UNIVERSITY OF SOUTHAMPTON
Faculty of Medicine, Health and Biological Sciences
School of Nursing and Midwifery.

From patient stories to changing practice.

An action research study to develop models of practice that reflect the needs and aspirations of patients.

Gill Allen, RGN.,RM.,ONC.,DipNurs(Lond).,RCNT.,NPDip.

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ABSTRACT

Master of Philosophy

FROM PATIENT STORIES TO CHANGING PRACTICE

An action research study to develop models of practice that reflect the needs and aspirations of patients.

By Gill Allen

This study is an action research enquiry designed to gain a better understanding of the needs and aspirations of patients and to develop models of practice that address those needs and aspirations. The focus of the study is upon patients with complex and long-term needs and, in particular, upon patients living with long-term neurological conditions such as multiple sclerosis, stroke or Parkinson's disease.

The study starts with the collection of stories from patients about their experiences of care and their views on how they would choose to experience care. The common themes from patient stories were identified using thematic analysis, narrative analysis and conversation analysis. The prevailing model of practice, multidisciplinary team working, was subjected to critical scrutiny against the experiences and desiderata articulated by the patients

Through a series of "thought experiments" involving visualisation and the development of "rich pictures", the author and her colleagues developed a model of practice which she called transdisciplinary practice. This model suggests the evolution of a new kind of practitioner who would have the competences and scope of practice to address 80% of the healthcare needs of the patient without having to cross-refer to other practitioners and agencies. She suggests that this would lead to a more integrated and holistic experience of care.

The author, in partnership with a University, developed a post-graduate curriculum to prepare practitioners for transdisciplinary practice.

The study reports the reactions of practitioners and patients to the concept of transdisciplinary practice and identifies the organisational and attitudinal barriers that would have to be overcome to secure implementation of the model. The study also draws some general conclusions about barriers to innovation in the National Health Service and relates these to the current political context of the NHS.

Acknowledgements

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I would also like to thank my colleagues in the Research Team from Hounslow and Spelthorne Community and Mental Health NHS Trust, staff in the Department of Health Studies at Brunel University and to Juliet Davis and Helen Roberts for their administrative support.

I also wish to thank the (now) South West London Workforce Development Confederation for agreeing to fund some of the research and development activity which has informed this work. Invaluable support was given by Prof. Christine Beasley CBE, Director of Nursing and Organisation Development at London Regional Office and Prof. Charles Easmon, Director of Education at London Regional Office.

Last, but not least, my gratitude to the patients who so generously contributed their 'stories' to help me on my journey in this thesis. I hope that their efforts in sharing their stories will better prepare us, the practitioners, to meet their health and social care needs.

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CHAPTER 1 INTRODUCTION

The focus of this thesis is upon innovation in clinical care within the National Health Service (NHS) in England. More specifically it seeks to address the role of the patient in the process of innovation, to explore some of the factors that limit this role and to propose measures that could be implemented to enhance the role of patients in the innovation process.

The research on which this thesis is based is concerned with the development and implementation of a new model of practice, *transdisciplinary practice*, to better meet the needs of patients with complex and long-term care needs such as those arising from conditions such as Multiple Sclerosis (MS), stroke, or Parkinson's Disease (PD).

The context in which the thesis is written is that of the "modernisation agenda" for the NHS – implementing the goals and aspirations set out in "The NHS Plan" (2000). This in turn can be viewed as part of the wider debate about the modernisation of public services in the UK in the first decade of the 21st century.

The development of the model started with listening to stories told by patients/clients about their real experiences of care and their aspirations about how they would wish to experience care. The messages from patients/clients caused us to critically examine how care was designed and delivered for a particular group of patients/clients, those living with long-term neurological disabilities. This examination led us to the conclusion that the aspirations of this group of patients/clients were unlikely to be delivered within the existing care paradigm (multidisciplinary practice) and led us to develop an alternative paradigm which we called transdisciplinary practice. We then went on to tease out the practical implications of the new paradigm in terms of preparation for practice, organisational arrangements and policy implications. The model was then tested out in various ways with patients/clients and with practitioners.

Methodologically, the study is located in the traditions of action research (Lewin 1946), action science (Argyris 1993) and co-operative enquiry (Reason .1994). Some elements of the study draw upon the traditions of narrative psychology (Josselson 1996) and more generally on the study of lived experience (Josselson 1996) and story-telling (Riessman 1993) as methods of enquiry.

During the study, I worked initially as part of a research team and latterly as project manager for a development team. I have used *we* to refer to the work of the team as a whole and *I* when I am expressing a personal view or describing an action taken by me rather than the team. Apart from my own reflections, for which I must take full responsibility, all of the work on which this thesis is based was carried out with colleagues sometimes working as a team, more often working as a rather more loose community of practice (Wenger 1998).

As with much research of this nature, it is an incomplete story, a continuing journey of enquiry and of action in which I am still actively engaged. Although, for reasons discussed later in this thesis, the model of transdisciplinary practice has not as yet been implemented within the NHS, I have been able to implement the model and its underpinning principles as an independent practitioner working with the private healthcare sector. One of the reasons for writing up my research formally at this stage is to set out clearly for policy makers in the public sector the potential benefits of transdisciplinary practice and to share with them the evidence base and thought processes on which the model is predicated.

About transdisciplinary practice

As Reason (Reason and Bradbury 2001) and others have pointed out, the "map" for an action research enquiry is not always drawn at the beginning. Each cycle of action and reflection leads to more questions rather than to neat and tidy answers. The world in which the enquiry is undertaken does not stand still; the NHS Plan did not exist when I started my journey and "modernisation" was not part of the vocabulary of the NHS or of the government.

Similarly, in action research, there is often no single researchable question which "stands still" throughout the enquiry, rather a series of questions and answers to reflect the emergent nature of knowledge about complex social and psychological phenomena. To facilitate ease of reading of this thesis, I am going to set out the map as it is now although it is not a map that was apparent at the start of my enquiry.

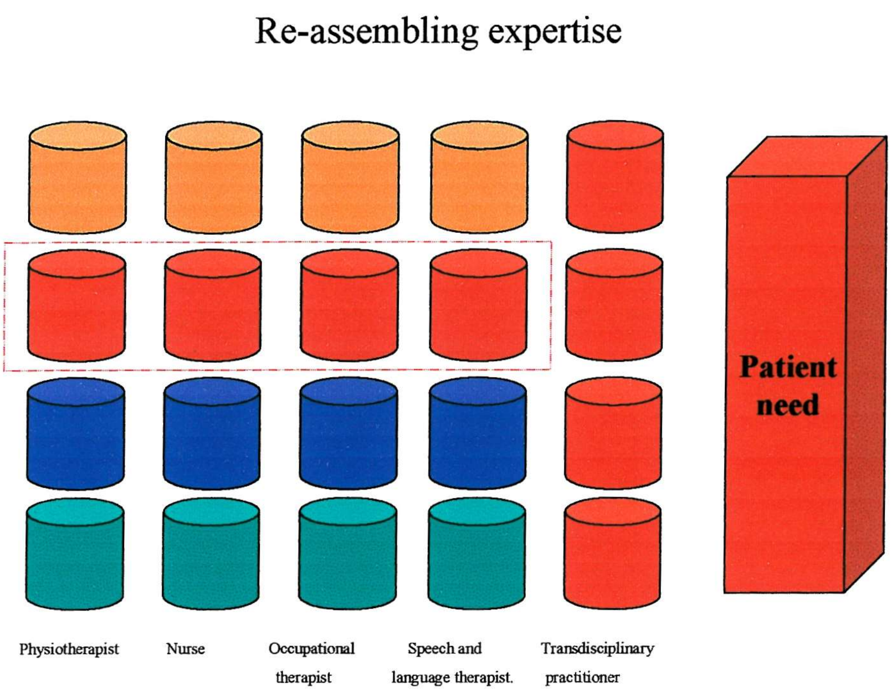
Transdisciplinary practice suggests that it is both possible and desirable to develop practitioners who have the competence, scope of practice and legitimate power to meet all or nearly all of the health and social care needs of groups of patients/clients with the same or similar health and social care needs. The particular focus of this research has been on patients/clients with long-term neurological conditions such as multiple sclerosis, stroke or Parkinson's disease but it would seem that it is possible to generalise the model to other groups of patients/clients with complex and/or long-term needs for treatment, care and rehabilitation.

The model is a challenge to traditional ways of organising clinical skills and knowledge within professional boundaries. It is also a challenge to traditional models of service-delivery such as multi-disciplinary team working.

It can be argued that safe and effective transdisciplinary practitioners can best be developed by providing additional training, education and experience for practitioners who are already qualified within their own discipline and who also have significant experience in working with a particular patient/client group. I differentiate between "generic working" which is often seen as a "dumbing down" process and transdisciplinary practice that is a form of advanced practice requiring extensive study at post-graduate level.

Transdisciplinary practice may be defined as a form of practice in which the competences and practices of the practitioner are determined by the needs of a particular group of clients or patients rather than by the body of knowledge and scope of practice determined through possessing a particular professional identity: As the diagram below indicates, transdisciplinary practice is about organising clinical knowledge horizontally to align with the needs of patients/clients rather than vertically to align with notions of distinctive professional groups.

Diagram 1.1 Aligning expertise with patient need



The diagram shows conceptually how the expertise relevant to a particular patient, or group of patients, could be abstracted from the expertise repertoire of each of the individual professions and "re-assembled" to create a practitioner whose expertise would be in meeting the needs of a particular patient or group of patients.

Traditional professional demarcations and associated educational programmes produce practitioners who are expert in particular aspects of care for many patients. The transdisciplinary paradigm proposes a practitioner who is, by contrast, expert on many aspects of the care of a particular patient.

Box 1.1

What is a transdisciplinary practitioner?

A transdisciplinary practitioner is defined as one who, having completed his or professional training in a single clinical or social care discipline, has acquired sufficient additional skills and underpinning knowledge to enable the practitioner competently to meet most of the health and social care needs of a particular client group.

The concept challenges the traditional model of organising competences by profession across a broad spectrum of clients and suggests that, in a truly client focussed organisation, skills and knowledge would be clustered around the needs of particular groups of clients. Rather than having (say) a physiotherapist who has physiotherapy skills and knowledge in relation to many different types of client, we would have a practitioner who has many different professional competences in relation (say) to the needs of people living with neurological disabilities.

Box 1.2

What would a transdisciplinary practitioner do?

Essentially, the individual transdisciplinary practitioner would fulfil the function which is currently fulfilled by a multidisciplinary team. The skills and knowledge available to meet the needs of the patient and his/her carers would be precisely the same but they would be located in an individual rather than a team.

In addition to the delivery of multidisciplinary care, the practitioner would have a care management/case management role.

Box 1.3

How might we create transdisciplinary practitioners?

In the model which has been developed during this research project, we have concluded that transdisciplinary practice should be a further career step for practitioners who are already qualified in a single discipline and who have substantial experience in working with the client group for whom they wish to become transdisciplinary practitioners.

An important part of this research project (see Chapter 6) has been to develop a proposed educational process to develop competent and confident transdisciplinary practitioners.

Box 1.4

Multidisciplinary practice

Many professional perspectives are required to adequately assess and meet the needs of the patient with complex needs. Practitioners from a range of disciplines form a multidisciplinary team.

Each practitioner who is thought to be relevant makes his or her own assessment of the patient. These assessments are shared through some process such as a case conference. An overall treatment strategy or care plan is produced following the case conference and the practitioners involved are then responsible for delivering their part of the care plan. A co-ordinator or key worker may be appointed.

Multidisciplinary reviews may be held at various stages during the implementation of the care plan.

Usually, but not always, each practitioner maintains his or her own notes which may or may not be available to other members of the team.

Assistants or support workers may also be members of the team. In some teams they are a collective resource and in others they are dedicated to and trained to support a particular professional discipline.

The balance between accountability to a team leader and to a professional lead varies significantly from team to team.

Scope of practice

Whatever the professional origin of the transdisciplinary practitioner, each would be regulated by the scope of practice defined by the appropriate regulatory body. For example, the UKCC Scope of Professional Practice for Registered Nurses, Midwives and Health Visitors (1992).

About the researcher and the research team

I am a Registered Nurse and Midwife. The first half of my career was in an acute setting specialising in orthopaedics and trauma. In this specialty, I have practised as a Ward Sister in a London Teaching hospital and as a Clinical Nurse Specialist. After completing Nurse Practitioner Training in a primary care setting, I worked in a "Hospital at Home" team in a Community Trust and then in a Community Team specialising in neurological rehabilitation. It was in this team that I developed a particular interest in meeting the needs of patients/clients living with long-term neurological disabilities.

Whilst working in the Community Rehabilitation Team, I (and another senior nurse colleague) were invited to take part in a research project to investigate the extent to which current models of practice met the needs of patient/clients. The project involved using patient stories as a method for trying to better understand the actual and desired experiences of patients.

Involvement in this initial project was the starting point for the study that is the subject of this thesis.

As the scope of the enquiry widened and more people, including colleagues in higher education, became involved, the original small research team became transformed into a group that demonstrated more of the characteristics of a *community of practice* rather than of a clearly defined team. The extracts quoted in the box below describe neatly the characteristics that emerged within the group of people exploring and developing the concept of transdisciplinary practice.

Box 1.5

Communities of practice

"Communities of practice are groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis.

These people don't necessarily work together every day, but they meet because they find value in their interactions. As they spend time together, they typically share information, insight and advice. They discuss their situations, their aspirations and their needs. They ponder common issues, explore ideas, and act as sounding boards. They may create tools, standards, generic designs and other documents – or they may simply develop a tacit understanding that they share. However they accumulate knowledge, they become informally bound by the value they find in learning together. This value is not merely instrumental for their work. It also accrues in the personal satisfaction of knowing colleagues who understand each other's perspectives and of belonging to an interesting group of people. Over time, they develop a unique perspective on their topic as well as a body of common knowledge, practices and approaches. They also develop personal relationships and established ways of interacting. They may even develop a common sense of identity. They become a community of practice."

("Cultivating Communities of Practice", Wenger E., McDermott R and Snyder W.M., Harvard Business School Press, Boston, 2002).

About the enquiry

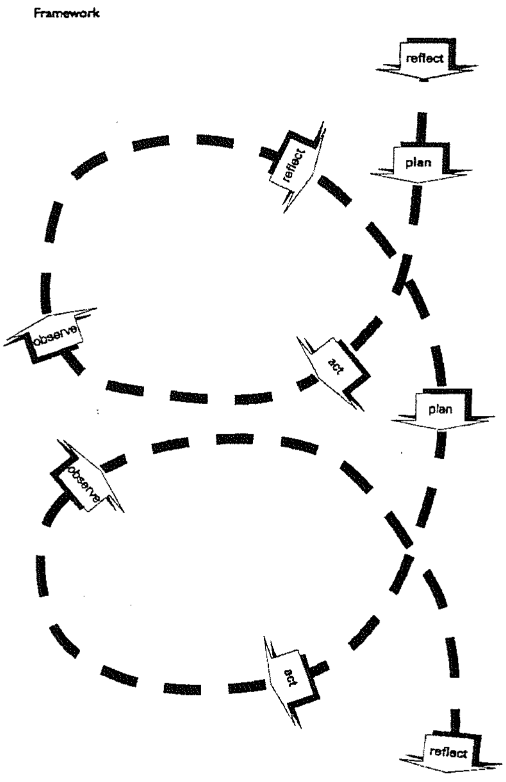
This story starts with where, arguably, much research into health and healthcare research should start, listening to patients talking about their lived experiences in their interactions with health and social care agencies and health and social care practitioners. The power of the stories told by patients compelled me to question why my own professional practice and the pattern of service delivery of the organisation in which I worked were so divergent from the expressed needs and wishes of patients.

This process of questioning in turn led to an examination of whether there is a problem of ***implementation*** - the basic model upon which current practice is based is sound but there is a failure in execution - or whether the basic models and assumptions underlying some aspects of health and social care delivery have to be challenged at quite a fundamental level. I came to the conclusion that the basic models and assumptions did need to be so challenged and this led to a process of re-imagining (Morgan 1998) how patients might have very different experiences and what the organisational and professional consequences of such re-imagining might be. If imagining differently is to lead to acting differently, an overall vision needs to be translated into a "rich picture" – how could things be different in practice and what would be entailed in bringing about the required changes.

Action research, as the name implies, entails *action* as well as data gathering, reflection and theory building. The emergent ideas were, therefore, tested out in practice in various ways including a conference for professionals, focus groups and individual interviews with patients and staff in a community hospital and through the development of an educational programme in partnership with a local University. I am currently engaged in testing and evaluating the concepts of transdisciplinary practice in my own day-to-day work with patients/clients.

As the diagram below indicates, action research is a cyclical process.

Diagram 1.2 Action Research



Each cycle begins with a reflection upon the current situation. This reflection often includes a careful observation or analysis of the situation involving the collection of data through processes such as “patient stories”.

The reflection process then leads to planning how to act next to move the enquiry forward. This might be a further investigation, an experiment or a change in practice. The plan is put into action and the effects observed.

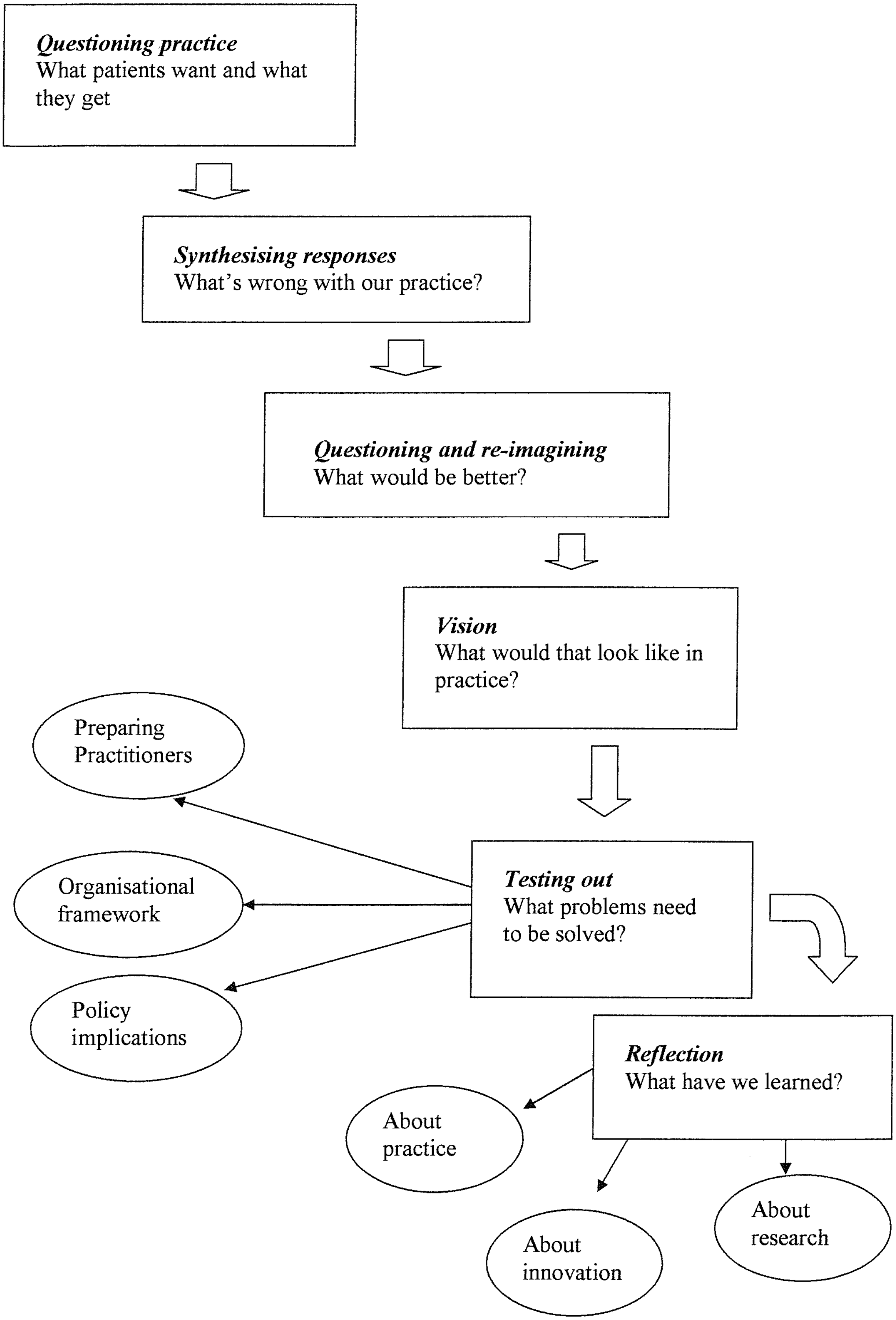
The data from these observations is then fed into a further process of reflection.

Adapted from “Action Learning and Action Research”, Kember D., 2000, Kogan Page

Box 1.6 The cycles of enquiry which constitute this study are as follows

Cycle	Description	Main methods	Outcome	Chapter references
1	Collecting patient stories	Narrative analysis	Themes in the actual and desired experiences of patients/clients.	3
2	Imagining alternative models of care	Mental models Thought experiments	Concept of transdisciplinary practice.	4
3	Developing and testing the model	Focus groups Interviews Workshops Design team.	Developed model of transdisciplinary practice	5
4	Developing policy implications and proposing an educational process	Reflection	Policy implications	6

Diagram 1.3 A map of the enquiry



Organisation of the thesis

I have discovered that one of the challenges in writing a thesis is to tell a coherent story about a journey which was, in practice, tentative, uncertain and exploratory with neither the destination nor the precise route being clear at the outset.

The introduction has raised the concept of the transdisciplinary model of practice and outlined the nature of the study and cycles of enquiry.

The next chapter (chapter 2) discusses the methodology of the study and explains why particular methodological approaches were taken in each of the cycles of enquiry.

Chapter 3 describes the first cycle of enquiry in which the patient stories are captured and analysed.

Chapter 4 describes the second cycle of enquiry in which the model of transdisciplinary practice is developed.

Chapter 5 describes the third cycle in which the model is tested with patients, clinicians and managers.

Chapter 6 describes the fourth cycle in which the issues raised in the third cycle are addressed and the policy implications formulated.

Chapter 7 captures my reflections on the research process and on my own learning and proposes areas for further research.

