual agreement for sharing resources. Together the projects hold interviews with over 250 innovators in the field of hospice and pain medicine.

Summary of activities undertaken

- Oral history interviews with Mary Southam (Vice President, Technology assessment) and Robert Gale (Product Development Manager) at ALZA Corporation.
- Oral history interview with Dr Betty Ferrell, Research scientist in cancer care and oncology at the City of Hope National Medical Centre (Cancer Centre).
- Oral history telephone interview with Professor Lonnie Zeltzer, Co-Director Paediatric Pain Clinic, Professors of Paediatrics; Anaesthesiology, Psychiatry and Bio behavioural Sciences, UCLA; Director of Pediatric Pain Program; Associate of Cancer Survivors Programme.
- Attended a meeting of the Interdisciplinary Pain Study Project at which there was discussion of the project ‘Chronic Pain Problems in Children: Toward an Effective Treatment Model’. This study is investigating the development of chronic pain problems and the effectiveness of therapeutic interventions in children treated at the UCLA Pediatric Pain Clinic, and utilises qualitative interviewing methods.
- Attended a seminar in the series ‘UCLA Programs in Medical Classics’. Trudy Dehue, Professor of Theory and History of Psychology, University of Groningen, Netherlands, presented on ‘Experimenting with heroin: The hidden assumptions of randomised clinical trials’.
- Meetings with Russell Johnson, Archivist, regarding the John Bonica papers in the John C. Liebeskind History of Pain Collection. Specifically,

to consider the selection of documents in order to maximise available time in the collection.

- Review of papers in the John Bonica collection. Documents selected relate to key meetings, lectures and studies between the years 1954-1990.
- Review of Agency for Health Care Policy and Research (AHCPR) records. These were donated to UCLA by Dan Carr, Anaesthesiologist. Professor of Pain Research, Tufts University, and relate to the development of the Cancer Pain Guidelines (USA), published in 1994. Documents selected are in connection with the initial public meeting (1991) which called for comment on the proposed cancer pain guidelines and, subsequently, the final draft.⁴

Discussion of activities undertaken

Oral history interviews: ALZA Corporation

1. Mary Southam

Vice President, Technology Assessment.

2. Robert Gale

Product Development Manager.



Fentanyl, a synthetic short-acting opioid, is fifty to one hundred times more potent than morphine and was first synthesized by Paul Janssen and colleagues in 1962.⁵ During the early 1980s, the ALZA Corporation, a research-based pharmaceutical company founded in 1968, were expanding their base of drug delivery technology and recognised that transdermal technology was applicable to potent drugs in many therapeutic categories. ALZA began developing, under joint agreements with major pharmaceutical companies, several therapeutic systems for the transdermal delivery of



⁴ Agency for Health Care Policy and Research (1994) *Management of Cancer Pain: Clinical Practice Guideline*, US Department of Health and Public Service, AHCPR.

⁵ Dahl, J (1996) The three faces of fentanyl, *Focus on Pain* (Wisconsin Pain Initiative), Spring issue: <http://www.wisc.edu/wcpi/>

drugs, and in 1980 the company introduced the first rate-controlled TRANSDERM – V scopolamine system for the treatment of motion sickness. ALZA considered that transdermal delivery could also benefit patients with chronic disease who have difficulty following regimens requiring several daily doses of medications, which can cause unpleasant symptoms. Transdermal systems require less frequent delivery, once or twice weekly, and can therefore reduce adverse effects. The prospect of these benefits encouraged the development of further transdermal products and consideration of transdermal delivery as a feasible treatment for pain.⁶ ALZA completed a New Drug Application (NDA) for Duragesic (Fentanyl Transdermal System) in 1990. Developed by ALZA and introduced commercially by Janssen, Duragesic went on to initiate a new market for fentanyl in the management of chronic pain requiring continuous opioid analgesia.⁷

Mary Southam and Robert Gale, pioneers of transdermal drug delivery, were responsible for the development of Duragesic from the outset. This interview was an opportunity for their personal roles in this process to be placed on the historical record and, in this sense, the meeting was important in its own right. However, the testimony broadens knowledge of development beyond published data and informs a study of transdermal fentanyl undertaken as part of the Sheffield group's study of innovations in cancer pain relief.