Chapter 8 captures my own reflections on the transdisciplinary practice model and seeks to draw more general conclusions about innovation in health and social care drawing on my experience in developing the transdisciplinary practice model.

This structure does not follow the precise chronology of the research journey but I hope that it will constitute a narrative that enables the reader to follow my tracks.

CHAPTER 2 METHODOLOGY

The methodology of this study has evolved as the nature of the problem or question that under investigation revealed itself more clearly. At different stages in the enquiry, research tools, techniques and traditions were used which seemed to offer the best chance of making sense of the data and, importantly in trying to come to some conclusions of practical relevance.

The enquiry is set most clearly in the traditions of action research (Schön 1974 and Lewin 1951) and action science (Argyris and Schön 1974) rather than in the hypotheticodeductive traditions which characterise much mainstream clinical research. It was also influenced by concepts summarised by researchers such as John Heron and Peter Reason as "new paradigm" research (Heron and Reason 1991). As the starting point for the enquiry was listening to patient stories, it seemed likely that the data with which I would be dealing would be "characterised by uniqueness, uncertainty and instability" – the defining characteristics of action science proposed by Friedman (Handbook of Action Research Chapter 14) rather than by simple controllable variables.

Action science and action research have in common their emphasis on seeking to engage with the complexity of real world problems and to develop "useful" knowledge, that is, knowledge which will be expressed in the form of new practices.

Action science, in contrast with action research, explicitly seeks to bring together the exploratory nature of action research and the robustness of more traditional scientific paradigms.

Both action research and action science are concerned with learning or discovering how to practice more effectively and that was both the aim of, and the justification for, this study. I wanted to develop ways in which the needs and aspirations of patients/clients could be met more effectively.

Argyris and Schön have stated that the goal of action science is to develop better "theories of action" (Argyris and Schön 1974, 1978). These theories of action take the form:

- In situation X (conditions)
- Then do Z (strategy)

- To achieve Y (goal).

(as cited in Reason and Bradbury 2001 p.161)

In this study I hoped to develop more effective ***strategies*** for achieving ***goals*** which better matched the expressed needs and aspirations of patients with particular characteristics and in particular circumstances (***the conditions***).

As indicated in the introduction, this study was undertaken by a group of practitioners with the membership of the group changing over time as the study developed. The group was held together by "a shared concern, a set of problems and a passion about a topic" (Wenger 2002) and by a desire to "deepen their knowledge and expertise in this area by interacting on an ongoing basis" (ibid) – the group became a *community of practice".* The membership of the community changed as the nature of the problem changed and as different people discovered that they had both a concern and a passion in common. At the start of the enquiry four practitioners were involved. By the end, this had risen to over twenty including colleagues from our local University.

Wenger describes communities of practice as “vehicles for knowledge creation” (Wenger 2002). Argyris and his colleagues talk about “creating communities of inquiry within communities of practice” (Argyris, Putnam and Smith 1985). This process of creating communities of inquiry within communities of practice, of undertaking systematic enquiry within the context of practice and with the goal of enabling better practice, they define as “action science”.

In the introduction, I seek to make clear that I regard this as an incomplete study, merely a story so far. Thought of as a study in the tradition of action science, it is incomplete in the sense that the conclusions which have been reached have not, as yet, been subjected to the “rigorous testing” which Argyris et al. (1985) advocate “to integrate the descriptive context-rich power of the interpretative approach with the rigorous testing of validity demanded by the positivist mainstream” (Argyris et al., 1985:54). I believe though that the work has been taken to a stage at which it could be exposed to such rigorous testing in the form of a randomised controlled trial comparing the transdisciplinary model with alternative forms of care.

In action science terms, the study is incomplete. Action research, views the research enterprise as a continuing journey proceeding through a set of cycles of enquiry each of which builds upon its predecessor cycles. Action research accepts and indeed celebrates the unfolding, exploratory and contingent nature of research into practical social and human problems. The author is more confident in claiming that this study does fit the structure of an action research enquiry.

Kember (2000). suggests that action research is characterised by:

- Taking as its subject matter a social practice and regarding it as a form of strategic action susceptible to improvement.

- The project proceeds through a spiral of cycles of planning, acting, observing and reflecting.

- The project involves those responsible for the practice in each of the moments of the activity, widening participation in the project gradually to include others affected by the practice.

In summary, Kember suggests that action research is:

- Concerned with social practice.
- Aimed towards improvement.
- A cyclical process.
- Pursued by systematic enquiry.
- A reflective process.
- Participative.
- Determined by the practitioners.

The roots of action research are to be found in the work of Dewey (1933) and in the subsequent work of Kurt Lewin (1951). More recent developments in action research have been in the move towards Participatory Action Research (John Heron and Peter Reason) with a more clearly stated emancipatory focus and the engagement of communities rather than merely professionals and practitioners as co-researchers.

Thought of as an action research study, the main cycles of enquiry which form the infrastructure of the study are:

- Collecting and making sense of the patient stories.
- Imagining alternative models of care.
- Developing and testing the transdisciplinary model.
- Developing policy implications.

A future cycle of enquiry would involve a randomised controlled trial to evaluate the efficacy and cost-effectiveness of the transdisciplinary model against alternative models of care delivery.

Alongside action research, the other methodological thread which has informed this study comes from the tradition of narrative psychology and related disciplines, essentially using story telling as a way of capturing data about complex social phenomena. The power and relevance of this tradition is that it acknowledges the validity of subjective lived experience whilst also acknowledging the formidable methodological problems that this presents. Most particularly, I have drawn upon the work set out in "The Narrative Study of Lives" (Josselson 1996). I have also drawn heavily upon the increasing canon of narrative based research in the field of health care published in "Qualitative Health Research". For example, "The Challenge of Adversity" Paris and Bradley Qualitative Health Research Vol 11 Number 5 September 2001.

To me, it seems that health, illness and disability are fundamentally subjective experiences. Feelings of health and illness, of ability and disability may be associated with biochemical events in the body but they remain intensely subjective experiences. The fact that illness and disability can be objectified through the attachment of diagnostic labels and categories does not take away from their fundamentally subjective nature. I believe that clinical practice can usefully be understood as the co-creation by patient and practitioner of a particular story or narrative.

In making sense of the patient stories, I have drawn upon the work of George Psathas on Conversation Analysis (Psathas 1995) and Catherine Riessman's work on Narrative Analysis (Riessman 1993). Both writers suggest rigorous approaches to aid the researcher in the systematic analysis of narrative accounts and the elicitation of themes and threads from unstructured narratives. Whilst recognising the essentially interpretative nature of such analysis and, therefore, the inevitable subjective involvement of the researcher, they suggest how the author can best safeguard against unreliable or unjust conclusions being drawn from narrative data.

Ethical considerations

de Raeve (1997) suggests that the aims of nursing research are twofold

- To understand what nursing is.
- To promote good nursing care and understand failures of practice with the aim of rectifying the situation.

This study is not exclusively concerned with nursing practice but with the work of other practitioners (doctors, social workers, therapists) in addition to nursing. It does, however, set out to promote good care and to rectify failures in practice. I agree with de Raeve in believing that there is an "ethical imperative" driving the search for better ways of meeting the needs and aspirations of patients/clients.

Although this study did not involve directly intervening with patients or modifying in any way the care and treatment that they were receiving, a number of important ethical considerations had to be addressed in the design and conduct of the study. As the study consisted of a number of cycles of enquiry rather than being completely defined at the outset, I needed to attend to the ethical context and implications throughout the study and to be alert to emergent ethical issues as the study moved forward.

The particular ethical considerations that were taken into account in the design and conduct of the study are discussed below. The headings are taken from Research Ethics published by the Royal College of Nursing (1998)

Integrity of the researcher

The Royal College Guidelines stress the need for nurses involved in research to be in possession of the relevant skills and knowledge compatible with their proposed involvement. The Guidelines go on to suggest that "nurses who are learning to do research should work under the guidance of an experienced researcher" (RCN p13).

I came into the category of a "nurse learning to do research" and as such, I worked closely under the supervision of an academic supervisor herself an experienced nurse, researcher and supervisor and a project facilitator with considerable experience in action research. For particular parts of the study such as facilitating focus groups and capturing patient stories, I undertook specific training prior to undertaking these activities as well as reading extensively about the techniques and their implications.

I reflected on my own personal prejudices and biases to ensure that these would not unduly colour the conduct of the research, the collection and analysis of data or the conclusions drawn from the research. Interpretation was an essential part of this research study and interpretation is necessarily personal and reflective of the beliefs, values and views of the person undertaking the interpretation.

Safeguards against unacceptable researcher bias were provided by:-

- Having a number of researchers engaged in data collection.
- Undertaking interpretation as a research team rather than in isolation.
- Testing emergent conclusions with large numbers of peers (through the workshop) and with practitioners and patients/clients in the community hospital. Further critical scrutiny of the data, the analysis and the conclusions formed an integral part of the development of the transdisciplinary educational programme.

All of the data collected throughout the study was stored under conditions of security both in electronic form and as paper documents. Information attributable to patients, such as the patient stories, was safeguarded by patients being identified by a code identifier only with the names of patients being known only to the author and professional colleagues involved in collecting patient stories.

Selection of research participants

During the first cycle of enquiry, the collection of patient stories, the medical consultants responsible for the care of patients with long-term and complex needs living in the community were asked to identify a number of patients who could be approached by the research team and invited to participate in the study. All of the patients identified were approached and all agreed to take part in the study.

In the subsequent cycle involving patients in the community hospital, patients who fell within the definition of having long-term and complex needs were selected by the senior nursing staff of the hospital.

Informed consent

Each patient invited to take part in any aspect of the study was approached individually by me or by one of my co-researchers (either a registered nurse or a therapist working within the NHS). The patient was seen in his or her own home or in the community hospital. The patient was encouraged to have carers or family members present during these conversations.

The researcher explained carefully the nature and purpose of the study, how data would be collected and how it would be used. Assurances were given about the confidential and non-attributable nature of data being collected. Patients were encouraged to ask questions and it was stressed that they were under no obligation to take part in the study.

I am confident that in all cases fully informed consent was freely given.

Summary

Formally, this study is best regarded as an action research enquiry characterised by a number of cycles of planning, acting, observing and reflecting.

Within that overall framework, I have incorporated the notion of the community of enquiry within the community of practice drawn from action science. As the study progressed, I became engaged with two communities of practice, the community of clinicians and the community of educators and was presented with the challenge of trying to create a single community of enquiry and practice from these two diverse communities.

In seeking to understand the needs, aspirations and experiences of patients, the starting point for this enquiry, I have drawn upon the traditions of the study of subjective experience using narrative and conversation.

As yet, the model that has been developed has not been exposed to the rigour of a randomised controlled trial. This would be an essential future step if the potential of the study is to be realised. I hope, at least, to have laid the groundwork that would enable such a trial.

In my reflections on this study, I have come to believe that the richness and validity of this enquiry could have been enhanced through the continuing engagement of patients as co-researchers, thus framing the study more clearly in the tradition of participatory action research. Regrettably, I did not think to fully engage patients (and their carers) as co-researchers in the traditions of participatory action research and this may well be a fruitful field for further enquiry.

CHAPTER 3 THE FIRST CYCLE OF ENQUIRY

STORIES FROM PATIENTS

As indicated in the introduction, the starting point for this enquiry was the collection of narratives from a selection of patients. The intention of the enquiry was to identify sources of satisfaction and dissatisfaction in the patient's experience of care from the NHS Trust in which I was working and, if possible, to identify ways in which the Trust could improve the quality of the services provided and better align the process of care delivery with the needs and aspirations of patients. The Trust was particularly interested in the experiences of patients requiring complex care, which could be delivered in both a hospital and a community setting.

My role was to be an empathetic and informed listener and to gently question as necessary to move the narrative along and to clarify her own understanding of the story that the patient was telling. The Trust had decided to use two senior nurses to collect patient stories, as it believed that nurses were likely to enjoy the trust of patients and to have the interpersonal skills necessary for this form of data collection. The Trust also believed that nurses were accustomed to dealing with sensitive and confidential data and would be bound by their own code of professional ethics in the management of such data.

These beliefs are supported by the work of Leslie and McAllister (2002). They argue that nurses experienced in clinical settings, in common with other health care professionals, are likely to "*have the ability to listen empathetically, to ask gently probing and focused questions, and to practice regular reflection and clarification*" (Leslie and McAllister p701). They also comment on the "cultural construction of nursedness" (p701). Quoting Taylor, they suggest that "*Because people believe nurses to be trustworthy, caring, practical, and worldly, accustomed to dealing with matters that can be private, delicate, intimate, frightening, or even unspeakable, people tend to relate to nurses openly, faithfully, and expectantly*" (Roy Morgan Research Centre, 2000;Taylor, 1994).

Prior to undertaking discussions with the patients in the study, I and my fellow nurse researcher met with the project facilitator to discuss story telling as a research methodology, to explore the ethical and interpretative issues associated with the methodology and to simulate the process of story telling.

I felt well prepared for this phase of the study. My own experience of the reactions of patients reflected the assertions put forward by Taylor about general beliefs about and attitudes towards nurses and patients seemed willing to tell their stories "*openly, faithfully and expectantly*". This was also the experience of the other nurse researcher involved in this stage of the study.

In this chapter, after a brief description of the methodologies for collecting and analysing the data, I have highlighted the themes emerging from the analysis of the patient stories and the questions that they raise in relation to practice and the organisation of care delivery. I have also summarised a number of stories, retaining as far as possible the patient's own words, and indicated the key themes and messages that emerge from each story.

Method

How patients were selected:

A sample of 22 patients was recruited as potential participants in the study. Recruitment took place by approaching a number of consultant medical staff and asking them to identify patients whose care involved both hospital-based care and community care and whom they felt would be well enough to participate in the study.

The table below shows the specialties of the consultants involved in recruiting the sample.

Table 3.1 Specialties of consultants recruiting sample

A	Trauma and Orthopaedics
B	Genito-Urinary
C	Gastro-Intestinal
D	Gynaecology
E	Psychiatry – Chemical Dependency
F	Endocrinology
G	Cardiology
H	Respiratory Care

The table below shows the primary diagnoses of the patients who were recruited into the study.

Table 3.2 Primary diagnoses of sample population.

Primary diagnosis	Number of patients
Fractured neck of femur	1
Fractured tibia and fibula	1
Spinal cord injury (incomplete)	1
Total Hip Replacement	1
Total Knee Replacement (TKR)	1
Removal of TKR due to infection	1
Total Abdominal Hysterectomy (and unstable diabetes)	1
Laparotomy and division of adhesions	1
Abdominal Perineal Resection	2
Cystectomy	1
Substance Misuse	4
Unstable insulin dependent diabetes	2
Cardiac disease	2
Respiratory disease	3

Names and telephone numbers were passed on to the two of us, we then made the initial contact (very basic explanations of the research and of what would be involved had been given by the Consultants concerned) to ask if the patient would be willing to discuss taking part in a study of this nature. All patients who were contacted agreed to a preliminary discussion with one of the nurse researchers.

How informed consent was obtained:

Each patient was visited in his or her own home. The purpose and design of the study were explained and the patient was encouraged to ask questions. Reassurances were given about the confidentiality and anonymity of data collected.

Consent forms were signed by the patient with one copy being given to the patient, one retained by me as lead researcher and one being placed in the patient notes.

The story-telling process:

All interviews were tape recorded (using a small Dictaphone so as to be as unobtrusive as possible) and subsequently transcribed. Participants were asked to recount their story about their most recent experience of the local health care system in relation to the primary diagnoses set out above. They were asked to describe first how their experience had been and then to explain how they would have liked it to have been. The process was non invasive and unobtrusive and did not cause unnecessary exhaustion. In fact whilst initially planning one hour as a reasonable amount of time, nearly all the subjects wanted more time.

Analysis of the data

The analysis process began by carefully re-reading the transcripts to locate themes. Each transcript was copied and circulated to the five members of the research team (see table below).

Table 3.3 Research team professional backgrounds

The research team for cycle 1 of the enquiry	
Nurses	2
Speech and language therapist	1
Physiotherapist	1
Psychologist/facilitator	1

Each member of the team independently read each transcript and marked up what he or she considered to be key themes. The team then met to share their analyses and interpretations. This process involved:

- Agreeing a common set of constructs, category labels or descriptors by probing the language we had used in labelling themes to elicit common meanings and real differences.

- Identifying the threads that ran across several stories.

- Re-reading transcripts in the light of the analytic categories that we had developed to test the extent of correspondence with the original transcribed narrative.

- Revising themes as necessary in the light of the re-reading.

The themes

The themes identified by the research team through the process described above were as follows, together with the number of times they were mentioned in the six stories printed:

- Positive attitudes towards individual clinicians. (x3)
- Lack of continuity of care – too many different people involved.(x5)
- Lack of responsiveness to requests for help and information.(x2)
- Lack of recognition of the patient's concerns about his/her "non-patient" life.(x3)
- Lack of valuing of the patient's opinion or experience.(x4)
- Frequent moves around the hospital.(x2)
- Poor communication between professionals and across organisational boundaries.(x6)
- Waiting (at many stages in the care process).(x4)
- Lack of understanding of the patient's social circumstances.(x6)
- Stigmatisation.(x4)

Synthesizing and raising questions for practice:

The themes above occurred fairly consistently throughout the stories that were collected. In reflecting on these themes, the research team generated a number of questions about clinical practice and the organisation of health care delivery that the stories suggested.

- Although individual doctors/nurses/ health care professionals continue on the whole to be held in high regard by patients – the' whole system' in which they work is not. How can we shift the culture of healthcare so that everyone takes responsibility for the quality of care the 'whole system' delivers?

- With regard to specific tasks and procedures how do we go about improving the quality of care for patients receiving such procedures (i.e. intra-venous infusions) Should these be regarded as basic core skills of say a nurse, or should 'teams' become specialist/proficient in a range of skills commonly used/needed by a client group?

- To whom can patients complain about not feeling listened to? How do we change the attitudes of health care professionals towards patients, and help make them feel an integral part of the care team?

- Whose responsibility is it, for giving the patient all relevant information?

- How can joint working be improved across boundaries? (health, primary, secondary & tertiary care, social care, local authority, voluntary sector, education, housing.) How can we ensure an equitable service?

- How can we improve the way in which we involve patients in decision making?

Reflections on the story telling process

The collection of such data (retrospectively) in decontextualised ways, requires people to reflect on thoughts, feelings and events and this may in some instances lead to distortion. In the capturing of these patient stories, the events were sufficiently fresh in their lives that distortion was thought to be minimal. Although the stories may be embellished and slanted to convey desired messages and meanings, they nonetheless contain important truths for improving care.

A number of the patients indicated that they had not previously had an opportunity to talk about 'their story' and the effect it had had on their lives. Providing this opportunity for them to reflect on the consequences, may have been beneficial. Vezeau, 1994,(as cited in Qualitative Health Research Sept 2001) suggests that narratives in health care are noted for their healing properties and the potential they hold for making meaning out of life events.

Analysis of these stories suggests that these narratives can be read as experience-based statements of underlying concern and heartfelt wishes. I found myself continually asking 'just how closely are we (all healthcare professionals) really listening to the messages coming back to us from the very people we seek to help?' It is also worth recording that we were shocked, saddened, shamed and angered by the stories that the patients recounted. None of the patients involved had raised formal complaints and we had every reason to believe that they were a representative cross section of the patient population. Even though patients were consistently complimentary about most of the individual professionals involved in their care and grateful for their efforts, the members of the research team viewed some of the experiences as indicative of intolerably poor standards of practice verging at times on simple lack of humanity and compassion.

The results from this small study inspired and impelled us to take the enquiry forward and to see if we could develop strategies that would address the issues raised by these patients in telling their stories.

The second cycle of enquiry takes as a starting point, the themes emerging from the patient stories. In the second cycle, the author seeks to understand why the patient stories were as they were and to imagine a different model of practice that might deliver more acceptable patient experiences.

Illustrative stories

The following selected and summarised stories serve to illuminate the key _themes_ emerging from this first cycle of enquiry.

…Frequent moves around the hospital – but a positive attitude towards individual clinicians…but a lack of responsiveness to requests for help and information…

i) Introduction:- Six months ago Mrs T was knocked over by a car whilst on a zebra crossing, sustaining fractures to her left tibia and fibula, the tibia was internally fixed with a pin and plate. She was discharged home after 4 weeks with a wound infection and had methylcillin resistant staphylococcal aureus. Subsequently she had two re-admissions with recurrent wound infections.

" Before I say anything I do want to say that on the whole, all the doctors and nurses have been fantastic, but I wish I could say the same about 'the system'.
Too much, probably unnecessary hanging around in A&E. My accident happened at 20.30, I arrived at A&E at 21.00. I eventually got into a bed at 03.30. More important than that though was the fact that as soon as I arrived at the A&E I pleaded with the nurses (there were several dealing with me) to 'phone my husband (as he was expecting me home after my evening job after 20.30, so I knew he'd be worried) They didn't 'phone him until 23.30, he was out of his mind with worry. My two step-daughters were out with their dogs walking the streets looking for me on the route home, that I would normally walk. My husband was 'phoning the Police and the hospital, they said that I hadn't been admitted (I wasn't on the computer or something) Eventually just before midnight. The Police 'phoned and let my husband know of the accident. What with the pain in my leg and the worry of my husband (he's a diabetic and it doesn't do to get him upset) by the time I was transferred to the ward and in a bed I couldn't sleep anyway.

The next day I had my operation and when I was coming round I had an 'out of body experience' in fact I still have nightmares about it now. The doctors and nurses have all been kind and understanding about it all though.

I'd like to say something about those intra-venous things. They're really painful and I don't think that doctors and nurses always think that they are, you know. Us patients always know when they've packed up but we're not always believed, other patients have said exactly the same. You can tell one that has been put in well, and you know who you like putting them in! You talked about a Specialist Nurse? Well I think it would be good if there could be one who just did those intra- venous things.

One thing about the system, I feel I must tell you is about all the moves you have, it isn't just me, the other patients too. I was moved three times in four weeks, it isn't good you know and because you have to go into the outside, it's not right when you've got an infection, in fact I blame it all on that, too much moving around and hence too many different nurses doing your dressing. See that fly? He's been flying around the ward, that can't be good for wounds can it? When you're moved, I do wish they'd give you more notice and /ring your next of kin. It really worried my husband when he visited and found a different patient in my bed. Then walking from this surgical block over to the medical block is quite a long way. In fact all this leg trouble over the last six months has caused my husband to have a breakdown and his diabetes to go haywire, but that's another problem.