The interviews with Mary Southam and Robert Gale cover learning processes in the early days of research which involved “thinking outside the box” and utilising non-traditional pharmaceutical practice, viewed as “a key element of ALZA's success”. It was necessary to develop new clinical trial designs to test transdermal fentanyl and the process of leading and advising the Food and Drug Administration (FDA) is discussed. Specific issues in development are raised, specifically that a “big problem” emerged in the use of silicon adhesive and fentanyl as it became “as sticky as this table after a month”. Three years and a great deal of expense later, a silicon compound was developed which did not combine with the drug and was sufficiently adhesive to skin. Further questions regarding the future of transdermal products at ALZA elicited cautious replies, including that in the field of analgesia Southam and

⁶ ALZA 1980 Annual Report.

⁷ ALZA website: http://www.alza.com/alza/tl_1990a

Gale “can’t imagine many products coming to market that don’t have a delivery system associated...”.⁸

Oral history interview: City of Hope National Medical Centre (Cancer Centre)

3. Dr Betty Ferrell

Research scientist in cancer care and oncology



City of Hope is a Comprehensive Cancer Centre which provides in-patient care focused on disease treatment and symptom relief. Within the centre, the City of Hope Pain/Palliative Care Resource Center (COHPPRC) operates as a ‘clearinghouse to disseminate information and resources to assist others in improving the quality of pain management and end of life care’. Established in 1995, COHPPRC is a central source for collecting a variety of materials, including pain assessment tools, patient education materials, quality assurance materials, end of life resources, research instruments and other resources.⁹

Betty Ferrell has spent her entire career in cancer care and oncology and has worked in research at the City of Hope since 1989. In her interview she discussed her PhD research in the early 1980s with family members caring for relatives at home; work which focused on pain management, quality of life and the experience of caring for a dying loved one. She learned that, whilst wanting to talk about pain, people were keen to talk about the *whole* experience. Her interests took her into palliative care and three years faculty at the University of Oklahoma where she launched her own research program into home pain management, to understand how experiences compare with hospital treatment. A key finding was that many patients did not take the opiates supplied to them due to fears of addiction. This work led to quality of life measurement of as outcome of pain management and prompted Ferrell’s interest in the role of family caregivers in pain relief, and particularly their impact on patients’ pain experience. Qualitative methods were becoming predominant in Ferrell’s work, but she explained that much of it was remaining quantitative and she had the feeling

⁸ Oral history interview with Mary Southam and Robert Gale, ALZA Corporation, 8/1/04. Recorded by Michelle Winslow and Marcia Meldrum.

⁹ City of Hope: <http://www.cityofhope.org/>

of “not getting it”. A colleague’s comment of “why don’t you just ask them”, encouraged Ferrell to conduct interviews, which she described as “wonderfully rich”. Family members explained the burden of being “accountable for someone else’s pain” and Ferrell became conscious of pain as a shared experience, with the caregiver as the person who often had to decide, not once but four hourly, whether or not to medicate. The advent of long acting analgesics, including transdermal therapies, made an impact on this situation as the ethical quandaries of giving pain relief were less frequent.¹⁰

At the City of Hope, Ferrell continued with studies of family experiences of pain management. In-depth interviews with family members generated a rich source of understanding which led to the creation of her first pain intervention study in 1991. Drawing on experience, teaching materials were developed for use in home and health care teaching programmes with the aim of improving pain management and overcoming misconceptions.¹¹ The caregiver study was later repeated with children in pain. An unforeseen finding was that parents did not necessarily give medication to their child, or aggressively seek pain relief for them, since to deny the pain was to deny the illness. Pain was strongly associated with death and being “out of control” and this study acknowledged the importance of psychological and spiritual aspects of pain.¹²

¹⁰ Oral history interview with Dr Betty Ferrell, City of Hope National Medical Center, 9/1/04. Recorded by Michelle Winslow.