I really don't want to complain because as I said, all the doctors and nurses have been fantastic"

...*Poor communication between professionals and across organisational boundaries...and much waiting.....*

ii) Introduction:- Mr N had left and right meniscectomies 'years ago' and presented with osteoarthritis in both knees. The left total knee replacement was performed six months ago, he has had two re-admissions with recurrent wound infections.

"The actual operation went just fine, in fact when I left the hospital I couldn't wait to be admitted for the other one to be done, I'd be a new man and might even be able to say goodbye to the sticks, but not now.
I reckon I should have been told, before I went home, about all the warning signs to look out for about wound infections, I mean I knew I was 'out of sorts' but didn't connect it to my knee and by the time I did, well it was too late.
I went to my GP. He wasn't interested really, 'rest and take some paracetamol' he said. Well I had been doing that already and it hadn't helped. It got no better, in fact the pain got worse and it was getting all hot and swollen all round my knee. So on the next trip to the GP, he gave me a months supply of antibiotics, he asked me when I was next due to see my Consultant ...'stay on the antibiotics until you see him, no need to bring the appointment forward'. Well, I just couldn't stand the pain anymore. After a week I got into a taxi (it's expensive you know when you're on Income Support) and got to A&E here.
Had to wait hours and hours to see a doctor, and they (the nurses) couldn't give me anything for the pain, because it has to be prescribed by a doctor apparently. I'd arrived at 09.00 and at 10.15 a nurse told me that the Orthopaedic doctor couldn't see me until 15.00 because it was a Saturday – I didn't really understand that bit. Then when he came, I was in so much agony, he said 'Oh I can't treat you as I work for the other Consultant, so you'll have to go home and come back to his Outpatient Clinic on Tuesday'. He still didn't give me any injection or tablets for the pain. So I had to get back into a taxi back home, I just couldn't have got on or off a bus. So I came back by taxi again on the Tuesday, this time with my suitcase, I wasn't going to go home

again, they had to do something. When the doctor saw me, he looked a little bemused when he saw my case and then when he saw my knee it was like a balloon, red, hot and swollen, and this big blister about to burst, in fact it did a bit later, and oh dear the pain, it was terrible. He said 'You've got problems haven't you?' In fact he was cross with the other doctor who didn't do anything for me on the Saturday, and he was also cross with my GP.

Because I wasn't allowed onto the ward because I was a 'dirty case' (and that doesn't make you feel good does it?) I had to stay in clinic from 14.00 until 17.00 before I could go to theatre. Then the receptionist lady said to me 'You can't stay here', but the doctor said I had to, and fixed it for me to go to A&E and lay on a trolley. In the mean time, I had to walk there and carry my suitcase, that wasn't easy, a stick in one hand, a suitcase in the other hand, and I had a needle thing for the antibiotics in the back of my hand. Then in A&E I had to wait in fact, until just before midnight before I had my op, to clean out all the infection. At least after that they did keep asking me about the pain, although it was painful, it was nothing compared to the pain I'd been through.

I got moved to two different wards, but I ended up on the right ward. Stayed there a month and then went home, but that was terrible: the stairs, trying to cook, couldn't get out to do any shopping or get to the post office re: my benefits, I live all on my own you see.

Things were eventually OK, you learn to cope don't you, you have to. Then three weeks later, it all seemed to flare up again. This time I decided I'd go straight to the hospital with my suitcase. Things were better, I did get admitted and the intra-venous

started, but then I had to wait three days until there was space in theatre, everything was booked up and again I had to be last on the list as a 'dirty case'. In the end, I had to change Consultants in order to get on his list as they didn't want me to wait another three days until it was my original Consultants list. It is all so much red tape isn't it? So I've changed Consultants which I wasn't happy about, but it is all OK now. So this time, I had to have the whole knee joint removed and this splint thing applied and I can't walk on it so I'm hopping around on crutches. If, and only if, I stay clear of infection by the end of June, this different Consultant, he's a very nice man, said he'd put *another new joint in. This time though they're sorting out things for me at home. The Occupational Therapist is fixing up things, but more red tape because where I live is just outside the A boundary and come under B, so she has to make extra 'phone calls.*

If you had come here to see me this morning you would have seen me in a terrible state, I didn't know what came over me. I just couldn't take any more and broke down, not good for a grown man to cry is it? J (the Health Care Assistant) was marvellous; she really seemed to understand and just held my hand and listened. I've pulled myself together now, I'm OK.

This intra-venous thing is getting me down. I had the antibiotics at 14.00 and told them it was hurting (you know when it stops working properly in a vein). The nurse said he'd pass it on to the nurse on the late shift, she has said that the doctor will do it at 18.00, when the next antibiotic is due, but it is so sore.

The thing is I've been waiting since 14.00 to be moved across to the rehab ward, so at 18.00, the doctor won't know where I am, which means they'll be given in the early hours and you get woken up when all the timings get out of sync.
Sorry I've been whinging, you've caught me on a bit of a bad day, it's been nice talking to you."

...<u>Positive attitudes towards individual clinicians....but a lack of valuing the patient's opinion or experience...</u>

iii) Introduction:- Mr G fell over whilst playing football with his two sons, four days a go, said he 'knew' he had broken his leg. He arrived in A&E within half an hour.

" I was dead impressed with the speed at which the ambulance came and got me in to hospital. I was in agony and said to them 'I know I've broken my leg' They obviously didn't like me making my own diagnosis so they put me round the back in the minor casualty bit, not the major bit. Had to wait ages for an X-ray, then they said that I had fractured my left tibia and fibula.
One hour later someone put a plaster on my leg I pleaded for some pain killers, only after five hours since I broke it did I get any tablets, I should have had something before the plaster went on.
Eventually I got to the Orthopaedic ward, things got better there. I had an injection for pain and that helped me sleep too. The bed is hard but better than the trolley in casualty. I had a drip put up and then went down to theatre for the op. I had a nail put in, so I don't need the plaster now. Can't really complain, things do get explained. I'm an inquisitive sort of person, but I think if you don't ask you won't always get told.
No everyone has been really nice, but I'm glad I'm going home today, only four days in hospital. Some poor souls are in here for much longer."

…*Lack of responsiveness to requests for help and information…*

iv) Introduction:- Mr S had a one year history of low back pain – treated conservatively and not very sympathetically by his GP. Eventually referred when left sided sciatica presented.

" Once I was referred I thought, at long last, something was being done. I was admitted from out patient clinic a week ago – the leg pain had gone but not the back pain, so I was still back on different painkillers. The results of the scan never came back from hospital 'A' - ? lost?
The next three months were hell, the pain got worse and worse, backwards and forwards to my GP who said I just had to keep chasing the hospital – what a performance and expense, that was so frustrating being put through to different people all the time, then put 'on hold'. I eventually got another appointment, they admitted me from clinic again, had an operation the next day (laminectomy and spinal decompression). When I woke up I couldn't feel my legs, my bottom or my private parts. I could move my legs, so to begin with I don't think the doctors and nurses really believed me that I had no sensation, only when I could feel in my tummy that my bladder was full, but I couldn't empty it. Then after the catheter business, the next day I realised that I was incontinent from my bowels. I was mortified, no way could I ever put that on. Once they began to worry they sent me back to hospital 'A' for another scan, but because they never found my original scans they couldn't compare. At 21.00 that same night, I got transferred to hospital 'B', supposedly for another operation on my back (? Due to trapped nerves from the first op). But can you believe it, the ward forgot to send over my notes, X rays and scans (from hospital 'A') so the Consultant from hospital 'B' refused to operate that night. These all duly arrived the next day and I had my op. At least my back pain went away at long last, but the sensation hasn't come back. Before I signed the consent form for the first op I said to the young doctor,' any chance of becoming paralysed during this op?' 'No of course not' he said. The Consultant at hospital 'B' said that things obviously didn't go quite according to plan during the first op, but he has done the best he can, and says that the

sensation may or may not come back, he can't promise, he says he doesn't want to se me again for six months.

Meanwhile, back here, well they want me to go home tomorrow. I've told them I'm not going home until I feel I can cope with all this incontinence. I've been taught how to do this intermittent catheterising and they've given me pads for the other end, but I don't think that this is satisfactory, and how can I walk and go upstairs back home?

They've said to move a bed downstairs. I have got a loo downstairs which is fortunate, I suppose, but I want to sleep with my wife, is that so unreasonable?

I know they want the bed and feel as if I'm being difficult in their eyes. I'm waiting now for a specialist appointment re: bladder and bowels at the spinal injuries hospital, but that could be weeks yet.

Sorry I can't be more positive about things"

...*Lack of recognition of the patient's concerns about his/her "non-patient" life...lack of understanding of the patient's social circumstances..and stigmatisation*... Note: Goffman suggests that stigma involves not so much a set of concrete individuals who can be separated into two piles, the stigmatized and the normal, as a pervasive two-role social process in which every individual participates in both roles, at least in some connections and in some phases of life." Source: Goffman,E. (1963). Stigma:Notes on the management of spoiled identity. (pp. 137-138)

v) Introduction:- Mr A a 42 year old man, attending the Chemical Dependency Unit as an out patient.

" I've been involved with psychiatrists and ordinary GPs for 30 years now. I've been to a Concept House, that was so bad I had a nervous breakdown there. They were doing it all on the American lines. You weren't allowed to see your family unless they said so. I run away once and my brother talked me in to going back, but they then said 'don't talk to your brother'

I started taking drugs so young, 13, with Mandrax. All my friends were one step of the doctors. The end of the line was getting smack out of the doctors cases. We were robbing cars. I've never seen a social worker in 30 years, tell a lie, only cos I was in prison.

Nobody talks to each other. The two psychiatrists I'm under, Dr M doesn't know what Dr C is doing in the same building. I'm desperate to see my daughter, she's eight. I can't see her, my wife won't let me see her. I started 90mls and I've got it down myself. I've got an appointment with D (the CPN) and I'm going to see what they can all do. There is treatment called sleep treatment and they let you deal with your withdrawals in your sleep.

You go to any of the waiting room areas and you'll hear what people are saying about how they are bypassing the system. I've been to the doctors round here about four times all under different names just to get the script I want. Makes you laugh, they've all got their diplomas on the wall and I've got nothing, but I'm smarter eh!

Because my first sentence was six months, in that time I worked out what you need to do and who you need to get on with. I come out of there as fit as a fiddle, I could run so fast the police couldn't catch me!

All these different institutions, they're all splinter groups of the same you know. I went to a borstal once and gave a talk on drugs, and that felt good, it felt as if I was able to give something back, cos they should really be asking people in the know to give these sorts of talks. It made me realise I should have been off the stuff years ago.
In my day you had to know ways of getting money. You had to have at least £400.00 a week or you got withdrawals. That's probably the hardest work I've done in my life.
I asked at the clinic for a CPN that could come round and visit. The woman who books appointments said 'I'll look in to it', but I know what that really means is when they get round to it, and by then they'll have forgotten what they were going to do.
There's apparently a group at my daughters school, a drop in centre, where separated parents can 'drop in' and see their kids, but I don't feel like going there, it's like a stigma. You panic when you've got kids cos of what people say social services will do. The solicitor suggests it's best if we sort out visiting between us, if we go to social services we'll end up in a fight over her.
There's many times I've used the hospital to get out of a prison sentence. If the judge is told that you're in the middle of treatment, he'll make sure you continue and he'll dismiss the case. It's great really, but do you know, it doesn't give me a lot of confidence in any of the systems".

...Lack of continuity of care – too many people involved

vi) Introduction:- Mr B is a 40 year old man attending the Chemical Dependency Unit

"I've had no problems with the service other than what I see being done to the NHS. I see a lot of stress in the workers, I see a lot of inadequacies. I know there's got to be financial control, but it seems like the accountants are running away with it.
A friend of mine went for a scan, because the staff were under pressure she got a curt answer, which upset her. I know that dealing with the public ain't easy, but there's no need for that though.

The government spend about 25 grand on a logo for the millennium; I could have done it just as good for a tenner! I believe in the NHS, but let the people who know about medicine and know what they're doing.....do it!

I haven't had much to do with my GP for a while, cos I come here to the hospital. I've been in situations with the social services for other people not for myself. My last relationship was with a woman who had seven children. When I first met her, they were all on the 'at risk' register, but we got it all turned round to only one being left on the register.

There was a big crossover between psychiatric and social services, but they didn't communicate with each other at first, it took quite a lot of work to get 'em pulling together. We missed out on three case conferences cos no one let us know, their excuse was the social worker was on extended leave. The boy should have come off the register, it was like he was being kept on through the social services inadequacies. I always maintained who was abusing who? There was a time when all the different agencies and all the different groups were in fact working quite well together, but it took a long time for it to happen though. The boy had a support worker working with him at school and at home, building up a good relationship with him. Then just a few weeks before the next big case conference was due, they took that support worker away, so we were back to square one – typical.

The new social worker who was brought in, wouldn't go to the case conference cos she didn't have the information she said. It seemed that people were dragging their feet. It just seemed that the left hand didn't know what the right hand was doing. We actually pulled them up and started saying 'Look this is causing more abuse to the boy, more emotional trauma cos he is being made to feel different and separate from the other kids'.

From my point of view I know what a hard task it all is for you, like the conditions you all have to work under, the length of hours you're expected to work. You can give people in the health and social a bit of slack really cos at the end of the day it is a hard job, but if only they'd just communicate.

CHAPTER 4 THE SECOND CYCLE OF ENQUIRY

IMAGINING ALTERNATIVE MODELS OF CARE

The second cycle of enquiry takes as a starting point, the themes emerging from the patient stories. In this cycle, I seek to understand why the patient stories were as they were and to imagine a different model of practice that might deliver more acceptable patient experiences. I argue that the concept of mental models is helpful in understanding why patient experiences were as reported and explore three particular mental models which I believe to have particular explanatory power. I also suggest that there is a lack of convergence between the reported experiences of patients and the espoused values of the NHS as set out in various policy documents including "A First Class Service" (1998).

I then report a series of "thought experiments" or acts of re-imagining stimulated by the work of Gareth Morgan (Morgan, 1997). These acts of re-imagining led to the evolution of the transdisciplinary practice model that is then developed and tested in the third cycle of enquiry.

About mental models

Senge (1993) and others (Gardner 1984,1985 Argyris1982) have commented on how mental models influence the ways in which organisations and individuals behave. Senge, in particular has commented on the extent to which inappropriate mental models can lead to dysfunctional organisational and individual behaviours and the failure of organisations and individuals to adapt successfully to changing organisational environments and, critically, to changing consumer needs and expectations. Senge writes

"*More specifically, new insights fail to get put into practice because they conflict with deeply held internal images of how the world works, images that limit us to familiar ways of thinking and acting*" (*op cit* p 174)

The analysis of the data from the Patient Stories cycle suggests that the services which the patients and carers in that study reported receiving and the ways in which those services were delivered aligned poorly with the needs and aspirations which they, the patients, articulated. Table 4.1 summarises the key discrepancies between the reported needs and aspirations of the patients and carers in the study and the reported experiences of the same patients resulting from the analysis of stories carried out by the researchers.

Table 4.1

Reported needs and aspirations contrasted with reported experiences.

Reported needs and aspirations	Reported experiences
Someone who really knows me.	Many different practitioners few of whom had built up a relationship with the patient and his/her family.
Being treated as a person not an illness.	Each practitioner focussing on specific problems rather than on the person.
Not having to repeat information.	Information not being passed from practitioner to practitioner.
Having things at the right time.	Discontinuous care process with very different waiting times for different services.
Fitting around the rest of my life.	Organised around service rather than patient convenience – e.g. being put to bed too early no out of hours service.
Having my own views respected.	Patient and carers often not listened to respectfully and professional views and beliefs prevail.

To me, it seems equally clear that the reported experiences of the patients in this study indicate divergence between the declared values and beliefs of the NHS as set out in a number of policy documents (A First Class Service, 1997, The NHS Plan, 2000) and the reality of patient experiences. This divergence can be interpreted in the context of Argyris' work as a gap between espoused theory and theory in use. (Argyris 1992).

Table 4.2 below summarises the key discrepancies between the espoused theory of practice of the NHS and the reported experiences.

Table 4.2

Espoused theory and theory in use.

Espoused theory (derived from policy documents)	**Reported experiences (derived from patient stories)**
The patient is at the centre of all we do. (6.61 in NHS Plan)	The professional/service/agency is at the centre.
Treating patients as individuals. (6.11 in NHS Plan)	Patients are categorised and expected to fit into a "one-size fits all" service design.
Partnership working. (7.2 in NHS Plan)	Poor collaboration between agencies. Examples of being "passed around like a parcel".
Seamless care. (2.34 in A first Class Service)	Many different practitioners and agencies with poor inter-practitioner and inter-agency communication.
Patient choice. (1.11 in NHS Plan)	Little or no effective choice.
Continuity of care. (1.11 in NHS Plan)	Many different practitioners.
The GP as coordinator of care. (1.14 in NHS Plan)	GP often having only a marginal role and not seeming to know what is going on.

To me it seemed that at least three strong and prevailing mental models were contributing to the variance between what was provided and what was wanted. Other mental models were considered such as the prevailing biomedical model of care and the mental model of patient as passive recipient as indicated in studies by Bloor (1977) and many others. The biomedical model and the "passive patient" model are particularly relevant to the nature of the encounter between individual practitioner and individual patient. We chose to focus on other themes that emerged particularly strongly from the patient stories. These themes emphasised the interaction between the *system* of care delivery and the patient rather than between practitioner and patient. For this reason, we felt that three other mental models might be more helpful in seeking to understand the experiences that the patients were reporting.

These three models are:

The model of professions.
The model of agencies.
The model of multidisciplinary working.

Each of these models addresses in different ways issues of fragmentation and specialisation and issues of boundary and boundary management. Several of the themes emerging from the patient stories related to experienced discontinuities as the care needs of patients transcended particular professional and/or agency or organisational boundaries.

The multidisciplinary model is relevant for two reasons, firstly:

> It is the prevailing model of care delivery experienced by the patients whose stories we were seeking to understand.
>
> Secondly,
>
> It is a model which specifically seeks to address the potential problems of professional, and sometimes, organisational specialisation.

These three mental models also proved helpful in the later stages of this enquiry in enabling me to understand some of the sources of resistance that we encountered in seeking to secure support for the transdisciplinary practice model.

The mental model of professions.

The Concise Oxford Dictionary (Sykes. 1982) defines profession as "*vocation or calling, especially one that involves some branch of advanced learning or science*" and also as "*body of persons engaged in a profession*". Usefully too, the dictionary suggests that the concept of profession derives from the notion of "*laying claim to*".

Leathard (Leathard 1994) suggests that "*Traditionally, a professional person is associated with control of entry to a particular profession, the requirement to undergo a recognised length of training, accredited and, in some cases, licensed, by an acknowledged professional body. At the end of training, the professional is recognised as having a certain expertise which legitimates practitioner action, usually bound by a code of ethics*". (pp6-7).

The notion of "profession" is an important and powerful social construct with a considerable history. Belonging to a particular profession confers certain privileges, some symbolic and some very real. Belonging to a particular profession also imposes certain restrictions and obligations.

That it is a current and potent construct, is reflected in the frequency with which the term and its derivatives, is used in the day to day discourse of people working within health and social care.

As indicated above, I have chosen to focus on the interaction between the system of care delivery and the patient rather than on the interactions between patient and individual practitioner. For this reason, in the context of this research, I am not particularly concerned with the power relationships between "professionals" and "patients" or with the oppressive character which some such relationships can display (see for example), Davis and Horobin (Davis and Horobin 1977) although this became an important issue in the development of the Transdisciplinary Practice curriculum (see Appendix B). I am more concerned with the way in which "professionalism" acts as a fragmenting force in the delivery of care and thus contributes to dissonance between the needs and aspirations of patients and the experiences of patients.

Professional identity is an excluding concept. One is a member of profession x by contrast with the others of humanity who are not in membership. Professional identity is about differentiation not about integration. It is atomistic rather than holistic.

Each profession has its own distinctive "professional gaze" (Foucault (1980) and 'The eye of power' in Gordon . The practitioner sees the patient from the practitioner's own "special" professional perspective, attending to those aspects of the patient's body and life which are "relevant" to that profession and relatively disregarding those which are professionally "irrelevant".

The distinctive professional gaze may be embodied in and symbolised by profession-specific instruments, investigations, methodologies and rights. The most potent symbols and embodiments are those that are *exclusive* to a particular profession.

I believe that the notions of professional identity and professional differentiation are deeply embodied in the culture of the NHS and in the mind-sets of the practitioners who work within it. The facts that the needs of many patients cut across the cellular nature of professional groupings has generally not led to a fundamental re-assessment of whether such professional differentiation is helpful to or even consistent with claims to want to deliver care which is holistic, patient-centred, seamless and fully integrated.

As I report in chapter 8, even mild questioning of professional boundaries can evoke strong and hostile reactions.

The mental model of agencies.

The mental model of "profession" is distinct from the model of agency or unit of organisation, which is much more a managerial and/or political construct.

Health and social care is delivered through a plethora of different statutory and non-statutory organisations. These may work within different frameworks of governance, have different priorities and have quite different organisational purposes.

Different organisations work within different and potentially conflicting performance management frameworks; that is, the formal criteria of organisational success are different and potentially conflicting.

There is no unit of organisation, even within central government, which has, as its primary purpose, meeting the needs and aspirations of patients. Even where there is apparently such a common purpose set out in the organisation's "mission statement" or some similar manifestation of espoused theory (Argyris 1992), it is clear that the organisation concerned does not have the resources or legitimacy to fulfil that purpose.

Just as professionals have a professional gaze, so too organisations have an "organisational gaze" (Foucault 1982)– the discharged patient is out of sight and out of mind and the unblocked bed is in clear focus – the patient has "disappeared", leaving only a paper or electronic record behind like the chalk marks which show where the murder victim once lay. Similarly, the patient admitted from primary care into hospital has "disappeared" until the discharge summary conjures him or her once more into existence.

In its most pathological form, the fragmentation of agencies and organisations can manifest in an unseemly shuffling around of the patient; whose responsibility will he or she be when the music stops?

As with the mental model of professions, the mental model of organisational boundaries, purposes, priorities and responsibilities acts as a fragmenting force that inhibits the delivery of the sort of experience that patients say they want.

Few, if any, sectors, completely avoid organisational fragmentation. The structural organisational orthodoxy of the 70s; vertical and horizontal integration has largely been replaced by process solutions through models such as supply chain management, just in time deliveries, collaborative models of competition and so on. Arguably, such process models work in manufacturing or service industries for a number of reasons:

- Strong consumer power over-rides temptations to pursue narrow organisational objectives.
- One organisation within the chain, typically the organisation that is the interface between the consumer and the supply chain (the finished good manufacturer or retailer) drives and orchestrates the rest of the supply chain.
- There is, in practice, a commonality of purpose – everybody wins or everybody loses.

None of these conditions apply to any significant degree in the public provision of health and social care.

The mental model of multidisciplinary working.

In many areas of health and social care, some form of multidisciplinary practice has become the norm. Pietroni (Pietroni in Leathard: Chapter 4. 1994) traces the history of team working in health and social care back to the emergence of the hospital in the 11th century. He traces the development of teams through the bureaucratisation and militarisation of healthcare and suggests that the theatre team is a well-developed model of multidisciplinary working with practitioners from a number of disciplines collaborating effectively on the task in hand.

Leathard (1994), points out that multidisciplinary working and its very many related concepts, multiprofessional working, integrated working and so on is an extremely ill-defined construct which means quite different things to different people. The book provides a comprehensive overview of developments in multidisciplinary working and a penetrating analysis of the difficulties which have to be overcome to make the concept of multidisciplinary working achieve its potential benefits for patients.

In reflecting on the stories from patients, I was compelled to ask why the multidisciplinary practice model appeared to be failing them when measured against their expressed needs and aspirations and their reported experiences...(patient story no ii)..." Oh I can't treat you as I work for the other Consultant, so you'll have to go home and come back to his Outpatient Clinic on Tuesday"...
..." The Occupational Therapist is fixing up things, but more red tape, because where I live is just outside boundary A and come under boundary B, so she has had to make extra 'phone calls"....

I investigated the practices that were in place in the multidisciplinary teams with which she was familiar and which were involved in the care delivered to the patients who had contributed their stories.

It appeared that the practitioners delivering care to these patients were working to what I would describe as a restricted, conservative or minimalist version of the multidisciplinary model. This restricted model has the following characteristics:

- No changes in the scope of practice of the individual practitioners constituting the team.
- No shared assessments.
- No shared records.
- No shared budgets.
- No shared performance management framework.
- No clear leadership.

The following processes were in place to promote collaboration and co-ordination amongst team members:

- Team meetings.
- Case conferences (in practice, allocation meetings).
- Cross referrals.

I recognise that there are examples of multidisciplinary working which are a good deal more radical than the ones with which she is directly familiar but the extensive research reported by Leathard (1994), indicates that, at best, multidisciplinary teams remain largely groups of professionals each of whom is marching to his or her own drum-beat and co-operating with other team members on the margins of professional practice. This is consistent with the reports from patients in the first stage of this enquiry.

It is possible to conclude that the multidisciplinary model may be basically flawed or, at best, a second-rate solution for meeting the needs of patients with relatively complex needs. It is a model based in co-operation rather than integration – certainly better than lack of co-operation but still some way from being able to meet the needs and aspirations of patients.

I also suggest that the model may actually be dysfunctional in a number of ways:

- It allows us to believe in the *fantasy* that patients are experiencing holistic, integrated, seamless care. The rituals of multidisciplinary working can support belief in this fantasy. (Patient story number v) ..." Nobody talks to each other. The two psychiatrists I'm under, Dr M doesn't know what Dr C is doing in the same building"...

- It is inefficient. The processes of co-operation and information sharing are time-consuming and costly. (Patient story number iv)..."But can you believe it, the ward forgot to send over my notes from hospital 'A' so the Consultant from hospital 'B' refused to operate that night"...

- It may make us behave in *more* specialised and more fragmented ways by making more different practitioners available to whom the patient can be referred. (Patient story number I)..." A Specialist Nurse? Well I think it would be good if there could be one who just did those intra-venous things"...

In summary

Authors such as Senge (1993) have commented on the importance of mental models as inhibitors of organisation and individual learning and change. In particular, Senge has pointed out how inappropriate mental models can prevent organisations and individuals from aligning what they do and how they do it with the changing needs and aspirations of consumers.

I suggest that mental models in health and social care have a significant influence in shaping the experiences of patients. I recognise that very many mental models are in play in shaping these experiences, including, of course, the mental models held by the patients themselves.

I have chosen to focus on three mental models in particular which I believe contribute to the fragmentary experiences that many patients reported. These three mental models are:

- The mental model of professions.
- The mental model of agencies.
- The mental model of multidisciplinary working.

I believe that the fragmentation of professions and the fragmentation of agencies and organisations are directly reflected in the fragmentation of the patient experience. I further believe that the inception of multidisciplinary working has, at best, papered over the cracks between professions and agencies and, at worst, led to a more fragmented and less efficient system of care delivery.

Mental models are deep-seated psychological constructs. In addition, the notions of “profession” and “organisation” are long-standing and pervasive social constructs.

Bringing about fundamental change in the experiences of patients may require these three mental models to be challenged and, if necessary, discarded and replaced. I go on to describe the process through which we set out to challenge the existing mental models.

Imagining A Different Model

Gareth Morgan (1997) coined the word *imaginization* to describe the process of challenging the metaphors which we use to conceptualise and make sense of our worlds and the organisations in which we work. There is considerable resonance between Morgan’s notions of organisational metaphor and Senge’s concept of mental models.

Faced with the evident discrepancy between the needs and aspirations of the patients in our study and the reported experiences of care delivered, the research team decided to attempt to use some of Morgan’s ideas to understand why such a discrepancy might exist and how it might be addressed.

Account of the re-imagining process.

The word “imagine” has connotations both of a mental act and of a visual or pictorial representation. Both of these flavours of the word were present in the re-imagining process that is described below.

The research team (see Appendix A) met together in a Conference Suite that was plentifully equipped with flip charts and white boards to facilitate visual representation of our thinking and talking.

We met for a full day with a facilitator (see Appendix A) who is not a clinician but whose normal field of practice is organisation development within the NHS. As indicated in Chapter 1, all of the other members of the team were practicing clinicians from a range of disciplines.

The task that we set ourselves for the day was to try to understand *why* multidisciplinary practice did not appear to be meeting the needs and aspirations of patients in the ways identified through the first cycle of enquiry.

The key steps in the re-imagining process were as follows:

> The facilitator explained the concept of re-imagining and suggested some guidelines that were similar to those which apply to "brain-storming". (Buzan 1993).
>
> We reviewed the key messages from the first cycle and re-checked that we had a shared understanding of those messages.
>
> Using white boards, we then attempted to draw the processes and relationships that are inherent in multidisciplinary working. (all of the practitioners present worked as members of multi-disciplinary teams and, therefore, had direct experience of this modality of practice.)
>
> Using the visual representations that we had constructed, we then set out to identify reasons why multidisciplinary team practice might not be successful in meeting the needs and aspirations of patients.
>
> We then scrutinised our provisional list to:
>
>> Clarify understanding.
>>
>> Eliminate duplication.
>>
>> Cluster where appropriate.
>>
>> Transfer items that did not seem to be to do with multidisciplinary team practice *per se* (e.g. resource constraints) to another list of *confounding variables*.

Our facilitator then introduced and explained the concept of metaphor as a way of understanding what is going on in teams and organisations (Morgan 1998). He particularly emphasised that any particular metaphor would illuminate certain aspects of organisational life but might conceal or distort others. He then invited us to suggest some metaphors that might help to make sense of multidisciplinary team structures and processes and their relationship to the experiences of patients.

The group successively identified two metaphors that might help our thinking. The second metaphor was developed following discussion of the first metaphor. The process of metaphor development was therefore incremental rather than discrete.

The two metaphors that we developed are described below:

1: The multidisciplinary team as a person.

The first metaphor was shaped by reflecting primarily on the aspirations and expectations of patients. We thought that they really needed the multidisciplinary team to behave as if it was a single (mentally and physically competent) individual.

If the team did behave as a single mentally competent individual, patients and their carers would not experience phenomena such as poor information sharing, cross referral and fragmentary episodic care.

In our elaboration of this metaphor, we also realised that the "team as person" would also have to be close to omniscient and omnipresent to fully meet the needs and aspirations of patients.

This line of thought took us into a discussion of the historical development of healthcare with its roots in religious orders who might well have been prepared to dedicate the totality of their lives to the care of the sick and dying. It also caused us to reflect on the problems caused by the growth of knowledge and specialisation as a way of managing a body of knowledge that came to exceed the cognitive capabilities of a single individual. We commented on the ways in which specialisation is an effective way of managing large amounts of knowledge but has significant drawbacks when it is necessary to recombine knowledge in many different ways.

At this stage, it occurred to us to stand the metaphor of "team as person" on its head and to explore the metaphor of "person as team".

2: The person as multidisciplinary team.

In developing the metaphor of the "team as person", we had started with the needs and aspirations of patients and their carers. In this thread of discussion, we started with an exploration of the *advantages* of the multidisciplinary team model, particularly as a way of managing and mobilising large amounts of knowledge.

Important advantages that we identified included:

- Making more knowledge available to address the needs of the patient and his/her carers than would be possible with a single individual.
- Making services available at all times – a team does not need to sleep, go on holiday or have a home life although its individual members may!
- Making more physical effort available than would be possible with a single individual – for example, in tasks such as moving patients.
- Enriching knowledge and learning through dialogue between team members.
- Transcendence in the sense that individual team members could leave but the team could have a sort of immortality.

Each of these metaphors offered significant advantages in meeting the needs and aspirations of patients identified in the first cycle of enquiry. However, each also had significant weaknesses that contributed to the areas of patient dissatisfaction identified in the first cycle. The exploration of practice through the lenses of these two metaphors suggested that it might be fruitful to attempt to construct a new model of practice that would seek to combine the strengths of the two metaphors whilst reducing or eliminating their apparent disadvantages.

Diagram 4.1 below shows the process of synthesis of the two metaphors to envisage a new model of practice.

Diagram 4.1

From two metaphors into a single model.

The team as person

Holistic

Continuity of relationship

Continuity of care.

Continuity of information.

Avoidance of duplication.

The person as team

Extensive knowledge.

Extended availability.

Reliability.

More effort available.

Enriching knowledge.

Transcendence.

A new model

Holistic

Continuity of relationship

Continuity of care.

Continuity of information.

Minimisation of duplication.

Extensive knowledge – through specialist education.

Acceptable availability – through changes in terms and conditions.

Necessary effort – through transdisciplinary practice teams.

Enriching knowledge – through transdisciplinary practice teams and transdisciplinary clinical supervision.

The concept of the transdisciplinary practitioner.

In developing the new model, we thought that it might, in principle, be possible to envisage a form of practice that would incorporate the following advantages of the "team as person" metaphor:

- Having a single individual as provider of most care.
- Having a single individual as *orchestrator* of care.
- Having a single individual as information interface with the patient and his/her carers.

From the second, "person as team" metaphor we thought that we could incorporate:

Making more knowledge available.

We also thought that, with radical changes in terms and conditions of employment, it might be possible to go some way towards increasing the availability of the individual without requiring the re-development of convents and monasteries as the main institutions of health care delivery.

In exploring the metaphors, we recognised that some form of team working would be necessary to address issues of physical effort and transcendence and to address practical issues such as holidays and absence.

Towards the end of the day, we started to think about examples of practice in which some of the aspects of the new model might already be embodied. The example that seemed closest to the model was that of the independent midwife, particularly in terms of changing working practices to provide continuity of care through a single individual.

By the end of the day, we believed that there was some merit in further exploring the new model that we characterised as "*a different kind of practitioner working in a different kind of team*". We coined the terms "transdisciplinary practitioner" and "transdisciplinary practice" to describe the model which we were investigating.

We had also come to the conclusion that simply trying to improve the functioning of the existing multidisciplinary team model would be unlikely to bridge the gap between the aspirations and the experiences of patients, although we did, of course, identify ways in which existing team processes could be made more efficient and more effective.

Developing The Model Through A Series Of Thought Experiments.

At the end of the "re-imagining" day, the team members had agreed that we wished to meet together again to see if we could take the transdisciplinary practice model further. Our view was that it had sufficient merit to justify a further investment of time and effort.

The concept of the transdisciplinary practitioner is a simple and powerful vision – an individual who has the skills and knowledge to meet all or nearly all of your health and social care needs. My belief was that without significant further development this vision could be no more than an interesting idea or possibly another piece of rhetoric like "holistic care" or "patient-centred care" or "a first class service".

I discussed my concerns with our project facilitator who pointed me towards some of the work that had been done in other areas such as computer system development involving the concept of rich pictures. He also explained how he had used the approach in his own organisation development work within the NHS.

My own study of the literature around visualisation and rich pictures (see for example) Lippitt's "Visualising Change" (Lippit 1973) suggested that this might be a fruitful approach. In my reading, I had also come across the concept of the "thought experiment" as an approach to developing and testing out ideas.

Bruner (Bruner 1960) suggested that there were three stages to visualisation of complex situations, *doing, picturing and symbolic* (cited in Lippitt 1973). In a way, we wished to reverse this process and to move from the abstract or rhetorical concept of transdisciplinary practice, through a richly detailed picture and thence into doing or action.

I believed that there were two reasons for moving from the top-level vision into a richly detailed picture:

> I needed to test the feasibility of the concept to build my own confidence and belief.
>
> I needed to be able to convince others both of its value and its feasibility.

In a way, the rich picture process could be considered as a "thought experiment" (see for example, Dennett. 1995) designed to test the hypothesis that transdisciplinary practice is feasible and would better meet the expressed needs and wishes of patients.

The thought experiments

Thought experiments are relatively inexpensive and very powerful ways of testing out and elaborating conceptual models. They rely upon the imaginative powers of the experimenters but place an emphasis on critical analytical thinking rather than on creative thinking.

In the thought experiment, we were engaging in a process that is analogous to trying to disprove a hypothesis, that is, we were trying to identify the reasons why the transdisciplinary practice concept might not work in practice. We wanted to elicit and tabulate the disadvantages and problematic aspects of the model.

The thought experiment also involves a *crafting* process. Taking the rough concept of transdisciplinary practice and elaborating and enriching it.

In this, we were guided by some of the approaches developed by the National Computing Centre in Manchester (NCC) in the 1970s in their attempts to find ways of developing computer systems which would better meet the needs of end users (see for example Mazijoglou and Scrivener Vol 7, pp. 157-175, 1998)

NCC developed the concept of the "rich picture" as a precursor to developing technical specifications for computer systems. In the rich picture methodology, system designers and system users work together to envisage exactly how the system to be developed needs to behave, step by step, from the perspective of the system user.

What we wanted to do was to think through in rich detail how transdisciplinary practice might work from the perspectives or viewpoints of:

Service user (patient or client).
Practitioner.
Employing organisation.

In adopting the service user perspective, we were trying to envisage in detail how transdisciplinary practice might be experienced by a service user (a patient/client).

In adopting the practitioner perspective, we were seeking to understand what a "day in the life" of a transdisciplinary practitioner might be like. We were trying to address issues such as what would be reasonable caseloads, how the practitioner might organise his or her work and not least, how attractive and rewarding the role might be.

Examining the model from the perspective of employing organisations was important in getting a clearer understanding of the policy and human resource management implications of the model. We had realised, for example, that for the transdisciplinary practitioner to be effective, he or she would need to have the authority necessary to mobilise resources from a number of organisations, agencies and professional groups.

Who was involved?

The people who took part in the original *imagining* workshop were involved in the thought experiment. We also decided that it would be helpful to have the same facilitator. For reasons that are discussed in my reflections on the project, we did not engage service users or carers in the thought experiment. Although I think this was a weakness in the design of the process, our work was firmly grounded in the patient stories and we made constant reference to the stories throughout the thought experiments.

The process

We had originally envisaged the thought experiment as a single one-day event. As it turned out, four sessions were needed to reach a point at which we felt we had tested and crafted the concept as far as we could through the thought experiment methodology. Each session had a particular focus as shown in the table below:

Table 4.3 Thought Experiments

Session	Focus
One	Talking through patient journeys.
Two	Acting out patient journeys.
Three	Experimenting with transferring competences across professional boundaries.
Four	Addressing organisational issues such as team organisation and clinical supervision.

The key steps in the first thought experiment process were as follows:

> I gave a brief account of the circumstances of a patient with whom I was currently working. The patient had complex longterm needs and was receiving care from a variety of agencies and from a multidisciplinary community-based neurological rehabilitation team.
>
> Members of the group asked whatever clarifying questions about the patient which they thought necessary.
>
> We then stepped through each encounter that we thought the patient might have with a transdisciplinary practitioner. To illustrate the process, Table 4.4 below summarises the encounters that we envisaged for the case study presented by me.

Table 4.4

Imagined encounters with a transdisciplinary practitioner

Establishing contact and arranging assessment visit.
Assessment visit.
Discussing and agreeing the care plan.
Delivering hands on care.
Overseeing aids and adaptations.
Review visit.

At each stage we paused to discuss:

How the encounter might be.
What problems and issues it might present for the transdisciplinary practitioner.
What problems and issues it might present for a service based on transdisciplinary practice.

During this part of the thought experiment, we tried only to capture the issues that were being elicited rather than to suggest how to address those issues.

An important aspect of the process was teasing out the different perceptions or mental models with which each member of the group had left the previous workshop. It revealed that although we had often used the same words and, therefore, appeared to have reached consensus, there were important differences of meaning and image concealed behind the shared language.

By the end of this part of the process, which took all day, we had generated large quantities of flip chart containing the issues which would need to be satisfactorily resolved if transdisciplinary practice were to be developed into a practical model for use in the NHS and its partner agencies. We were able to do a certain amount of clustering of issues and to develop an agenda for further thinking. The issues, after clustering, are summarised in Table 4.4 below

Table 4.5

Clustered issues emerging from imagined transdisciplinary encounters

Time required for a transdisciplinary assessment.
Viable case loads for assessment and care management.
Training in a wider range of assessment skills.
Access to specialist tools for assessment including licensing to use instruments.
Making appointments.
Attitudes towards patient.
Involvement of carers and other family members.
Access to medical notes
Assurances of confidentiality.
Knowing limits of own confidence and competence.
Telephone consultation with specialist practitioners.
Arranging a more specialist assessment
Requesting tests and investigations
Recording the assessment – use of laptops.
Copy of assessment and care plan for patient and carers.
Format of assessment and care plan
Authority to commit resources
Possible role for transdisciplinary assistant.
Nature of care management.
Educational requirements for a transdisciplinary practitioner.
Constraints on scope of practice.
Patient preferences – gender and ethnicity.

We had three further thought experiment workshops to address some of the issues which had been elicited from the first thought experiment workshop.

At the second workshop, we decided that, rather than simply *talking* through the process of transdisciplinary practice, we would walk it through as an enacted role-play. We also used this role-play approach to test out how the model might work with other types of patients and other health care delivery settings.

The process of enactment added further richness to the concept, brought about further clarification and sharing of our individual images and interpretations and, inevitably, threw up further problems which needed to be solved.

At the third workshop, we decided to explore in depth one of the core issues that had been elicited by our earlier work, the feasibility of transferring professional competences across professional boundaries.

A number of members of the team agreed to prepare clinical teaching sessions for the other team members to test the feasibility and difficulty of competence transfer.

These simulated clinical teaching sessions were invaluable in helping us to identify what would be a useful and realistic scope of practice for prospective transdisciplinary practitioners.

At our final thought experiment workshop, we focussed on the organisational setting in which transdisciplinary practice might occur. This workshop led us to address issues such as clinical supervision, remuneration, care management and team composition.

The outcomes

In total, the thought experiment phase of the project took ten days with most time being devoted to testing the transfer of competences through the simulated clinical teaching sessions.

By the end of the thought experiment phase we had:

- Reached the conclusion that transdisciplinary practice could be an effective model of practice offering real benefits to patients and their carers, to practitioners and to health and social care organisations.

- Developed a philosophy and set of principles that would characterise transdisciplinary practice.

- Identified a number of problems that would need to be solved in order to implement transdisciplinary practice effectively.

- Decided that none of the problems identified were insuperable.

We had reached the conclusion that transdisciplinary practice could be an effective model of care by first of all *talking* through each of the experiences of the patients who had provided stories as they might be in a transdisciplinary practice model and then by *walking* through each of these journeys.

In particular we could see that transdisciplinary practice could deliver:

> "Someone who really knows me."

> "Not having to repeat information."

Or, in our terms, continuity of care and holistic care.

Our ability to deliver other patient aspirations depended not on the mechanics of a transdisciplinary practice model but on the values and philosophy underpinning that practice. For example, a transdisciplinary practitioner might still:

> "Treat someone as an illness not a person"

and might not enable the patient to:

> "Have things at the right time"

> "Fit around the rest of my life"

> "Have his/her own views respected"

Delivering on these aspirations implied much about the selection and development of transdisciplinary practitioners, about how they were organised into transdisciplinary practice teams and about how they were given the authority to undertake case management.

The problems that we identified included:

- How to assure safe and competent practice.
- How to provide clinical supervision and continuing professional development.
- How to maximise continuity of care whilst recognising that an individual practitioner could not guarantee to be available at all times.
- How to decide what changes to scope of practice would offer the greatest patient benefit for the least investment in re-training.
- How to decide what mix of skills and experience would be optimal for particular client groups.
- How to define client groups most usefully.

In parallel with the thought experiments, we also investigated the statutory limitations that would impinge on the concept of transdisciplinary practice. We were surprised to discover that there were relatively few statutory barriers to the model of practice which we had in mind although very many which might best be described as "custom and practice".

Examples of statutory barriers included prescribing and certifying benefits.

Examples of custom and practice included referral rights and protocols and acceptance of assessments from particular professionals and/or particular professionals within particular agencies.

The outcomes from our thought experiment work are summarised in the description of the philosophy of transdisciplinary practice that follows. Key points that are worth emphasising are:

- Transdisciplinary practice is only meaningful and feasible in relation to a particular group of patients who have similar health care needs and who, therefore, require access to a particular set of clinical competences.

- Transdisciplinary practice requires higher order expertise than that offered by a practitioner working within a single discipline.

- There is a point at which it is neither useful nor feasible to transfer competences across professional boundaries – in designing transdisciplinary practice in relation to a particular client group it is of critical importance to define the *optimum* scope of practice rather than the maximum scope of practice.