¹¹ *Selected publications: Pain*

Ferrell B, Wisdom C, Wenzl C, Schneider C (1989) Quality of Life as an Outcome Variable in the Management of Cancer Pain, *Cancer*, 63: 2321-2327

Ferrell B, Wisdom C, Wenzl C, Brown J (1989) Effects of Controlled-Release Morphine on Quality of Life for Cancer Pain, *Oncology Nursing Forum*, 6 (4): 521-526

Ferrell B, Grant M, Padilla G, Vemuri S, Rhiner M (1991) The Experience of Pain and Perceptions of Quality of Life: Validation of a Conceptual Model *The Hospice Journal*, 7 (3): 9-24

Ferrell B, Dean GE (1995) The Meaning of Cancer Pain, *Seminars in Oncology Nursing*, 11 (1): 17-22

Ferrell B (1995) The Impact of Pain on Quality of Life: A Decade of Research, *Nursing Clinics of North America*, 30 (4): 609-624

¹² *Selected publications: Pediatrics*

Ferrell B, Rhiner M, Shapiro B, Dierkes M (1994), The experience of pediatric cancer pain. Part I: Impact of pain on the family, *Journal of Pediatric Nursing*, 9 (6): 368-379. Part I of this 2-part article explores family caregivers’ descriptions of their child’s cancer pain. Qualitative data from 31 family caregivers is included in tables by key themes describing the child’s pain and family impact.

Rhiner M, Ferrell B, Shapiro B, Dierkes M. (1994) The experience of pediatric cancer pain. Part II: Management of pain, *Journal of Pediatric Nursing*, 9 (6): 380-387. Part II of this 2-part qualitative study, includes interviews of 31 family caregivers. Key themes are identified in response to questions about 1) the role of parents in managing their child’s cancer pain, 2) how nurses and doctors can help relieve pain, and 3) what advice would these parents give to parents in a similar situation.

Ferrell explained that the USA maintains a culture of avoiding thoughts of pain and death, which “gets worse with high tech” since something can always be done in a curative sense. Palliative care remains associated with failure and patients still fear addiction. Nevertheless, Ferrell recognises that great strides have been achieved in pain relief during the course of her career: “Pain is no longer a hidden problem”. In 1977: “...no value was placed on the management of pain”. There was little in the way of literature and no Pain Society. Hence, “... what has been accomplished is in many ways very impressive... but there’s still a long way to go.”¹³

Oral history interview: UCLA

4. Professor Lonnie Zeltzer, Professor of Paediatrics

- Medical Director, Trinity Kidscare Hospice
- Co-Director, Styles Integrative Oncology Program, UCLA Jonsson Comprehensive Cancer Center
- Associate Director, Patients and Survivors Division, Prevention and Control Research Branch, UCLA Jonsson Comprehensive Cancer Center
- Director, Pediatric Pain Program, Departments of Pediatrics, Anesthesiology, Psychiatry, UCLA School of Medicine
- Director, Pediatric Pain Fellowship Program. (1989-1994, 1997-1998); Faculty, Anesthesiology Pain Fellowship Program; Faculty, UCLA VA Hospital Psychiatry Pain Fellowship Program.



‘The Pediatric Pain Program is an interdisciplinary program that includes research, clinical service, and education. It is based within a mind-body framework (biopsychosocial model) that takes into account the complex interaction between physiology, emotions, cognitions, and the environment in all aspects of clinical evaluation and treatment as well as in research. The research program has three areas of focus: 1) pain and other symptoms, 2) young adult survivors of childhood cancer

¹³ Oral history interview with Dr Betty Ferrell, City of Hope National Medical Center, 9/1/04. Recorded by Michelle Winslow.

and the pediatric cancer experience in general, and 3) complementary and alternative medicine.’¹⁴

Lonnie Zeltzer is a pioneer in the management of pain in children, with particular interests in cancer pain and pain-associated disability syndrome. Since 1990 she has run a unique Pediatric Pain Clinic at UCLA, which employs a multi-disciplinary approach to the treatment of chronic and re-current pain problems. The interview with Lonnie Zeltzer, conducted via telephone due to her research commitments, recalled how her interest in pain began in 1975. Her primary speciality was adolescent medicine until 1986 when she received a National Cancer Grant Research Career Development Award; this enabled her to focus on pain and symptoms in children with cancer. She also spent time at Great Ormond Street Hospital, London, where she was involved in mutual storytelling with children with cancer, pain, and who were withdrawn as a result. Her research explored the usefulness of an approach which involved guiding childrens’ narratives to help them make use of imagery and symbolism as they worked through issues at the end of life.

Back in California, Lonnie Zeltzer worked on a large scale project with survivors of childhood cancer which involved twenty three sites and 20,000 survivors. Using interviews, questionnaires and medical records, this project explored issues affecting survivors. These related to the impact of disease on fertility, transition to adulthood, relationships, education, employment, health insurance etc. All are common worries amongst young adults, but in cancer survivors they are heightened by fears of possible effects of their disease. These issues emerged as more prominent than fears about whether their cancer might recur. Interviewees were asked whether they have pain which they connect to their earlier cancer, and a surprisingly high number reported that they did.¹⁵

¹⁴ UCLA Pediatric Pain Program: <http://www.healthcare.ucla.edu/pedspain/overview.htm>

¹⁵ *Selected publications*

LeBaron, S, Fanurik, D, Zeltzer, L (2001) The Hypnotic Dreams of Healthy Children and Children with Cancer: A Quantitative and Qualitative Analysis. Abstracted in *The International Journal of Clinical and Experimental Hypnosis*, 49 (4) 305-319

Bursch, B, Zeltzer, L (in press). Pain management in children. In Behrman, R.E, Kliegman, R.M, & Jenson, H.B. (eds.) *Nelson Textbook of Pediatrics*, 17th Edition

Zeltzer, L, Bursch, B (2001) Psychological management strategies for functional disorders, *Journal of Pediatric Gastroenterology and Nutrition*, 32, S40-S41

Lonnie Zeltzer is also Medical Director of Trinity Kidscare Hospice, the only paediatric in-home hospice in Los Angeles County.¹⁶ She discussed pain medication and treatment in the hospice where the approach is to “stay away from IVS and needles”, in favour of non-invasive oral and transdermal medications. Anxiety and other symptoms are addressed with the children and, crucially, parents are educated in understanding their child’s condition, treatment and feelings, whilst helping them to move beyond fears of administering opioids.¹⁷

Pain collections: John Bonica

Russell Johnson, archivist with the John C. Liebeskind History of Pain Collection, was extremely helpful in conducting searches for papers in the John Bonica collection which related to cancer pain relief. However, the sheer volume of material available in this collection was an issue since, in the time available, it was clearly going to be difficult to view the contents of all boxes identified.



Criteria were established for the selection of papers. They should relate to:

- cancer pain
- opiates (narcotics)
- non-opiate (narcotic) analgesia
- pain measurement
- key pain meetings
- other approaches to analgesia

Bursch, B, Zeltzer, L (2001) Pain: A story. In Kahn, S. & Fromm, E. (eds.) *Changes in the Therapist* Erlbaum Associates, Mahway, New Jersey, 81-96

Chen, E, Zeltzer, L, Craske, MG, Katz, E (2000) Alterations of memory in the reduction of children's distress during repeated aversive medical procedures. Abstracted in *Evidence-Based Mental Health*, 3:12

Chen, E, Zeltzer, L, Craske, M, Katz, E (2000) Children's memories for painful cancer treatment procedures: Implications for distress. *Child Development*, 71, 933-947