- Transdisciplinary practice is a team-based concept rather than a model of individual practice. This is necessary both to meet continuing care needs of patients and to enable access to more expert competence than can feasibly be embodies on the person of the transdisciplinary practitioner.

The statement of philosophy of transdisciplinary practice was developed to capture and summarise the outcomes from the second cycle of enquiry and thus to map the work which would need to be undertaken in the third cycle.

PHILOSOPHY OF TRANSDISCIPLINARY PRACTICE

The aim of transdisciplinary practice

To enable clients and their carers to experience care which meets their needs in a fully integrated way.

Transdisciplinary practitioners

- Transdisciplinary practitioners will already be expert within their own professional discipline and with regard to the client group with whom they practice.

- Transdisciplinary practitioners will extend their expertise by acquiring additional skills, knowledge and perspectives from expert practitioners in other professional disciplines.

- Transdisciplinary practitioners will have deep insight into the practices and underpinning philosophies of colleagues in other disciplines.

- Transdisciplinary practitioners will be allowed to exercise an extended scope of practice including clinical practices that have traditionally been restricted to other professional disciplines.

- Transdisciplinary practitioners will have access to consultant opinion, clinical supervision and expert intervention from colleagues in other professional disciplines.

    - Transdisciplinary practitioners will be expert in care management for the client group with whom they are qualified to work.

- Transdisciplinary practitioners will be expert in providing consultant opinion, clinical supervision and continuing professional development for transdisciplinary practitioners from other professional disciplines.

- Transdisciplinary practitioners can be supported by assistants who are not professionally qualified but who have been trained to work within a transdisciplinary setting under supervision.

- The extra value and competence of transdisciplinary practitioners should be recognised in their pay and grading.

The rationale for transdisciplinary practice

Transdisciplinary practice moves beyond multi-disciplinary working. There is recognition that many people who access health and social services have needs that cannot be met fully by practitioners who have only trained in a single clinical discipline.

Historically, we have attempted to address this problem by creating multidisciplinary teams whose collective expertise can meet the needs of the client and his or her carers.

Whilst in many respects the multidisciplinary approach has been helpful to clients and their carers, there are several disadvantages:-

- Clients *can* experience care as fragmented with little co-ordination or information sharing between different professionals.

- Clients *can* find the multi-disciplinary team overwhelming and invasive. They tell stories of intimidating case conferences and of too many different people being involved in their lives.

- Individual professionals, whilst claiming to provide holistic care, still inevitably tend to see and engage with the client through the filter of their own professional training and socialisation.

- The system of multi-disciplinary working can be very costly. At its extreme it can represent a Taylorist approach to service delivery with each member of the "production line" only being competent in a narrow specialised area of work.

The alternative is ***not*** generic working, as the term is usually applied within the NHS with associated connotations of "dumbing down" and undermining the status and claim to expertise of qualified professionals. Clients with complex needs require ***more*** expertise rather than less. Transdisciplinary practice may be more akin to the notion of advanced genericism proposed by Eraut (1994) as exemplified in the role of the General Practitioner and in certain Nurse Practitioner roles.

The team recognise that the body of specialist knowledge is too great to allow people to be trained across the *full* body of knowledge of more than one clinical discipline. Indeed the rate of growth of knowledge is tending to lead to increasing specialisation.

What the team believe is that it is possible to transfer skills, knowledge and perspectives across traditional professional boundaries within the framework of a particular client group.

Thus whilst it is neither useful nor practicable to expect a nurse to have the full range of skills and knowledge of a physiotherapist, it may be useful and practicable for a nurse working with clients with a neurological disability to acquire much of the body of knowledge of physiotherapy which is relevant to the needs of that client group. Similarly, whilst it is neither useful nor practicable for a Speech and Language Therapist to acquire the full body of knowledge of a Clinical Psychologist, it may well be helpful and useful for him or her to acquire much of the body of knowledge of clinical psychology in relation to children with learning difficulties.

The practicality of transferring professional expertise across traditional boundaries can be enhanced if we ensure that:-

- Practitioners have deep insight into and respect for the practices and underpinning philosophies of other disciplines.

- Practitioners can easily access advice, support and interventions from colleagues who do have the full body of knowledge of their own discipline.

- Practitioners have access to clinical supervision and continuing professional development from colleagues in other disciplines.

- Practitioners work within a clear framework of protocols and guidelines that ensure safe and effective practice.

Reflections On The Re-Imagining Process

The team said how much they found the re-imagining process enormously energising. All of us had had experience of "brainstorming" but this process seemed to be more focussed and more productive.

The "metaphor" approach seemed particularly useful both in structuring our thinking and in enriching it. Working at the metaphorical level also seemed to "give us permission" to think about how things *might be*, without being distracted too much by the practical difficulties.

Although the general shape of each of the days was as described above, the process was more lightly structured and more usefully chaotic than this narrative re-construction suggests. Finding the right balance between holding direction whilst enabling exploration is of critical importance in making this sort of process work well.

Although I have concentrated on three particular metaphors, other sub-metaphors and imaginings also came into play. We had, for example, an extended discussion centred around the image of the conductor of an orchestra and what that might tell us about care management, about team leadership and about team processes.

In my view, the background experiences of the members of the team were important in making the process as productive as it was. For example, one member of the team (a paediatric diabetic nurse specialist) did practice in an unconventional way by giving parents her home telephone number and mobile number and inviting them to call her any time they needed to. This was an "unofficial" practice on her part but her experience of providing open-ended access was that it was highly valued by parents and not unduly burdensome for her.

Other members of the team reported incidents that they had come across in their practice where they had "wished they had the skills to do something about it on the spot".

I believe that being able to start the process with some hard data (from the Patient Stories) help to give shape, focus and a sense of purposefulness to the imagining process.

In conclusion, I found the process helpful in helping to surface and then to challenge existing mental models and in developing possible alternative ways of thinking about the world. It seems a useful way of giving people permission and process to "think the unthinkable".

Reflections On The Thought Experiments

The collection and analysis of patient stories suggested that our current model of practice was failing to meet their needs and aspirations. The act of re-imagining suggested a possible model of practice organised around the needs and aspirations of patients. The thought experiment allowed us to take this very rough possibility, to hold it up to critical scrutiny and to craft and elaborate the vague shadowy concept into something approaching a workable idea. The thought experiments, or more accurately, series of thought experiments, were pivotal in shaping the future direction and scope of this enquiry.

The particular benefits which this activity added to the overall enquiry were:

- Ensuring that, within the action research group, we really did have a shared picture of what we meant by transdisciplinary practice. It forced out into the open differences of meaning and differences of interpretation and enabled us to deal with such differences constructively and effectively.

- Enabling us to anticipate many of the practical implementation issues that we were to confront and to prepare appropriate solutions.

- Clarifying how the transdisciplinary practice model might work and, equally important, identifying its constraints and limitations.

- Helping us to scope the rest of the enquiry accurately.

- Highlighting implications of the basic model such as:
    - The educational implications.
    - The organisational settings which would enable transdisciplinary practice
    - The human resource implications of introducing such a model of practice.
    - Issues around clinical supervision, care management and referral within the practice team.

Although the primary purpose of the thought experiment activity was to identify problems with the model and to evaluate its downsides, the thought experiment also enabled us to identify additional benefits inherent in the model. In particular, we came to see that the development of transdisciplinary practitioner posts might help to address problems of retention of clinical staff within the NHS by providing a coherent development pathway for experienced clinicians who wished to remain in clinical practice rather than moving into managerial positions.

The thought experiments also proved useful in reinforcing the commitment of the action research group to the enquiry. We had spent a day coming up with the basic idea. Spending four days subjecting it to rigorous scrutiny built our collective confidence.

A possible outcome from the thought experiments would have been to reject the concept as impracticable or as being too difficult or costly in relation to the likely benefits. As it happened, this was not the conclusion that we reached but, had we done so, we would still have felt that our time had been well spent.

I believe that there are important lessons to be learned about innovation in the NHS from this part of the overall research enterprise. In my experience, ideas are often promulgated within the NHS that has clearly not been subjected to any rigorous scrutiny. Practitioners and NHS managers are then faced with the challenge of trying to put into practice initiatives that have not been well thought through. As a consequence some ideas that are potentially of great value to patients and carers fail in practice either at a pilot study phase or during full implementation.

The value of thought experiments and rich picture methodologies in forcing out shared meaning and in highlighting differences of interpretation has struck me as being of particular importance. In my experience, initiatives can fail because there is not shared understanding of the desired outcome, the implementation process or of the implications of the initiative. These reflections are elaborated in my reflections on the whole research enterprise later in this thesis.

An as yet unanswered question is the extent to which the nature and value of the thought experiments would have been altered by the inclusion of patients and carers in the thought experiment process. Instinctively, it seems that this would have been a useful and valuable thing to do. On the other hand, there was already so much variety and complexity within the research group that we might not have been able to manage additional perspectives.

Moving to a third cycle of enquiry

In the second cycle of enquiry, we had sought to understand why the reported experiences of the patients in the study were divergent both from their expressed needs and aspirations and from the espoused values and beliefs of the NHS.

Through the use of metaphor, we had explored existing models of practice and we had envisaged an alternative model of practice that might better meet the needs and aspirations of patients with complex needs. Through a series of thought experiments, we sought to build a rich picture of the alternative model of practice and to tease out the practical issues that would have to be addressed if such a model were to be implemented.

We had convinced ourselves, the research team, that the new model was both practical and desirable although it would challenge a number of traditional ways of thinking and doing things within the NHS and its constituent professions. We were, however, acutely aware of the dangers of "group think" setting in and of our critical faculties being clouded by our enthusiasm for "our big idea". In designing the third cycle of enquiry, we wished to expose our thinking to critical scrutiny from a wider circle of our clinical peers, from senior clinical and managerial leaders within the NHS and from patients who had not been involved in the first cycle of enquiry.

CHAPTER 5 THE THIRD CYCLE

TESTING THE MODEL.

In the preceding chapter, a process of re-imagining was described and a series of thought experiments through which the concept of transdisciplinary practice was developed, critically evaluated, refined and elaborated. By this stage, the research team had developed what we considered to be a relatively robust concept and we had developed potential solutions to a number of the problems that had been identified through the series of thought experiments.

Our next cycle of enquiry would involve testing our ideas with practitioners and with patients and their carers none of whom had been involved in our work to date. If the thought experiments are analogous to laboratory experiments designed to test hypotheses, this third cycle emulates disseminating and peer review.

I designed two processes for sharing and testing our ideas. The first was a working conference for practitioners and clinical and managerial leaders. The second consisted of a series of interviews and focus groups with a sample (n=7) of staff and a sample (n=7) of patients in a community hospital which provided care for patients with complex long-term needs.

The Working Conference

We were fortunate to gain support from the Director of Education and Training for the local Region of the NHS and from the Director of Nursing and Organisation Development for the Region. They considered that the work on transdisciplinary practice was convergent with much of their own thinking on the longer-term strategic direction which workforce development within the NHS would have to take. Their support consisted of agreeing to fund the conference and, more importantly, agreeing to speak at it.

The conference was attended by about 80 senior practitioners and clinical and managerial leaders from a range of clinical disciplines drawn from NHS organisations across the Region.

At the conference, we shared the work that we had been doing and presented the transdisciplinary practice model (see diagram 1.1) positioned very much as “work in progress”.

We then moved into a number of small group workshop sessions to enable participants to think through in detail some of the propositions that we had been putting forward.

Feedback from participants

On the whole, the concept was well received. Participants could see the potential benefits to patients and their carers of practitioners who would have a scope of practice aligned to the needs of particular groups of patients. Many could also see the potential attractions of the model in providing an additional career development step for clinical practitioners.

There were many questions on points of detail. The value of the thought experiment process was again demonstrated as there were few if any questions which had not arisen during our own discussions and for which we had developed potential solutions.

In a minority of participants, we evoked an unexpectedly hostile reaction. On further discussion, it became apparent that they were interpreting transdisciplinary practice as "generic working" involving devaluing of specialist professional skills. This had arisen as an issue in our own discussions and we thought that we had been particularly careful in differentiating transdisciplinary practice from generic working. Clearly, we had not been successful from the perspective of a number of participants.

Participants who heard the message "generic working" were opposed "on principle" to what we were proposing and were, therefore, uninterested in any of the detailed discussions which followed.

One participant claimed to have already implemented transdisciplinary practice. On closer examination, it transpired that this consisted of a degree of multi-skilling at the Therapy Assistant/Health Care Assistant level.

The main issues and concerns that other participants raised clustered into three over-arching categories:

> Access to funding for training and for staff replacement costs.
>
> The extent to which transdisciplinary practice would be an attractive career option.
>
> Difficulties that practitioners might encounter in working across organisational boundaries.

These were all valid concerns. We recognised that transdisciplinary practice would not be an attractive career move for *all* practitioners but would be very attractive for some. Difficulties in working across organisational boundaries are not particularly associated with transdisciplinary practice, but the successful implementation of transdisciplinary practice would certainly require the problem to be addressed and solved whereas current models of practice allow it to be avoided.

The discussion about releasing staff for training was particularly useful and informed our thinking in the development of the educational process which is described in the next chapter.

Reflections on the conference

On the whole, the conference was a positive experience. The model presented had stood up well to scrutiny from our peers. We had anticipated many of the problems and issues that emerged from their discussions and the solutions that we were proposing were seen as satisfactory.

It was also reassuring to find that the direction of our own thinking was convergent with the wider workforce development strategic thinking that was being undertaken at Regional Office.

We were surprised by the depth of feeling around generic working and how powerful this was in blocking any further thought or discussion. From this I learned that initiatives which fail or which are seen as having had intended or unintentional adverse consequences leave a footprint or shadow behind which can inhibit the consideration of ideas which evoke memories of the failed initiative. We tend to think of organisational learning as a “good thing”. Organisational learning and organisational memory can, as in this case, sometimes be counter-productive.

We were disappointed by the outcomes to our follow-up activity. The overall response had been warm and enthusiastic and we had expected to be able to move into a piloting phase, after almost four years on the project. The reasons for failing to secure pilot sites are explored fully in my overall reflections and conclusions. Here they can be summarised as falling into two categories:

> Excellent idea – but this is the wrong time for us.
>
> Excellent ideas – but too difficult to implement.

The slides and handouts used during the conference are included in Appendix D.

The Community Hospital

Originally, it was had hoped to test out some of the principles of transdisciplinary practice experimentally through a pilot study .I decided however, that it would not be possible to prepare practitioners sufficiently in the time available. I considered that it would be unethical to expose patients to practitioners who had not been fully trained. I decided, therefore, to use a combination of focus groups using particular patient cases with staff (Morgan 1988) and individual interviews with patients to further test and elucidate the transdisciplinary practice model. This particular study was funded by the local Consortium non - medical education and training monies and the full report of the study is attached as Appendix C.

The hospital concerned is a community rehabilitation facility in the local area. It provides care both on an in-patient and day care basis and specialises in long-term neurological disabilities.

The focus groups

The focus groups with staff were designed to replicate an element of the work that had been undertaken by the research team in cycle two. In cycle two, the research team had "walked through" a number of patient journeys. The staff focus groups would carry out the same process for cases with which they were currently involved but would focus particularly on how the patient journey would be if care were provided through the transdisciplinary practice model. I believed that this process would be helpful in securing a critical evaluation of the model by practitioners who had not been involved in its development and in identifying problems and issues that had not been identified by the research team during cycle two. After the "walk through" of the cases and a general discussion of the issues emerging, I used the nominal group technique (Delbecq, Andrew, Van de Ven, Andrew , Gustafson, and David 1975) to clarify, cluster and prioritise the issues which emerged from the discussions.

As preparation, I arranged a series of seminars for hospital staff to explain the concept of transdisciplinary practice and the nature of this particular study. The staff members involved in the focus group were:

- 1 Consultant Medical Practitioner
- 1 Senior Nurse Manager ('I' grade)
- 2 Staff Nurses ('E' grades)
- 1 Physiotherapist- Therapy Coordinator (Superintendent 1 grade)
- 1 Occupational Therapist (Senior 1 grade)
- 1 Speech and Language Therapist (Senior 1 grade)

After clarification of the transdisciplinary model, members of the focus group were invited to present a number (n=4) of cases of a patient with whom they were currently working. The group then "walked through" this patient journey to explore how transdisciplinary practice might have been applicable and beneficial in the cases presented and to tease out some of the practical issues involved in implementing the model in practice.

The four case studies presented were three cases of stroke, each with different patterns of impairment and one case of poorly controlled Parkinson's disease (PD). These cases were selected by the focus group members and myself as having the characteristics of complex long-term needs which transdisciplinary practice is designed to address and currently having those needs addressed through a multi-disciplinary team model.

After an initial presentation of each case, the practitioners involved in care "stepped through" the patient journey, identifying how care is delivered in the current model of practice and how it might be delivered within a transdisciplinary practice model.

Case Descriptions:

Box 5.1

Patient case 1 Mrs H – History and résumé of care:

Mrs H was an eighty two year old lady who suffered a stroke on 26/01/99. She was admitted to the local District General Hospital (DGH), transferred to the Community Hospital (CH) on 10/02/99 and discharged to a nursing home (NH) on 04/05/00. She continues to attend the CH as an outpatient. She previously lived alone and was independent in all activities of daily living. She has close family, was previously very outgoing and a keen and active gardener.
Her stroke left her with the following residual impairments:

- Right hemiplegia
- Expressive and receptive dysphasia
- Memory problems
- Incontinence

Potential areas for skills transference:

- Skills related to the management of incontinence from the Nurse to the Speech and Language Therapist
- Skills related to the establishment of alternative communication strategies from the Speech and language Therapist to the Nurse
- Skills related to mobility from the Physiotherapist to the Nurse
- Skills related to washing and dressing from the Occupational Therapist to the Nurse

Issues raised:

- Isolation and loneliness in relation to breaking away from the conventional multidisciplinary team and all that is good about that
- Nothing left to do for individual specialist
- The stage at which transdisciplinary practice occurs – some merit in maintaining traditional practice during acute phase of illness and then moving to transdisciplinary practice during the less acute, maintenance phase of the illness
- Which set of patients would benefit the most from this type of practice?

Box 5.2

Patient case 2 - Mr S – History and résumé of care:

Mr S is a ninety three year old man. He was transferred from the local DGH to the CH five days after admission following his stroke. He lived with his wife and was fiercely independent in all his activities of daily living. Prior to hospitalisation he was able to drive, walk, garden and manage all his affairs.
Following his stroke he was left with the following residual impairments:

- Right hemiplegia
- Aphagia and percutaneous endoscopic gastrostomy feeding tube (PEG)
- Dysphasia
- Depression
- Stress incontinence
- Constipation
- General lethargy, weakness and frailty

Potential areas for skills transference:

In this instance one person was thought able to provide most of the care required by Mr S through "extended roles". The key issue in this man's care was the need for one person to develop a strong link with him.

Issues raised:

A transdisciplinary practitioner was considered to have potential in this case since there was only one major difficulty to be addressed.

Box 5.3

Patient case 3 Mr SS – History and résumé of care:

Mr SS is a seventy three year old man who was admitted to the DGH on 29/06/98, he was transferred to the CH on 24/08/98, and discharged to his own home on 28/01/99. He lives with his wife and brother. Previously independent in all activities of daily living, he enjoyed driving and visiting friends and family.

Following his stroke he was left with residual disabilities related to:

- Left hemiplegia
- Dysphagia and PEG feeding
- Cognition and problem solving
- Emotional lability

Potential areas for skills transference:

The Speech and Language Therapist was the identified key worker in this man's care and the group identified that as certain skills were transferred this practitioner could have moved towards transdisciplinary practice.

- Skills related to seating, posture and transfer from the Physiotherapist and Occupational Therapist to the Speech and Language Therapist
- Skills related to chest physiotherapy from the Physiotherapist to the Speech and Language Therapist
- Skills related to PEG management from the Nurse to the Speech and Language Therapist

Issues raised:

- Inefficient dealings with social services regarding housing. This could have been enhanced if a single practitioner had been involved
- Discussion of plateau reached after each individual practitioner has "finished" their part in the rehabilitation process – would a transdisciplinary practitioner minimise deterioration during the period prior to discharge – or hasten discharge if they could move through to provide some care in the community

Box 5.4

Patient case 4 Mrs C – History and résumé of care:

Mrs C is a seventy five year old lady who was admitted to the DGH on 29/01/99 due to poorly controlled Parkinson's Disease and falls. She was transferred to the CH on 09/03/99.
Following admission she retained the following residual impairments:

- General stiffness
- Depression
- Moderate dysarthria

Potential areas for skills transference:

- Skills related to swallowing from the Speech and Language Therapist to all other members of the team
- Skills related to home adaptation from the Occupational Therapist to all other members of the team
- Skills related to the identification of depression from the Doctor, Psychologist, Nurse to all other members of the team

Issues raised:

- Complex situation linked to inability to provide the right package of care to Mrs C (and her Aunt who lived with her) Community focussed transdisciplinary practitioner may have been able to facilitate this.

Discussion of the staff focus groups

The benefits of transdisciplinary practice identified by the practitioners involved included:

- Continuity of therapy – in particular providing rehabilitative activity on a seven day rather than five day basis. Practitioners believed that this would reduce "slipping back" and would probably lead to better and faster outcomes.

- Continuity of relationship with fewer different practitioners being involved with each patient.

- Prompter responses to the needs of patients.

- Avoiding gaps in treatment and care that arose when there were vacancies or when particular staff were absent.

"Continuity of Care" (NCCSDO 2001, p 3) makes reference to the boundaries which get in the way of 'continuity across the secondary/primary care interface-concerning discharge from specialist to generalist care'

The practitioners identified the types of skill and knowledge transfer that would be appropriate in each case and agreed that these would be feasible through the educational process that we had outlined.

A point raised that I found of particular interest was the view that transdisciplinary practice would actually be *safer* than current practice in which practitioners were tempted to "have a go" in well-meaning attempts to address the needs of patients in the absence of the relevant professional.

The practitioners involved also believed that the implementation of transdisciplinary practice would help to create an overall rehabilitative environment rather than patients experiencing "care" with episodes of "rehabilitation".

The process and outcome is described fully in the report attached as Appendix C.

The three most important benefits identified by participants were:

- Better communication and co-operation between practitioners, the patient and the patient's family.
- Continuous rehabilitation.
- A person-centred service.

The most important barriers or concerns identified were:

- 'Jack of all trades' (loss of distinctive professional identity).
- Professional jealousy.
- Acceptance by patients.