¹⁶ UCLA pediatrician/researcher wins award for accomplishments in cancer-related pain management, *UCLA News*, 31/10/2001: <http://www.cancer.mednet.ucla.edu/newsmedia/news/pr103101.html>

¹⁷ Oral history interview with Professor Lonnie Zeltzer, UCLA Pediatric Pain Program, 13/1/04. Telephone interview recorded by Michelle Winslow. Lonnie Zeltzer's full CV is available online: <http://www.canceralternatives.mednet.ucla.edu/drzcv.html>

- methods of analgesia delivery

Additionally, Marcia Meldrum offered advice on targeting potentially valuable files and suggested papers of key meetings could be especially helpful; from her own work amongst the papers she was aware of a tendency for early research findings to be reiterated in later years.

Papers excluded were those associated with pain in areas of dental and general surgical anaesthesia; acupuncture; obstetrics; and Multiple Sclerosis drugs. Also general correspondence was not considered relevant in this instance since, it mostly referred to administrative and organisational matters. A separate study of this correspondence would shed further light on Bonica's activities and interests, but would involve a more detailed and lengthy review than was possible during this research visit.

Hence, material was selected which related to meetings, lectures and studies between the years 1954 and 1990. Copies of key files were made and are currently available at Trent Palliative Care Centre, University of Sheffield. In the long term, these will be archived and made available for research in the International Observatory on End of Life Care, Lancaster University.¹⁸

Documents copied include papers relating to the following meetings and presentations:

- Control of cancer pain, Annotated draft, 1954.
- Symposium on Cancer (12th : 25 April 1963 : Winston-Salem, NC)
- Northwest cancer conference (16 July 1964 – 17 July 1964 : Seattle WA)
- Symposium on cancer pain (16 March 1965 – 25 March 1965 : Rome, Italy)
- Symposium on cancer pain (16 March 1965 – 24 March 1965: Rome Italy)
- John Tomlin Memorial Cancer Lectures (28 July 1967 – 29 July 1967 : Medford, OR)

¹⁸ International Observatory on End of Life Care: <http://www.eolc-observatory.net/>

- Grant application 1/6/75 re First International Symposium on Cancer Pain, Florence, Italy. Outlines Bonica's goals and objectives (etc) of symposium
- Terminal Progress report: First International Symposium on Cancer Pain. IASP. Period covered: 30/6/75-31/12/76. Investigator/Director: John Bonica
- Symposium on Gynaecologic Cancer, Outline, 1977
- Man versus Pain, University of Siena, Draft, 1972
- Pilot study Pain 4 Selected cancers. File PP60 [was PP2A], 1 Nov 1978. For: Grant
- International Symposium on Pain of Advanced Cancer (24 May 1978 – 27 May 1978: Venice, Italy)
- International Association for the Study of Pain (3-4 September 1981: Edinburgh, Scotland)
- International Cancer Congress (14-21 Aug 1986: Budapest, Hungary)
- International Congress on Cancer Pain (2-14 June 1988. Rye, NY)
- Bristol-Myers Squibb Pain Award Selection (16-18 May 1990. NY)

Pain collections: Agency for Health Care Policy and Research (AHCPR)

The AHCPR records relate to cancer pain guidelines published in 1994 in the USA and were donated to UCLA by Dan Carr, Anaesthesiologist. Professor of Pain Research, Tufts University. The papers are a record of the development of the guidelines by an interdisciplinary panel of clinicians, patients, researchers, and experts in health policy. The resulting publication is a synthesis of scientific research and expert judgment which made recommendations on pain assessment and management. Approximately 470 health care professionals and 70 patients were involved either as consultants and peer reviewers or as participants in pilot testing. The guideline was designed to help clinicians understand the assessment and treatment of cancer pain and associated symptoms. It reflects a multimodal approach to the management of pain, and emphasises the need for careful and continuous assessment to match interventions to the sources of pain in individual patients.¹⁹

¹⁹ Agency for Health Care Policy and Research (1994) *Management of Cancer Pain: Clinical Practice Guideline*, US Department of Health and Public Service, AHCPR. Agency for Health Care Policy and Research website: www.ahcpr.gov

Documents copied for ‘Innovations in Cancer Pain Relief’ relate to the initial public meeting in 1991 and the final draft. Both stages called for comment on the developing guidelines.

Other activities

During my visit a scheduled meeting of the Interdisciplinary Pain Study Project took place, where I was able to meet team members from diverse disciplinary backgrounds. One focus of the meeting was the project, ‘Chronic Pain Problems in Children: Toward an Effective Treatment Model’, which is using qualitative interviewing methods to investigate the development of chronic pain problems and therapeutic interventions in children treated at the UCLA Pediatric Pain Clinic.

Following the meeting I attended a seminar in the ‘UCLA Programs in Medical Classics’ series. Trudy Dehue, Professor of Theory and History of Psychology, University of Groningen, Netherlands, presented her study of a randomised control trial of heroin users in the Netherlands: ‘Experimenting with heroin: The hidden assumptions of randomised clinical trials’.²⁰

²⁰ Dehue, T (2002) A Dutch Treat. Randomized controlled experimentation and the case of heroin maintenance in the Netherlands. *History of the Human Sciences*. 15, 2, 75-98. Full text available at: <http://www.ppsw.rug.nl/~teng/dutch%20treat.pdf>

Findings

A key aim of this research visit was to review papers in the John Bonica and AHCPR collections and gather material relating to historical landmarks in cancer pain relief. The Bonica papers are accessed regularly by researchers, however, the contents of this large collection have yet to be thoroughly evaluated. During this visit, a focus on documents relating to cancer pain and its treatment enabled a representation of the actions of key players as they sought to understand cancer pain and disseminate their knowledge to a global audience.

Oral history interviews with present-day key players in cancer pain relief made possible consideration of more recent developments in the USA. Betty Ferrell and Lonnie Zeltzer described research with patients which brought their voices to the attention of health care professionals. As a consequence, recognition of problems faced by patients and carers, especially in relation to opioid administration, has led to better understanding of needs and dilemmas and to improvements in care. In respect of dilemmas faced when cancer pain is managed at home, Betty Ferrell stressed the value of transdermal analgesia. She explained that a positive characteristic of the fentanyl patch is that re-application is only necessary at intervals of 48-72 hours. Thus relieving the caregivers' burden of regular decision making about whether or not to administer opioid treatment; a therapy that some patients and carers associate with incurable disease and dying.

Research which generated information on patient experience, reflected upon in oral history interviews with Betty Ferrell and Lonnie Zeltzer, complements and extends the oral data offered by Mary Southam and Robert Gale. Much of the interview at ALZA focused on the positive attributes of transdermal fentanyl as identified during its development period. While Ferrell and Zeltzer offered perspectives of the product in use by adult and paediatric patients in their own homes - away from research and development monitoring.

Areas for future research

Extensive historical research into cancer pain relief and related fields has been carried out at the University of Sheffield during the course of the study, ‘Innovations in cancer pain relief’. This project has benefited from sharing knowledge and resources with UCLA, through collaboration with Marcia Meldrum. Jointly, our two centres have gathered over 250 oral history interviews with key players in the pain field; a collection which is unique in the history of medicine. The process of collecting oral history and related resources is an important activity in its own right, and is vital while key people are available to contribute their professional and personal memories. Continuing this work into the long term would maintain this process, whilst offering an opportunity to broaden the collection’s scope to include the experiences of a wide range of health care professionals who work with patients in pain. Broader representation of experience would enable greater understanding of developments in the pain field and allow for richer historical evaluation.