Interviews with patients and staff

Seven patients consented to be interviewed. Consent was also obtained from the Consultant under whom they had been admitted and from other staff closely involved with their care.

The interviews closely followed the story-telling model used in the first cycle, in that patients were invited to tell their stories about their experiences of care and then to discuss how they would have preferred it to be. An important difference was that the interviewer probed for responses to a transdisciplinary model of practice at appropriate points in the narrative about preferred experiences.

Where possible, I also interviewed the key staff involved with care delivery for each of the patients interviewed to get their perspective on the care provided and the problems they encountered in delivering a satisfactory patient experience.

The process and outcomes are described more fully in the report attached as Appendix C.

Important findings included:

From the patient's perspective

Lack of information about diagnosis.
Not being given enough knowledge about medication.
Time delays in social services "producing the goods".
Too boring at weekends – not enough therapy.
Staff can be patronising.
Too many assessments, too much duplication and repetition.

From the staff perspective

Not enough trust between professions to accept each other's assessments.
Too much time delay by all segments of the service not "getting their act together".
Greater emphasis needed on one patient: one practitioner leading to better continuity of care and service provision.

Reflections on the community hospital-based study

As indicated earlier, I would really have liked to try out the transdisciplinary model in practice in a real clinical setting. I believe, however, that testing the model by walking through real and immediate case studies with practitioners who were involved with the cases under discussion and who had not been involved in the development of the transdisciplinary concept added extra value and provided some important insights. It is also relevant to note at this point, that there was no need to seek 'Ethics Committee' approval, as at this stage it was approved as 'service development', the Clinical Effectiveness Group within the Trust were contacted, and their approval sought and approved.

The concerns expressed by practitioners were not new. All of these had been expressed during the Regional Conference (see above). It is interesting to note though that the practitioners involved concluded that the benefits to patients greatly outweighed the concerns of professionals.

The discussions with patients suggested that many of their concerns would be addressed through the implementation of transdisciplinary practice. However, some concerns (being patronised, poor information) did not relate directly to transdisciplinary practice.

Planning the fourth cycle

The third cycle of enquiry enabled me to test the transdisciplinary model with a wider community of patients, clinicians and clinical and managerial leaders. This scrutiny process raised a number of issues that had not been adequately addressed in the second cycle.

In the fourth cycle of enquiry that is described in the following chapter, I seek to address these issues. In particular the fourth cycle addresses:

> How might transdisciplinary practice be organised in a way that combines the advantages of transdisciplinary practice and multi-disciplinary team working?
>
> How would issues such as remuneration, clinical governance, professional accountability and evidence-based practice be addressed?
>
> How might transdisciplinary practitioners be prepared for practice?

In addressing the question of preparation for practice, I worked closely with colleagues in a local University to develop a possible educational model.

CHAPTER 6 THE FOURTH CYCLE

ORGANISATIONAL IMPLICATIONS OF THE MODEL

In the UK health and social care system, practitioners do not, as a rule, practice in isolation. They contribute to an overall system of care and are typically employed by an organisation in the statutory, voluntary or private sector.

In developing the model of transdisciplinary practice, I attempted to work through how the model might work in an organisational setting and what the implications for organisational behaviour might be.

In an earlier chapter, it was proposed that transdisciplinary practice is a team activity. There are several reasons for this:

> If the patient is to experience continuity of care and a service that is there when he or she needs it, the service cannot be based on a single individual. One of the advantages of team working is that the team is still present when individuals are on holiday or off sick or when individuals move on in their careers. Teams can offer a round the clock presence and can have an existence which transcends the availability of a particular individual.
>
> One of the problems that we were seeking to address was to minimise the extent to which patients had to be referred to another agency or another service. Although I believe it is possible to develop a wide range of competences in the transdisciplinary practitioner, I recognise that it is not feasible to incorporate all of the expertise of a unidisciplinary practitioner. A model of organisation which enables a degree of access to more expert opinion within the team is, therefore, highly desirable.

> For this reason, I advocate the existence of a transdisciplinary team which contains within it transdisciplinary practitioners from a range of clinical backgrounds so that specialists can be called in from within the team.
>
> A significant amount of care can be delivered through support workers who are appropriately trained to work under the supervision of a fully qualified and registered practitioner. I therefore, envisage a team consisting of transdisciplinary practitioners and transdisciplinary assistants. The optimum mix would depend on the nature and size of the patient group for whom the service is being designed.
>
> I believe that clinical supervision is an important process in maintaining and developing the quality of clinical practice and the continuing professional development of practitioners. The design of a team which contains within it transdisciplinary practitioners from a range of professional backgrounds opens up the possibility of providing peer to peer supervision models with a particular emphasis on helping the practitioner to develop the skills which are "new" to him or her.

Given the maturity of the people whom I would expect to become transdisciplinary practitioners, I would expect a transdisciplinary team to be largely self-managing (Kimball Fisher 2000) although it would also be worth investigating the practice manager or chambers manager model of organisation.

In developing the model, I came up with a number of possible organisational arrangements for transdisciplinary teams: (see diagram 6.1)

Model 1 – The Transdisciplinary Team

This model would be appropriate for a large client group and a relatively large catchment population where the majority of clients currently require interventions from several different types of professional.

Examples include:

- Neurological and physical disability including stroke.
- Adult mental health.
- Older people.
- People with learning difficulties/disabilities.

In this model, the team would:

- Contain sufficient transdisciplinary practitioners to manage the caseload in terms of need and numbers.
- Contain a sufficiently wide range of original disciplines to enable internal consultancy and transdisciplinary supervision.
- Contain an appropriate mix of transdisciplinary practitioners and transdisciplinary assistants to deliver high quality care at the lowest cost per case.
- Aim to meet (say) 90% of client needs from within their own resources.
- Call in rarely used resources as necessary from outside the team.

- Use specialist external resources such as imaging and pathology as necessary.
- Operate clear guidelines for referral to and discharge from the team.

Model 2 – The Virtual Team.

Model 2 would be appropriate under the following circumstances:-

- Most clients have needs that require clinical competences from a restricted range of traditional disciplines.
- A few clients require input from disciplines outside this restricted range.

An example of this type of team would be a Child and Adolescent Mental Health Team working in primary care to address level one and two health care needs. It would access specialist consultancy and supervision from a team focussed on levels three and four and would refer clients on to them as necessary.

In this model, the team would:-

- Contain sufficient transdisciplinary practitioners to manage the caseload in terms of need and numbers.
- Contain a smaller range of original disciplines to enable frequently required internal consultancy and transdisciplinary supervision.
- Draw upon people outside the team for less frequently used consultancy and transdisciplinary supervision.
- Contain an appropriate mix of transdisciplinary practitioners and transdisciplinary assistants to deliver high quality care at the lowest cost per case.
- Aim to meet (say) 90% of client needs from within their own resources.

- Call in rarely used resources as necessary from outside the team.

- Use specialist external resources such as imaging and pathology as necessary.

- Operate clear guidelines for referral to and discharge from the team.

Model 3 – The Hybrid Team

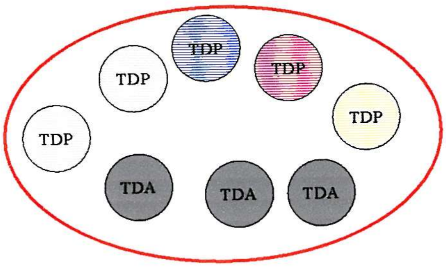
This model would be appropriate where it was not possible to provide all forms of consultancy and clinical supervision from within the transdisciplinary team because transdisciplinary practitioners with the appropriate professional backgrounds are not available.

In this model, the transdisciplinary team would access specialist consultation and supervision from other teams or individuals within the health and social service system.

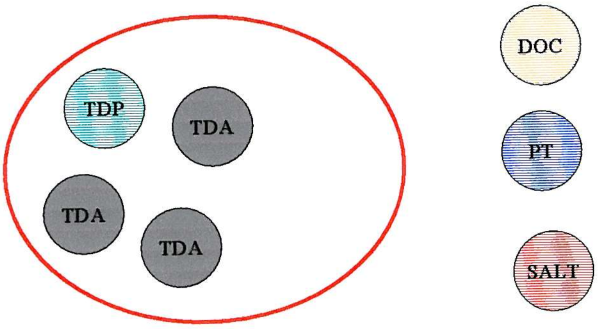
Another variation of the hybrid model would be where two transdisciplinary teams exist in close proximity and team one accesses the resources of team two for specialist consultation and supervision.

Diagram 6.1 Possible team arrangements

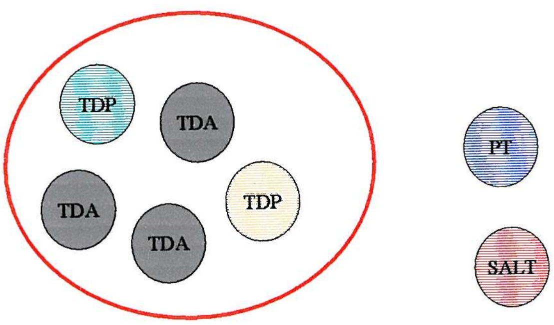
Transdisciplinary Team



Virtual Transdisciplinary Team



Hybrid Transdisciplinary Team



Impact of the modernisation agenda

During the course of this study, the NHS Plan (2000) was published followed by a number of other policy statements and initiatives which are described collectively as "the modernisation agenda".

Most recently a policy document "Shifting the Balance of Power within the NHS – Securing Delivery" (2001) has been published. The central thrust of this document is to advocate the empowerment of front-line practitioners and to develop a more patient-centred focus. It is perhaps worth quoting two paragraphs from "Shifting the Balance of Power".

"The challenge now is to reform the way we deliver healthcare. Delivering the NHS Plan will involve new ways of working across the service. There needs to be a more equal relationship between the NHS and patients. Patients must be better informed and more in control of their care. New approaches to the delivery of care will be needed to speed up treatment and increase responsiveness. And new approaches to tackle the traditional demarcations between different professional groups and services will pave the way for innovative care pathways which better meet patients' needs." (Para 9)

"This challenge cannot be met from Whitehall. The improvements to services can only be delivered by frontline staff working with patients and the public – reform must come from within the NHS. The reforms will be achieved through decentralisation and empowerment." (Para 10).

When this study was started, organisations within the NHS were relatively hermetically sealed from each other and professional boundaries were also impermeable. Recent developments such as Cancer Networks (Cancer Plan 2000), disease-based collaboratives (NHS Collaboratives in the Eastern Region, 2002) and nurse prescribing (Medicinal Procedure: Prescriptions by Nurses Act, 1992) start to create a climate in which a concept such as transdisciplinary practice may seem less unusual.

Developments such as NHS Direct (1998) and Walk-in Centres (1999) have also played an important part in starting to change the organisational context within which transdisciplinary practice might be implemented.

It is important to examine three specific organisational issues that were raised during our conversations with other practitioners and service leaders. These are remuneration, clinical governance and accountability and evidence-based practice.

Remuneration

The proposed transdisciplinary practitioner is an entirely new kind of practitioner. He or she would have extended competences, extended scope of practice and extended personal responsibility. We would expect to see this reflected in the remuneration and grading of such practitioners.

My recommendation would be that remuneration should be on a par with Nurse Consultants/Therapy Consultants. Preliminary calculations suggest that the additional "productivity" which would emerge from the transdisciplinary model of practice would fund this level of remuneration and still deliver significant gains in cost-effectiveness to the employing organisation.

This suggested level of remuneration is likely to be attractive to practitioners from nursing, therapy and social work backgrounds. It may not be sufficient to attract practitioners from relatively highly paid areas such as clinical psychology and medicine.

Clinical Governance and accountability

I do not see this as a particularly problematic area. All transdisciplinary practitioners would be accustomed to being held accountable for their own practice and this would continue to be the case in the transdisciplinary model.

Holistic clinical governance would actually be facilitated by the transdisciplinary model.

Protocols and evidence-based practice

Protocols have been used extensively as a mechanism for enabling changes to scope of practice in a manner that maintains patient safety and reduces the perceived level of clinical risk involved in changing how we do things. Computer-assisted protocols are used extensively by NHS Direct and by Walk-in Centres and protocols and guidelines have been used successfully to enable staff such as Clinical Nurse Specialists to extend the scope of their practice.

I would see an important place for the development and use of evidence-based protocols and guidelines within a transdisciplinary setting. The existence of good protocols and guidelines should assist practitioners in extending the scope of their practice.

Preparing For Practice – A Potential Educational Initiative

One of the key principles of transdisciplinary practice (see statement of philosophy in Chapter 1) is that the transdisciplinary practitioner should be at least as *competent* and at least as *credible* as a comparable unidisciplinary practitioner from the perspectives of patients, carers and professional colleagues. Employing organisations would need guarantees of clinical competence and the ability to practice safely.

An early proposition to emerge from the thought experiments was that there would need to be a formal accredited programme of preparation for practice that would include mastery of the relevant clinical competences and underpinning knowledge.

For this part of the enquiry we needed to work collaboratively with a partner from the Higher Education sector. We chose to work with the Department of Health Studies at the local University which was one of our main education providers and with whom we enjoyed close working relationships.

In considering how best to prepare people for transdisciplinary practice, we wished to address the issues that had emerged during earlier stages of the enquiry. We revisited the data from the patient stories (Chapter 3), the work that we had done in creating rich pictures of transdisciplinary practice (Chapter 4) and the feedback that we had received when sharing the model with other practitioners and patients (Chapter 5).

The key issues that we wished to address in the educational process are summarised in table 6.1 together with an indication of the educational strategies that we developed to address each issue:

Table 6.1 Issues to address through the educational process

Issue	Source	Strategy
Being treated as a person not an illness	Patient stories	Patient partnership module to explore the nature of the relationships amongst patients, carers and practitioners.
Having my own views respected	Patient stories	
Having things at the right time.	Patient stories	Emphasis on developing case management skills using problem-based learning approaches in the core clinical modules.
Partnership working	NHS Plan	Module on how the health and social care system works.
Evidence based practice	Regional Conference feedback	Module on research skills and evidence-based practice.
Safe practice	Regional Conference feedback and rich picture development.	Clinical competence assessment running alongside “academic” modules. Problem-based learning approach throughout.

Issue	Source	Strategy
Appropriate for some client groups.	Regional Conference feedback and rich picture development.	Framework validation module that would enable other client-specific modules to be added as appropriate.
Clinical governance and clinical supervision.	Regional Conference feedback and rich picture development.	Module on health and social care system to include exploration of philosophies and practices to assure quality and governance.
Addressing 90% of patient needs.	Rich picture development.	Detailed design of client specific modules and associated clinical competence framework.

To symbolise the fact that we saw transdisciplinary practice as a higher order of practice than unidisciplinary practice, we wished to develop a programme that was validated at Masters level. This reflected the fact that, for most clinical professions, a first degree was the normal requirement for practice. Increasingly, Masters level qualifications were being expected for advanced practice and for undertaking new emerging roles such as Nurse Consultant and Therapist Consultant.

We formed a joint design group with staff from a local University to develop an appropriate programme. In our early discussions it became apparent that we would need to develop an innovative educational programme to complement and enable an innovative model of practice.

Just as transdisciplinary practice presented a number of challenges to established practices within the NHS and its partner organisations, the development of an appropriate educational model presented challenges to established thinking within Higher Education. These are summarised in table 6.2:

Table 6.2 Issues raised in higher education

Issue	Implication
Students would already be acknowledged experts in parts of the curriculum.	Acknowledgement of the need to blur the distinction between learner and teacher and to establish a meaningful learning community within a community of practice. Each student would develop his or her own pathway through the programme to build on prior knowledge. Academic tutors as learning facilitators rather than holders of expert knowledge.
Core clinical skills are not normally taught at Masters level.	Emphasis on underpinning knowledge and critical reflection rather than on learning how to perform tasks. Clinical competence framework running alongside the formal academic programme. Need to identify clinical assessors as well as academic assessors.
Need to develop confident and resourceful practitioners	Use of problem-based learning approaches to encourage self-reliance and self-directed learning.

Although our initial thinking on transdisciplinary practice had focussed on neurological rehabilitation, we believed that the model would be applicable to other patient groups such as people with learning difficulties, people with mental health problems and older people. We wished, therefore, to develop an educational framework that could be adapted to meet the needs of transdisciplinary practitioners working with other patient groups.

Our colleagues at the University were experimenting with novel approaches to clinical education such as problem-based learning and "e-learning" and in our discussions together we explored how such approaches could be employed to address the development of transdisciplinary practitioners.

The outcome

We succeeded in developing a two-year part-time MSc programme which met our design criteria and which was validated by the Senate of the University in 1999.

The MSc programme was designed on a modular basis with a number of core modules such as Patient Partnership and Service Management and other modules that were specific to particular patient groups.

The formal academic programme was complemented by a competence framework and a competence assessment framework that required learners to demonstrate particular clinical competences in relevant clinical settings.

During the process, we also defined the entry requirements for learners that included:

> Already professionally qualified and registered within their own profession.
>
> At least two years experience in practice with the relevant patient group.

It also became clear that each intake of learners would have to constitute a viable learning community with an appropriate cross-section of the relevant disciplines.

Reflections on the educational process

The transdisciplinary practice model challenges assumptions about traditional ways of working and about ways of organising competences into profession-based sets.

Equally, developing an appropriate educational process challenged assumptions about how higher education works in partnership with providers of health and social care.

In developing the educational process, we, in effect, had to establish a new action learning team half of which had been engaged in the development of the transdisciplinary practice model and half of whom had not. We had, therefore, to spend a significant amount of time reaching a shared understanding of what we were trying to achieve in much the same way as we had had to do during the thought experiment phase of this enquiry.

The research team and colleagues from the NHS had to understand the regulatory framework within which higher education institutes work and the mental models with which they operate. As most of the University staff were clinical practitioners themselves, they had much less difficulty in understanding our perspectives.

CHAPTER 7 REFLECTIONS ON THE RESEARCH PROCESS

In this chapter, I seek to capture my own reflections on being a researcher and to propose further areas of research that have been suggested in my reflections.

It has become very clear to me through this work that research is rather like trying to explore a jungle and attempting to make some sort of map as you go along. A particular research enterprise, like this one, is part of a sequence of explorations. In my research, I have drawn heavily on the maps of the territory that others have developed and I have also drawn on the methodologies of exploration and map-making that they have developed on their own journeys. Similarly, the most I can claim for my own research is that it may lead to a slightly better map in which some hitherto obscure features of the landscape are at least sketched out.

A map is not primarily a decorative object. It is designed to be a useful working tool that helps people to *act differently* in the world. It is my hope that the work which I and my colleagues have done will, in time, lead to differences in the ways in which the NHS and its partner agencies work with patients to meet their needs and aspirations.

The journey of the researcher is a faltering one. We do not stride out purposefully certain of our direction and certain of the firmness of the land beneath our feet. Rather we choose what look like promising directions, we head towards them testing the ground at every step of the way. During the journey, we can become more sure of our path as ideas and hypotheses are held up to scrutiny and tested out. Constantly, we fight the temptation to see what we want to see and hear what we want to hear.

This view of the research enterprise is very different from that with which I started out. Like many who have not previously been engaged in significant research undertakings, I had a fantasy that research would be a much more certain and deliberate process, with clear rules and procedures leading to definite outcomes. My holding of this fantasy may be partly attributable to the prevalence of the reductionist double blind randomised control trial approach which is still described as "the gold standard" in much of the discourse about research within the clinical professions.

I now believe that the carefully designed experiment in which one variable is manipulated and other potentially confounding variables controlled is an important part of the research process but one that comes towards the end of the journey rather than constituting the whole journey. I can envisage, for example, that it would be possible to design a robust experiment to test the claims that I have advanced for transdisciplinary practice. An experiment or series of experiments could measure the benefits which patients and practitioners perceive, compare the costs of the model with conventional models of practice and, perhaps, even measure different clinical outcomes. The design of such a trial would not be unproblematic but I have little doubt that it may be possible.

Looking back, I can see that this research enterprise has taken the journey to the stage where there is a testable hypothesis namely that for certain groups of patients, transdisciplinary practice may better meet their needs and aspirations than do current models of practice.

There are supplementary testable hypotheses to do with the impact on recruitment and retention and to do with costs of service delivery. These too could be subjected to rigorous testing using something like comparative trials.

The rigour and usefulness of such comparisons would be influenced by the researcher's ability to define and describe with some precision the models against which transdisciplinary practice was being tested. As the author has suggested earlier (see Chapter 4) this is by no means unproblematic. Implementations of (say) multidisciplinary team working, vary widely. We would, therefore, be presented with the challenge of seeking to identify a consensus about "best practice" within the multidisciplinary team model and comparing that with transdisciplinary practice.

At the outset of this enquiry, I did have a research plan and a reasonably clearly defined methodology. As I progressed through the research journey, I constantly had to challenge and change that plan and seek different methodological approaches to address the questions that were presenting themselves.

Peter Reason and Hilary Bradbury in their introduction to the "Handbook of Action Research" (Reason and Bradbury H 2001) write

> *"In action research knowledge is a living evolving process of coming to know rooted in everyday experience; it is a verb rather than a noun. This means action research cannot be programmatic and cannot be defined in terms of hard and fast methods, but is, in Lyotard's (1979) sense, a work of art."*

This sentence captures elegantly the interactive, contingent and exploratory nature of action research as the author experienced it. Planning research and selecting methodologies are processes – the plan is not important but the plan*ning* is.

I was clear that this research enterprise would be located in the traditions of action research. I wanted to learn by acting in the world and I aspired to bringing about useful change in the world by my actions. I was also clear about using story telling and narrative approaches as a way of better understanding the experiences and aspirations of patients.

The step in the research enterprise that I had not anticipated at all was that which I have described as a series of *thought experiments*. Perhaps I had another fantasy that the data gathered through patient story telling would suggest some relatively straightforward actions which could be taken to improve how services are delivered. I could then have followed a conventional action research approach by implementing measures to address the problems which had been identified, capturing more data about the impact of these measures and either moved on to another cycle of enquiry or decided that her research had gone as far as it needed to go.

The thought experiments were, I believe, an invaluable part of this research enterprise. I have used the term thought experiment because that is what it felt like. It would be equally valid to describe that part of the process as *theory building* – constructing a new theory about clinical practice which would be grounded in the data which we had gathered and which would form the basis for experimentation and hypothesis testing.

As things turned out, the research team and our colleagues needed to develop quite an elaborate theory of practice if we were to develop theory that contained the potential for action. To put it another way, to create useful knowledge, we needed a rich and elaborate theory to enable a complex series of actions that would address a complex problem.

I have given a good deal of thought to where research ends and development begins. On reflection, one of the choices that I and my colleagues made was to seek to develop a model in sufficient detail to allow it to go "into manufacture". It seems that this should more correctly be described as a development process rather than a research process.

On reflection, I can see that much of the power of action research as a methodology is its ability to treat the distinction between "research" and "development" as a false dichotomy. Working in an action research tradition, ideas and theories need to be worked up in sufficient richness of detail to enable the next cycle of action to occur. The whole point of action research is that we apply our early research insights and learn more from the process of application.

We could have taken a different route and attempted a “laboratory model” or prototype within our own service. We could, for example, have taken our experiments in skill transfer a little further and turned ourselves into something like transdisciplinary practitioners. This choice would have presented us with formidable ethical problems but we could probably have done it. One of the major advantages that we would have secured from this approach would have been being in a position to say “yes we have tried it out and it does work!” Certainly, in sharing our ideas with colleagues elsewhere in the service, many would have felt more positive about the idea had it been demonstrated somewhere in practice. There was a certain reluctance to pioneer an unproved idea.

Had we taken this route, we would probably have discovered many of the issues to do with education, clinical supervision and team organisation that we identified through our thought experiments and theory building.

It is not particularly useful to speculate on which approach would have been more effective. We took the route that we did and we are where we are. It does highlight for the author, however, that in any research enterprise, there are forks in the road and choices to make. The researcher has to learn to live with the consequences of the choices that he or she did make.

There is a choice that I made with which I remain deeply unhappy - my failure to include patients in the research enterprise other than as objects of investigation and providers of data. Peter Reason, John Heron and others (Reason and Bradbury 2001) have argued powerfully for a participatory and emancipatory approach to research. They advocate the active engagement of people like patients as co-researchers rather than as objects of research.

Although emotionally and intellectually attracted to this idea, like too many other researchers, I felt that it would add complexity and difficulty to an enterprise which I was already finding challenging enough. In effect, tI did what I criticise the NHS for, I organised the research enterprise around my own convenience. My rhetoric was about patient involvement but my practice was that "nurse knows best".

Post hoc, I could rationalise her decision not to include patients as co-researchers. I was working in the context of a community of practice that did not include patients and their inclusion as co-researchers would not have been appropriate. The truth is that I did not even consider it.

Something else that I have learned about research is that the researcher inevitably researches themselves as well as the world. Some of the conclusions in this thesis may be uncomfortable for the NHS. They are also uncomfortable for me.

I believe that my own sense of discomfort is evidence of how my engagement in this enquiry has changed me and my views about my own practice with my patients. Four years ago, I would have been content to be a compassionate, thoughtful and considerate nurse. Now I know that more is demanded of me in working *with* patients rather than simply caring *for* them.

I am determined to fight hard to get some of the ideas that have emerged through this enquiry put into practice. However, even if none of them were taken up more widely in health and social care, I am a much different and better practitioner than when i started this enquiry. I have also found an organisational setting in which I am able to put new ideas and new beliefs into practice with patients.

Action research is a transformational process. It is designed to transform some aspect of the real world. One of its true delights is that it can also transform the researcher.

CHAPTER 8 REFLECTIONS and CONCLUSIONS

Reflections on the Transdisciplinary Practice Model

At the time of writing, I have a clear model of how transdisciplinary practice might work and there is a validated educational process designed to create competent and confident transdisciplinary practitioners.

The idea has been shared with clinical professionals, with patients and carers and with senior NHS managers. The response from the majority of those with whom I have shared these ideas has been positive. Yet I have not been able to implement the model in practice, even on a pilot basis. Later in this chapter I will explore why I have not been able to secure implementation.

Given the rather important limitation that the model has never been tried out in practice, what do I now believe about the transdisciplinary model, given also that I have spent four years developing it?

In reflecting on the transdisciplinary practice model, I am contrasting a model of practice and of organisation that arises from a conscious process of ***design*** with an existing model of practice and organisation which has evolved over many years and which might be seen as exhibiting the ***self-ordering*** characteristics of a complex system. (Stacey 2001). I will explore the contrast between designed models and self-ordering in complex systems in my reflections on the wider modernisation agenda.

Transdisciplinary practice is designed to replace existing models of practice for certain patient groups and for meeting certain sets of health and social care needs. The transdisciplinary practice paradigm argues that, in some circumstances, the current model of organising competences and, therefore, scope of practice and professional roles within traditional professional and agency boundaries is sub-optimal and dysfunctional for patients and their carers.

In my critical reflection on current practice, I also argue that attempts to address the undesirable side-effects of tight professional and agency roles through measures such as multidisciplinary working and "partnership working" have not been particularly successful. My own conclusions are supported by many other writers (see for example Audit Commission 2000 and NCCSDO 2001 *Continuity of Care*).

At the heart of the transdisciplinary paradigm is the proposition that it is both possible and desirable to develop practitioners who have the skills and knowledge required to meet ***most*** of the health care needs of patients with particular disorders or disabilities without having to refer to other professionals or agencies. I argue that it is not possible for a patient to experience holistic care if the training of the practitioner providing that care is inherently atomistic. A professionally fragmented workforce is very likely to deliver fragmented care.

There is a parallel between this line of thought and developments in manufacturing industry in which the paradigms of "scientific management" (Taylor 1856-1917 as cited in Mullins 1996.) with its emphasis on job deconstruction and specialisation is gradually being superseded by models such as autonomous workgroups ("Management discovers the human side of automation" Hoerr & Pollock 1986)). Proponents of the move away from Taylorism/Fordism claim significant benefits in terms of:

Product quality.
Job satisfaction.
Cost-effectiveness.

I suggest that similar benefits can be realised in areas of health care through an analogous process of *job enlargement*.

To pursue the analogy of manufacturing industry further, Volvo do not suggest that every aspect of the enterprise needs to be built into the autonomous workgroup. The workgroup does not contain its own design engineers, marketing directors, accountants and so on. The issue is rather what skills, knowledge and capability is it helpful and effective to build into the autonomous workgroup and which are more appropriately provided from outside the workgroup.

This is also the question that needs to be addressed in developing a practical and useful model of transdisciplinary practice. There are skills which *could* be transferred across professional boundaries but where the benefits of doing so would be minimal. Similarly, there are skills that it would be beneficial to transfer but where the costs of transfer would outweigh the benefits.

The word *autonomy* is also relevant to transdisciplinary practice. In the autonomous workgroup in manufacturing industry not only are individual jobs enlarged through further training and education but the group is *empowered* to take decisions and to act in ways which were previously constrained by policies and procedures and by custom and practice.

Early in my intellectual exploration, the need for the transdisciplinary practitioner to be a *powerful* practitioner emerged as a critical requirement. If he or she is to be able to meet the needs of the patient, the practitioner must be able to mobilise resources complementary to his or her own skills, time and energy. The issue of practitioner empowerment is one that has ramifications beyond a discussion of transdisciplinary practice. These are explored more fully in my reflections on the modernisation agenda.

My work in this research project has been less concerned with the *principle* of transdisciplinary practice than with the *feasibility* of it. Stated at its most extreme the principle is self-evidently attractive:

> *"Do you think you would experience more integrated and satisfactory care if you received all your care from one person who had all the expertise to meet all your needs and who would always be available to you?"*

The real question that is addressed in this research enterprise is how close can I feasibly come to the desideratum implied in the question above?

I have come to the conclusion that, if I wanted to, I could come very close. Specifically, I could come *usefully* close and, in doing so, address several of the issues which emerged from patients through their story-telling.

Conclusions

With the important caveat that the model has not been tried out in practice, I have come to the following conclusions:

1. There are few statutory barriers to defining scope of practice in terms of the needs of particular sets of patients rather than in terms of traditional professional boundaries. Important ones include:
    i. Limitations on prescribing.
    ii. The requirement for medical practitioners to certify eligibility for certain types of benefit.
2. A significant array of useful competences can be safely transferred across traditional professional boundaries under certain conditions. The most important of these are:
    i. Practitioners are already confident and competent within their own discipline.
    ii. Practitioners are already confident and competent in working with the patient group for which transdisciplinary practice is being developed.
    iii. The patient group is sufficiently circumscribed and homogenous to enable a feasible scope of practice.
    iv. There is a robust, validated and credible educational process that addresses both clinical skills and underpinning knowledge.

3. Transdisciplinary practice is a *team* activity. This is necessary both to ensure continuity of care and to sustain and improve quality of practice. The team design also incorporates some of the benefits that are undoubtedly derived from effective multidisciplinary practice. The optimum composition of a transdisciplinary team and the model of team organisation depends on the nature and size of the patient group and on the wider organisational setting in which transdisciplinary practice is situated.

4. Transdisciplinary practice has the potential to provide additional job satisfaction for practitioners through job enrichment and job enlargement. By doing so, transdisciplinary practice may help us to address problems of retention of experienced practitioners within the NHS and its partner agencies.

5. Similarly, transdisciplinary practice *can* provide an attractive opportunity for career development for practitioners. It may help the NHS and its partner agencies to recruit and retain practitioners and, in particular, to retain experienced practitioners in front-line practice.

6. Transdisciplinary practice can be a more cost-effective model of service delivery. My research suggested significant levels of waste and duplication inherent in current models of care and models of organisation. A fragmented model tends not only to deliver poor care but also expensive care. Within any multidisciplinary and/or multi-agency model there are significant *transaction costs* associated with the transfer of information, intra and inter-team communication, and replication of tasks such as history taking and record keeping. These are reduced in the transdisciplinary model. Particularly in a community or domiciliary setting, the costs of *travel* (cash and time) are very significant. Reducing the *number* of different encounters between patient and practitioner has an immediate beneficial impact on the efficiency with which our resources are used.

7. In developing transdisciplinary practice, we should take the opportunity to reinforce emergent aspects of good clinical practice including:

    i. Valuing the patient and informal carers as active and equal partners in the therapeutic relationship.

    ii. Evidence-based practice and research skills.

    iii. Care management and case management.

8. Most importantly, transdisciplinary practice, if well implemented could provide many patients with a more satisfactory and probably more productive experience of health and social care and give new meaning to the word *holistic*.

Reflections on reactions to the proposition

Having reflected on the benefits of transdisciplinary practice and articulated some of the reasons why I believe it is not only a desirable model of practice in some circumstances but a feasible model, I want to reflect on some of the reactions that the presentation of the model evoked and on the objections to implementation which have been raised.

Clearly, the transdisciplinary practice model is seen as a challenge to existing notions of professional identity. As discussed earlier, a monopoly over certain domains of knowledge and/or over certain domains of practice is an important source of professional identity and professional self-esteem. The possession of such monopolies is thought to guarantee employment and status within a strongly status-differentiated system. Admission to a regulated profession through a formal process of education and examination confers status and certain rights and obligations on the person admitted. Professional identity is also created through symbols such as uniforms (or the absence of them) and tools of the trade such as stethoscopes. Some professions also constitute their identify by laying special claim to value systems, the caring of nurses or the holism of occupational therapists.

Within the NHS there is an elaborate system of co-created professional identities and of relationships between professional groups. Although a degree of "jostling for position" and "turf warring" does take place, the system is relatively stable and self-ordering. Transdisciplinary practice, to a degree that I had not anticipated, threatens the stability of this self-ordering system. The challenge to professional identity by transdisciplinary practice appears to manifest in three ways:

Devaluing the educational process

> "*It's taken me four years to become a physiotherapist – why do you think it can be done in two years part time?"* (as quoted by a Physiotherapist participant at the Working Conference)

Devaluing specialist expertise

> *"Nursing is not just a collection of tasks – it's a whole body of knowledge"*(as quoted by a Nurse participant at the Working Conference)

Devaluing distinctive identity

> "*If you have your way, occupational therapists will disappear."*
> (as quoted by an Occupational Therapist participant at the Working Conference)

This reaction to challenges to existing professional boundaries is by no means unique to transdisciplinary practice. Similar reactions have been reported in relation to initiatives such as nurse prescribing. (Medicinal Procedure: Prescriptions by Nurses Act. 1992)

The transdisciplinary practice model also appears to challenge prevailing models of clinical education. To the best of my knowledge, all clinical education is based on the model in which the learner has a broad education in a particular profession briefly touching all or most patient groups and clinical settings followed by a period of specialisation. Thus one becomes a Nurse first and then goes on to become a Health Visitor or an ITU Nurse or a Community Nurse. One becomes a doctor first and then goes on to become a GP or a pathologist or a public health specialist.

Although I suspect that the work of a public health doctor is much more like the work of a public health nurse than it is like the work of a cardiac surgeon, the educational process appears to favour the establishment of a clear professional identity before focussing on the competences which will actually be required to perform in a particular role.

In fact, in developing this model of transdisciplinary practice, I did not seek to challenge this basic educational model. I considered the possibility of developing *ab initio* practitioners whose competences would be aligned with the needs of particular patient groups. I rejected this model for several reasons not the least of which was the difficulty which I anticipated in securing change in undergraduate clinical education. Nevertheless, some colleagues with whom I discussed my ideas saw transdisciplinary practice as an assault upon the prevailing model of education and registration.

It is interesting to note that the agenda in terms of educational development has been about extending the period of initial training, moving all clinical professions to graduate status and accrediting specialist practice at post-graduate level within profession. In other words, the agenda has been about further strengthening the distinctive identity and status of each of the professions in relation to other professions within the system. It is not apparent to me that this agenda is driven primarily by concern to deliver better patient care.

Within clinical education there have been some worthwhile initiatives to counteract the adverse consequences of exclusively uni-professional education. Initiatives such as the JUMP programme (Joined Up Multi-professional Programme, Imperial College London) and arrangements for clinical education at the University of East Anglia, have been designed to dilute the professional isolation which has been engendered by traditional approaches. Like me, the initiators of these projects have judged it unwise to tackle the fundamental basis of professional clinical education but have sought to bring about some useful softening around the edges.

Many of the service managers to whom I presented the concept of transdisciplinary practice simply saw it as too difficult or too difficult at this time. Typical concerns included:

> *"The professions will never agree to it."*

> *"We could not release staff for training."*

> *"We have other more important issues on our agenda."*

It seems to me that these objections were much less deep-seated than those that emerged from representatives of the clinical professions but were, nevertheless, very real.

The managerial objections could have been overcome through a combination of:

Earmarked funding.

A clear political or managerial directive that this was a priority.

Dedicated project management.

Other initiatives such as the implementation of nurse prescribing or the development of Walk-in Centres and NHS Direct have had these characteristics and have been implemented apparently without undue difficulty.

In the introduction to this reflection, it was suggested that transdisciplinary practice could have been implemented if the team had *wanted to enough*. Given that most of the people with whom I discussed the concept agreed with it in principle and agreed that it could be a significantly better model of care for particular types of patient, I am forced to conclude that, within the service, improving the quality of the patient experience is not a sufficiently strong driver to overcome the need to sustain professional identity and not a sufficiently strong driver to fight its way to the top of busy managerial agendas.

It has been suggested that the NHS and the wider health and social care system behaves as a self-ordering complex system. Other writers (Stacey 2001) have commented on the extent to which complex self-ordering systems are able to resist externally imposed change.

The professional and managerial structures and cultures of the NHS and its partner agencies are extremely deeply rooted and very strong. By contrast, the voice of the individual patient is little more than the distant echo of a faint whisper drowned out by a roar of professional, managerial and political self-interest. It is only when those voices are focussed and amplified by some national scandal like the Bristol heart inquiry (Bristol Inquiry Report 1995) or the organ retention issue initially at Alder Hey Hospital (Royal Liverpool Children's (Alder Hey) Hospital Inquiry. Jan 2001) that the system re-orders itself in response to the voice of the user amplified by the media and then by politicians. Like all the best complex adaptive systems, it conserves itself and its order by doing as little as is necessary to adapt to the new environmental situation.

It is disappointing that I have not been able, yet, to implement transdisciplinary practice to see if it can deliver all that I believe it can particularly for that group of patients in whom I have a strong personal interest. However, seen simply as a case study in patient-led innovation, I believe that it highlights issues which are relevant to the wider modernisation agenda and, perhaps, to the survival of the NHS in any form which we might recognise.

These topics are now elaborated.

Implications for policy makers

In July 2000, the NHS Plan (2000) was published. This set out an ambitious ten-year plan for reform of the National Health Service in England. The Plan should be seen in the context of a wider policy direction in terms of modernisation of the whole spectrum of public services in the UK. Within the NHS, the term "NHS Plan" features rarely and people tend now to talk about the "Modernisation Agenda" to encompass a whole basket of government initiatives designed to bring about specific changes in the NHS and how it works. In the context of this study, it is worth quoting from the Introduction to the Plan by the Secretary of State.

> *"At its heart the problem for today's NHS is that it is not sufficiently designed around the convenience and concerns of the patient. The NHS provides many patients with a good and reliable service. But it is simply not responsive enough to their needs. Patients have to wait too long for treatment. Records get lost. Wards are not clean. Standards are too variable. Old-fashioned demarcations between staff, restricted opening and operating times, outdated systems, unnecessarily complex procedures and a lack of training all combine to create a culture where the convenience of the patient can come a poor second to the convenience of the system." (page 15)*

In Chapter 2 of the Plan – The NHS Now, the Secretary of State writes

> *"In essence the problem is that despite the best efforts of doctors, nurses and other staff the NHS is not sufficiently centred around the needs of individual patients. There are two main reasons why this is the case. First, decades of under-investment and second, because the NHS is a 1940s system operating in a 21*st *century world." (Page 26 para 2.9)*

Whilst I have many questions and concerns about how the government is implementing the NHS Plan, I would completely endorse the observations and diagnoses embedded in these two quotations. I might have to question the assertion about "*the best efforts of doctors nurses and other staff*". There may be a false distinction between the culture of the organisation and the people who work in it. The culture is not the water and the people are not the fish. The people who work in the service to a large extent create the culture and the culture shapes the people. The relationship is an interactive and cyclical one. In the light of my research, I believe that it may be necessary to write a more complex statement such as:

> *"the best efforts of doctors, nurses and other staff in so far as their own professional interests are not threatened nor traditional ways of working challenged".*

If we are to take the NHS Plan seriously, we should be seeking to understand what matters to particular patients or groups of patients and then designing our services around their expressed needs and wishes. How we organise ourselves, how we practice, the roles that different individuals perform should all be subservient to the purpose of providing the experiences that particular service users would choose, given that they would probably prefer not to be using our services at all.

Undertaking this study has persuaded me that the service does not really think this way at all. The Secretary of State is right in his assertion that we are indeed "a 1940s system operating in a 21st century world". I believe that the value of traditional professional arrangements in guaranteeing standards of competence and conduct is now being outweighed by their role in inhibiting flexibility, responsiveness and innovation. The well-being of patients is subordinated to the well-being of professionals.

In one way, the system could be seen as *too efficient*. It is well fitted to deliver a particular style of service in a particular environment. Unfortunately that environment has changed dramatically and the service has not had the capability, or any strong imperative, to change with it. Like Henry Ford, we can make Ford Model T's in black better and more cheaply than anyone else in the world. If our patients had gone on being compliant and completely trusting in their clinicians, all would have been well. If patients with complex continuing care needs had gone on dying or accepting that nothing could be done for them, again all would be well.

In the 21st century, patients do not and will not behave in these convenient ways. Although individually the voices of patients are weak, the government is well aware that in the public perception, the NHS is a failing organisation.

This point is acknowledged in "The Expert Patient" (2001)

> *"The experience of people with chronic disease in using health services is very variable. In the better services people are given advice and information and their questions are answered. But few go beyond this to ensure that a patient's growing knowledge of his or her condition is developed to a level whereby self-management, within the boundaries of a medical regime, becomes a real option. The impact of this has been considerable. Individuals have experienced unnecessary pain and discomfort along with a severe limitation to their quality of life. There is also an economic cost to society from avoidable absence from work and inflated health and social care costs.*
>
> *The challenge for the NHS, working in partnership with patient organisations and other government departments and agencies, is to bring about a fundamental shift in the way in which chronic diseases are managed – a shift which will encourage and enable patients to take an active role in their own care." (Page 6).*

I believe that the government is also discovering that pumping money in, shouting louder and hanging a few admirals is not proving an effective strategy for restoring public confidence.

It is suggested that some lessons from this study may be helpful in realigning the NHS and its partner agencies with the expectations of the public.

Many of these resonate with the work of Rosabeth Moss Kanter (Moss Kanter 1989) who addressed the problem of how very large and complex organisations could learn to be as flexible and adaptive as small "start-up" enterprises. Although most of her work is concerned with the information technology industry in the USA, many of the lessons are, I believe, applicable to the issues confronting the NHS.

Professor Moss Kanter suggested that to become adaptive, organisations needed to be:

> Focussed – that is to have a very clear and simple sense of purpose or mission.
>
> Fast – have streamlined decision-making processes with decision-making close to the interface between organisation and customer.
>
> Flexible – able to change working practices quickly and easily.
>
> Fun – encourage and enable creativity and innovation.

If we are to deliver the aspirations of the NHS Plan, *designed around the convenience and concerns of the patient*, this needs to be clearly articulated as the over-riding purpose of the NHS and its partner agencies. Once the purpose has been articulated, it must then be reinforced by a performance management framework that reflects that purpose.

Within the NHS, each constituent organisation is individually performance managed. There is no attempt to performance manage "the whole system" or to see the quality of the patient's overall experience as the acid test by which every part of the system should be judged. In this study and, in particular, in my conversations with service managers and organisational leaders, it has become clear that they were so busy chasing intermediate local targets that the overall quality of the patient journey or patient experience was of little or no concern.

Similarly, clinical governance has been introduced and implemented on an organisation by organisation basis reflecting and reinforcing the fragmentary nature of care. In several organisations with which I have worked in developing and testing the transdisciplinary model, clinical governance was implemented on a profession by profession basis again reinforcing the atomistic pattern of care which so distressed the patients whose views informed this study.

Decision-making processes are remarkably slow and cumbersome within the NHS. In promoting the idea of transdisciplinary practice, I found no one who knew how such a decision could possibly be made.