Contact with Betty Ferrell, Lonnie Zeltzer and the Interdisciplinary Pain Study Project, established the necessity for research into paediatric pain in the USA. Much of this work is seeking to understand the cancer pain experience in children, and explore how carers’ attitudes (primarily parents) can influence the extent of pain relief achieved. A focus on collecting oral histories and resources in relation to paediatric cancer pain relief in the UK would lay down important foundations for future evaluation

Finally, it should be noted that the extensive John Bonica archive has yet to be fully evaluated and this work is a priority for the specialty of the history of pain into the future.

Appendix

Innovations In Cancer Pain Relief: Technologies, Ethics And Practices

ESRC/MRC Innovative Health Technologies
Programme: L218 25 2055
University of Sheffield
Prof D Clark, Dr J Seymour, Dr B Noble, Dr M Winslow, Prof H ten Have, Dr M Meldrum and Dr S Paz
April 2002 - March 2004



Abstract

We estimate that almost 5 million people worldwide are experiencing unrelieved pain from their cancer. Yet it has been argued that the knowledge and skills required to alleviate cancer pain are now well established. Our study focuses on innovations in cancer pain relief and adopts an inter-disciplinary approach, combining perspectives from sociology, history, bio-ethics and the clinical disciplines. We view "cancer pain" as a multi-faceted phenomenon subject to cultural filters that shape and influence not only how it is perceived, but also its clinical management in different contexts and the extent to which resources are made available to relieve it. We focus on the problem of understanding how innovations in cancer pain relief take place and how they make an impact. It is proposed to analyse this in two case studies: clinical innovation and public health innovation. Each case study will make use of documentary analysis and primary data collected from interviews with key innovators and will incorporate an ethical reflection to establish to what extent the ethical governance of innovation in cancer pain relief can be enhanced in the future. The case study of clinical innovation will focus on the dynamic interplay between clinicians, researchers, patient groups and the pharmaceutical industry in generating innovative approaches to cancer pain relief in the form of new drugs and modes of delivery. The case study of public health innovation will examine the variable impact of clinical innovation at the societal and population level, in the context of strategic approaches developed by the World Health Organization. Through the varied roles of clinicians, patient groups, pharmaceutical companies, researchers and health planners, the study will work towards the production of a statement to inform the improved ethical governance of cancer pain relief innovation in the future.

Background

Worldwide, we estimate that some 67-80% of cancer patients are currently suffering from under-treated pain. Yet, it has been argued that the knowledge and skills required to alleviate cancer pain are well established. This study will shed light on some of the processes that contribute to this mismatch by addressing cancer pain as a clinical problem, as a public health problem, and in particular as a moral and ethical problem. The study will assess the global development of innovative technologies for cancer pain relief, since 1945, making use of sociological, historical and ethical perspectives. Particular attention will be paid to drivers of innovation, variations in

application, links to structural inequalities, and associated cultural and moral meanings.

Research Design

The study is being conducted in two phases. It is supported by a multi-disciplinary reference group comprising key individuals from the clinical and social sciences of pain, health care ethics, health care policy and the pharmaceutical industry.

Phase one: A narrative history of cancer pain relief since 1945. We have identified key forms of technological innovation in cancer pain relief since 1945. These include: new pharmaceutical inventions and discoveries; the redeployment of technologies from other areas of health care; and the public health 'technology' of policy and strategic planning.

Phase two: Case studies of innovation. Three case studies of areas of innovation are underway. In these, documentary analyses are complemented by interviews with key innovators, and analysis of primary data collected in other studies. Each case incorporates an ethical component.

Policy and Academic Implications

This study is unusual in bringing together historical, sociological, clinical and ethical perspectives on how particular ways of managing cancer pain have been adopted. Our approach will allow an understanding of how issues of culture, history and politics are reconciled with consequences and costs of market led innovation. It has the potential to impact upon policy at two levels:

1. It is directly relevant to the UK government's current concerns to improve the quality and availability of cancer services.
2. It will suggest improvements in the way that cancer pain relief technologies are harnessed to relieve suffering in international contexts.