In analysing the reasons behind the unsatisfactory experiences of our patients, it became clear that the practitioners working with them did not have the authority they needed to deliver high quality care designed around the convenience and concerns of patients. Patients complained about their own disempowerment within the therapeutic process. Equally, however, practitioners complained about their own powerlessness. They could make very few commitments to the patient other than to write a referral letter or ask someone else to do something. A significant amount of "treatment" by clinicians actually consisted of paperwork and telephone contact to mobilise some other service, profession or agency. A fundamental precept of the transdisciplinary practice model is that the practitioner should be empowered primarily by extending his or her own scope of practice and knowledge base but also by removing bureaucratic barriers to effective service delivery.

The issue of flexibility is most immediately germane to this study of transdisciplinary practice. I argue that the way in which professions are demarcated and the rigidity of professional boundaries fossilises practice and prevents practitioners from responding flexibly to the needs and aspirations of individual patients and of their carers.

This study (and many others) suggests that the inherent inflexibility of the system both in terms of organisational structures and professional demarcations is deeply resistant to change and adaptation. Attempts to bring about even modest changes in traditional working practices require Herculean efforts and Job-like patience.

I believe that the concept of transdisciplinary practice, particularly if it had been seen as beneficial to practitioners as well as to patients, would have been a useful way of dispelling the anxiety about change in professional practice. It would have demonstrated that change is not necessarily life-threatening and may even be beneficial.

I believe that the government and the leaders of the NHS and its partner agencies will have to be more assertive, more adventurous and less risk-averse in taking on the vested interests which keep us a 1940s organisation. It should actively promote and support initiatives that challenge existing working practices and boundaries. A general rule for the Modernisation Board might be that if no one is seriously upset, then you are probably not being radical enough! Walk-in centres, for example, would probably be a great deal more effective if the Nurse Practitioners staffing them could prescribe extensively and if they could sign documents needed for benefit claims. Then there would be a diversion of demand from GP surgeries.

Fun is not, perhaps, the best word to encapsulate creating a climate of creativity and innovation. It is a good word to describe my own feelings in working on this research project. There was enormous enjoyment in working with a team thinking through how to make things better for patients and discovering that we could, if we chose, do things very differently. I would like to have been better at sharing this sense of fun and excitement when we were presenting our ideas. To some extent we did and we evoked some real enthusiasm and excitement in the moment.

Unfortunately, when people got "back to work" things which had seemed worthwhile, possible and exciting just came to feel like another problem, another difficulty another priority. People throughout the service are burdened with the mechanics of keeping the system working. They are hamsters on an exercise wheel without the emotional reserves or time to make change happen.

If we are going to create a 21st century organisation, we need to create conditions that enable innovation. I was immensely privileged to have some "time out" to think about what I was doing and to reinvent my practice. I did have to keep sending in progress reports and submitting business cases and bidding for funds on an annual basis but that seemed a relatively small price to pay for what I felt I was achieving.

If we are to modernise, we need to make the experience which we had much more the norm rather than the exception. We need to see groups of practitioners and patients working together to challenge how we do things and to constantly re-invent our practices and our professions.

Equally, we need to find ways of making innovation less difficult. We need to develop a culture of constant experimentation and to accept, as a necessary corollary, that some experiments will fail but that all will be useful in terms of individual and organisational learning.

Again, we need to be less risk averse and to have more of a "try it and see if it works" attitude. I have acknowledged the support I received from The Director of Nursing and the Director of Education at the Regional Office in pursuing this project. They did not ask for long papers or complex business cases. They listened to what I had to say and decided that it had sufficient *possible merit* to justify a modest commitment of their time and some funding. They role modelled the leadership which is needed to develop throughout the NHS if we are to become the 21st century organisation.

The story of developing and seeking to implement a different model of clinical practice, transdisciplinary practice, which forms the subject of this thesis suggests that there are several practical actions which the NHS, probably through the Modernisation Board and Modernisation Agency could take to increase the probability of the NHS transforming itself into a 21st century organisation. Amongst these are:

> Constantly clearly restating the purpose of the NHS as providing services that are convenient for patients and which address their concerns.
>
> Promoting a performance management framework that is centred on the totality of the patient experience rather than on the performance of component parts of the system.
>
> Promoting an approach to clinical governance that is centred on the totality of the patient experience rather than on the performance of component parts of the system and embedding this within the performance management framework.
>
> Identifying those constraints on practice (such as prescribing and authorising access to benefits), which most impede flexible working and pursuing an aggressive policy to remove such constraints.
>
> Requiring constituent organisations within the NHS and its partner agencies to identify similar constraints within their own organisations and to develop and implement action plans to remove these.
>
> Promoting an approach to workforce development that favours aligning the competences of practitioners with the needs of patients and their carers.

Providing an infrastructure to support and enable patient-centred innovation. Such an infrastructure would offer:

Access to small-scale funding.

Expert help with project design and management.

Access to sites that have volunteered to pilot new approaches.

Dissemination of learning from innovation.

The new Strategic Health Authorities may also have an important role to play in encouraging the development of models of practice that are more closely aligned with the needs and expectations of patients and their carers. In principle, at least, the Strategic Health Authorities provide a locus for "whole system thinking" at a relatively local level. Through their performance management role and their strategic development role, they have an opportunity to pull together the bits of the jigsaw to make a picture that will seem coherent from the view point of the patient.

Individual NHS Trusts and Primary Care Trusts have the capacity to change the experience of patients and, more generally, to create a climate of innovation, experimentation and managed risk-taking. As Primary Care Trusts start to take on their commissioning roles, an opportunity exists to commission services on the basis of whole patient journeys rather than on the inherently fragmentary "episodes of care".

Individual NHS Trusts and Primary Care Trusts can influence the quality of the patient's experience through:

> Their clinical governance arrangements – ensuring that they place an emphasis on the totality of the patient experience and the experience of their carers rather than on the quality of each of the component bits, although these too are clearly of great importance.
>
> In-service training and continuing professional development. In particular, placing an emphasis on multi-professional learning and holistic care and on making use of the expertise of the patient and his/her carers.
>
> Internal performance management – rewarding and reinforcing respectful and holistic care and showing disapproval or intolerance of care which is likely to be experienced as fragmentary and oppressive.

Education providers play an important role in shaping the attitudes and mental models of practitioners both during undergraduate education and through their role as providers of continuing professional education.

A recent study (Exploring Clinical Practice, 2002) indicated that education providers are increasingly recognising the need to encourage:

> Shared learning across professional boundaries.
>
> Problem-based learning approaches that encourage holistic models of care.
>
> Early patient contact which helps to develop the interpersonal skills and attitudes which encourage care which is respectful of the patient's needs and aspirations.
>
> Integration between providers of health and social care services and providers of education for practitioners in health and social care.

Just as the NHS and its partner agencies have significant barriers to overcome in developing services which would better meet the needs and aspirations of patients, so that education providers have to work within a formal accreditation framework which involves stakeholders such as the Royal Colleges and the educational establishment. Progress is unavoidably slow but the direction of travel is reasonably clear and grounds for some optimism.

I recognise that some of the measures proposed require raising the level of risk which the government and the NHS is prepared to tolerate. There are, for example, tensions between corporate governance, at least as we currently view it, and speed of decision-making. Some of the processes and measures that are in place to assure proper public accountability are extremely bureaucratic and cumbersome.

I believe, though, that we require a 21st century approach to risk and to corporate governance as much as we require a 21st century approach to anything else. Successful adaptive organisations are, if nothing else, good risk takers.

To be effective, the NHS needs to focus more on *getting things right* for patients and rather less on stopping things going wrong. To be effective, the NHS needs to measure the totality of the patient experience and to stop attempting to measure the multitude of intermediate variables that contribute to that experience.

This work with transdisciplinary practice is a tiny but illustrative model of how we need to work in the NHS and its partner agencies. I started by trying to understand the concerns of patients, identified the things that were getting in the way of addressing those concerns effectively and then worked through how to remove the obstacles to our delivering a good patient experience. I learned how to set to one side my own prejudices and the constraints that had been imposed on my thinking through the socialisation process involved in becoming a nurse. The measures that I propose above, would help others to replicate that "setting aside" process.

In my reflections on the research process (Chapter 7) I identifie the most immediate area for further research in the context of transdisciplinary practice as being to critically evaluate the model in practice. The most appropriate research paradigm would approximate a clinical trial as far as possible. This would be my own personal priority for further research.

Turning to the wider agenda of innovation within health and social care, I believe there is scope for researching more carefully into the factors which inhibit successful patient-centred innovation within the NHS.

Earlier in this chapter, I speculated on the factors that inhibit successful innovation within the NHS and indicated how I think these could be attenuated. Essentially the forces driving innovation are rarely strong enough to overcome the forces inhibiting innovation. Notable exceptions exist where innovations are driven by:

Strong political imperatives (Walk-in Centres).

Strong market forces (new medications or new medical technology).

In my view, the particularly fruitful areas of research are in to how we bring about innovation in the absence of such strong drivers. I believe that this will become particularly relevant with the increasing prevalence of poor health that is not susceptible to curative approaches. Here the useful innovations are likely to be behavioural and organisational rather than technological.

This is exemplified by the Department of Health paper on "The Expert Patient" (2001). This suggests that worthwhile and measurable differences could be made to the quality of patients' lives through the education of patients and the education, or re-education, of practitioners.

One of the conclusions which I draw from this study is that the effectiveness and efficiency of clinical practice could, in many cases, be significantly improved simply by removing organisational practices which inhibit good clinical practice; in other words by empowering practitioners to practice well.

There is a great deal of rhetoric about the empowerment of front-line practitioners but I believe there is a strong case for powerful action research to identify and demolish the organisational and professional behaviours and attitudes which serve to disempower practitioners.

Encouragingly, The National Listening Exercise carried out during 1999 by the National Co-ordinating Centre for NHS Service Delivery and Organisation Research and Development (2000,) identified a number of important themes for further research that are consistent with my own findings. These first five are:

- *Organising health services around the needs of the patient.*
- *User involvement.*
- *Continuity of care.*
- *Co-ordination/integration across organisations.*
- *Inter-professional working.*

(Listening Exercise page 6)

On the same page the report suggests that

> *"Research is not generally perceived as a lever for change in the NHS, and there is a gap between research evidence and implementation at both policy and local levels"*

Interestingly, the report acknowledges the importance of action research (page 6) and the need to develop "innovative ways of approaching the development end of the Research and Development spectrum" (page 7).

APPENDIX A

RESEARCH TEAM MEMBERS

Appendix A

The Research Team – from Hounslow & Spelthorne Community & Mental Health NHS Trust

Michael Faulkner – Facilitator
Gill Allen – Nurse Practitioner and Project Manager
Harmy Johal – Speech and Language Therapist
Vivienne Frost – Physiotherapist
Debbie Hammond – Clinical Nurse Specialist
Lucille Balcombe – Behavioral Nurse Specialist

The Educational Team – from the Department of Health Studies, Brunel University

Prof. Lorraine De Souza – Chair in Rehabilitation and Head of Dept
Dr Andree le May – Deputy Head of Dept
Marta Freundlich – Senior Lecturer/Medical Anthropologist
Linda Gnanasekaran – Senior Lecturer/Occupational Therapist
Anne McIntyre – Senior Lecturer/Occupational Therapist
(there was an acknowledgement of no Speech and Language Therapist on the team)

Clayponds Hospital Team – from West London Health Care NHS Trust

Angela Brooke – Specialist Rehabilitation Care Group Leader
Diane Topping – Care Group Leader – PAMS
Dr Ghosh – Consultant in Rehabilitative Medicine
Heather Hadizad – Senior Nurse
Anne Bisset-Smith – Therapy Co-ordinator/Physiotherapist
Rachel Veale – Occupational Therapist
Faith Benjamin – Staff Nurse
Agency/Locum – Speech and Language Therapist

APPENDIX B

CURRICULUM EXTRACT

Appendix B - Core Curriculum

The curriculum for the programme consists of a number of interleaved modules complemented by a parallel clinical practice development programme.

The modules are:-

Client centred practice

An exploration of health and healthcare philosophy and practice from a range of perspectives. Considerable emphasis is placed on gaining insight into the "mental models" of different professions and agencies involved in health and social care. Equally, emphasis is placed on gaining deep insight into the experiences of patients, families and carers and of the processes through which they make sense of health, illness and disability.

Clinical effectiveness and clinical governance

An in-depth treatment of concepts of effectiveness in health and healthcare and related areas of practice such as social work. The module introduces the key concepts from the government's clinical governance agenda and enables students to relate their own practice to this framework.

Service planning and management in the modern NHS.

The module aims to set clinical practice in the wider context of service planning and management at both strategic and operational levels. Students will explore points of tension and convergence between the managerial and clinical agendas in the context of current public policy.

Research skills

The module is designed to equip participants with the fundamental skills for planning, conducting and interpreting research in relation to clinical practice, health and healthcare. The module forms the foundation for the dissertation that each student is required to produce.

Client group specific modules

Two modules are taken in relation to the specific client group with which the student is concerned.

The modules employ a multiprofessional problem-based learning approach to the development of theory and practice in relation to the management of neurological disability OR child and adolescent mental health.

Appendix B - Clinical competence framework

Clinical competences and learning outcomes

Master of Science Degree in Neurological Disability

Clinical Competence	Learning Outcomes
To perform a physical examination appropriate to a neurological condition and to use the information gained, in conjunction with other forms of assessment, to develop an appropriate intervention strategy.	To demonstrate the acquired in-depth knowledge and understanding of the associated neuro anatomy and physiology in both normal and abnormal conditions necessary to safely and competently perform a physical examination appropriate to a neurological condition and to interpret the findings in the context of the individual's overall health and social context. To use the in-depth specialist contributions gained from other partner practitioners when carrying out or subsequent to the examination.
To perform a functional assessment appropriate to a neurological condition and to use the information gained, in conjunction with other forms of assessment, to develop an appropriate intervention strategy.	To demonstrate the acquired in-depth knowledge and understanding of the associated neuro anatomy and physiology in both normal and abnormal conditions necessary to safely and competently perform a functional assessment appropriate to a neurological condition and to interpret the findings in the context of the individual's overall health and social context. To use the in-depth specialist contributions gained from other partner practitioners when carrying out or subsequent to the examination.
To assess and manage issues around posture and seating making use, where appropriate, of other more specialist skills and resources.	To analyse and reflectively consider the implications of living with postural and seating problems associated with neurological impairments. To work in partnership with the individual concerned and his/her carers and family members to develop jointly agreed strategies to address current and potential future problems of posture and seating.
To assess and manage issues around mobility making use, where appropriate, of other more specialist skills and resources.	To analyse and reflectively consider the implications of living with mobility problems associated with neurological impairments. To work in partnership with the individual concerned and his/her carers and family members to develop jointly agreed strategies to address current and potential future problems of mobility.
To assess and manage issues around swallowing and nutrition making use, where appropriate, of other more specialist skills and resources.	To analyse and reflectively consider the implications of living with problems of swallowing and nutrition associated with neurological impairments. To work in

Clinical Competence	Learning Outcomes
	partnership with the individual concerned and his/her carers and family members to develop jointly agreed strategies to address current and potential future problems of swallowing and nutrition.
To assess and manage issues around elimination and continence making use, where appropriate, of other more specialist skills and resources.	To analyse and reflectively consider the implications of living with problems of elimination and continence associated with neurological impairments. To work in partnership with the individual concerned and his/her carers and family members to develop jointly agreed strategies to address current and potential future problems of elimination and continence.
To assess and manage skin integrity making use, where appropriate, of other more specialist skills and resources.	To analyse and reflectively consider the implications of living with problems of skin integrity associated with neurological impairments. To work in partnership with the individual concerned and his/her carers and family members to develop jointly agreed strategies to address current and potential future problems of skin integrity.
To assess and manage sleep disturbance, pain, discomfort and the adverse consequences resulting from increased or decreased muscle tone making use, where appropriate, of other more specialist skills and resources.	To analyse and reflectively consider the implications of living with problems of sleep disturbance, pain, discomfort and abnormal muscle tone associated with neurological impairments. To work in partnership with the individual concerned and his/her carers and family members to develop jointly agreed strategies to address current and potential future problems of sleep disturbance, pain, discomfort and abnormal muscle tone.
To assess and manage pain, discomfort and the adverse consequences resulting from increased or decreased muscle tone making use, where appropriate, of other more specialist skills and resources.	To analyse and reflectively consider the implications of living with problems of pain, discomfort and abnormal muscle tone associated with neurological impairments. To work in partnership with the individual concerned and his/her carers and family members to develop jointly agreed strategies to address current and potential future problems of pain, discomfort and abnormal muscle tone.
To assess and manage problems of cognition making use, where appropriate, of other more specialist skills and resources.	To analyse and reflectively consider the implications of living with problems of cognition associated with neurological impairments. To work in partnership with the individual concerned and his/her carers and family members to develop jointly agreed strategies to address current and potential future problems of cognition.

Clinical Competence	Learning Outcomes
To assess and manage problems of emotion making use, where appropriate, of other more specialist skills and resources.	To analyse and reflectively consider the implications of living with problems of emotion associated with neurological impairments. To work in partnership with the individual concerned and his/her carers and family members to develop jointly agreed strategies to address current and potential future problems of emotion in the individual and in family members.
To assess and manage other problems of motor or sensory impairment making use, where appropriate, of other more specialist skills and resources.	To analyse and reflectively consider the implications of living with other problems of motor or sensory impairment associated with neurological disease or disorder. To work in partnership with the individual concerned and his/her carers and family members to develop jointly agreed strategies to address other current and potential future problems of motor or sensory impairment.
To assess and manage problems of sexual function making use, where appropriate, of other more specialist skills and resources.	To analyse and reflectively consider the implications of living with problems of sexual function associated with neurological impairments. To work in partnership with the individual concerned and his/her carers and family members to develop jointly agreed strategies to address current and potential future problems of sexual function in the individual and in family members.
To assess and manage issues around death and dying making use, where appropriate, of other more specialist skills and resources.	To analyse and reflectively consider the implications of death and dying associated with neurological impairments. To work in partnership with the individual concerned and his/her carers and family members to develop jointly agreed strategies to address current and potential future issues around death and dying for the individual and for family members.
To be competent in the management of relevant aspects of the use of medication.	To demonstrate an understanding of the legal framework within which medications are used. To safely store, administer, document and monitor the effects of medication.
To be competent in monitoring the health and well being of the individual and of his/her family and carers in living with a neurological condition.	To be alert to changes in the health and wellbeing of the individual and his/her family and carers and to initiate appropriate action when indicated.

Clinical Competence	Learning Outcomes
To work with the individual and his/her family and carers to maximise their desired participation in society and to enable them to access the full benefits of citizenship.	To be aware of and have established sound relationships with other agencies relevant to the individual and family's participation in society. To demonstrate the ability to work in partnership with the individual and his/her family and carers to maximise their desired participation in society. To influence social institutions to reduce the handicapping effects of impairment or disability.

Clinical Competencies for
Child and Adolescent Mental Health
M Sc

Module HH5H

Clinical Competence	Outcome
To identify any variation from 'normal' physical, mental and social development in the child and adolescent.	Demonstrate in-depth knowledge of physical, emotional and social development in children and adolescents. Demonstrate the ability to identify deviation from the 'norm' and possible/probable causes for this.
To perform appropriate mental health assessment(s) and utilise the information to implement relevant treatment/management plan for the pre-school child, school age child and adolescent.	Demonstrate an in-depth knowledge of approaches to mental health/psychological assessments. Demonstrate an in-depth knowledge of treatment/intervention strategies. Demonstrate the ability to implement treatment/intervention for the benefit of the child/adolescent and family/carer. i.e. empowerment
Recognise the impact of family dynamics on child/adolescent development.	Demonstrate an in-depth knowledge of family dynamics and their bearing on child/adolescent psychological, social and physical development. Demonstrate an understanding through the implementation of appropriate intervention strategy.
Debate different theoretical frameworks and their impact on approaches to management in child and adolescent mental health.	Demonstrate an in-depth knowledge of theoretical perspectives and their relevance to practice. Ability to acknowledge the influence of differing theories on practice.
Identify cultural factors which impact on the child/adolescent and family/carer response(s) Recognise sociological factors affecting the child or adolescent's psychological development.	To demonstrate an understanding of cultural issues affecting families from ethnic minority groups To demonstrate cultural awareness/sensitivity in approaches to treatment/management. To demonstrate in-depth understanding of Jarman scoring and similar indicators of sociological grouping

Module HH5H cont'd.

Clinical Competence	Outcome
Approach management/treatment in line with relevant legislation. (?need to address abuse as a separate competence)	To demonstrate an in-depth knowledge of legislation relating to child and adolescent mental health. To demonstrate ability to identify when legislation is influencing practice e.g. child protection.
The ability to work collaboratively with the child/adolescent and their family/carer	To demonstrate in-depth knowledge of underpinning theory in collaborative working. To demonstrate the ability to analyse when collaboration/partnership is not successful and how to address these issues.
To liaise with other professionals for the benefit of the child/adolescent and family/carer, e.g. education and social services.	Demonstrate an in-depth knowledge of other professional roles and how they may impact on the child/adolescent, therefore, affecting the management plan. Demonstrate the ability to work in partnership with these bodies.
Ability to acknowledge the boundaries of professional competence (reflective practice)	Demonstrate the ability to identify when to 'call in' other professionals for the benefit of the child/adolescent and their family/carer.
Ability to identify the opportunity for health education input when working with the child/adolescent and family/carer	Demonstrate an in-depth knowledge of approaches to health promotion issues and their possible long-term benefit to the child/adolescent and family/carer. The appropriate inclusion of health education in the management plan.
The ability to make a diagnosis relating to a child or adolescent with a mental health disorder, (i.e. not diabetes etc.)	The ability to utilise the information gained to reach a definitive diagnosis.
Utilise negotiation skills when setting goals, success criteria and appropriate intervention with the child/adolescent and family/carer.	Demonstrate competence to amalgamate in-depth knowledge, diagnosis and treatment and transfer this appropriately to the child/adolescent and family/carer.
The ability to demonstrate safe practice in an appropriate range of intervention skills and strategies.	Gain in-depth understanding of under pinning knowledge.

Module HH5J

Clinical Competence	Outcomes
The ability to identify the impact of organic factors on child/adolescent mental health	Demonstrate an in-depth knowledge of organic influences on child and adolescent mental health. Demonstrate how this knowledge impacts the intervention in relation to the child/adolescent and family/carer.
The ability to make a relevant contribution to a professional network meeting	Demonstrate the utilising of in-depth knowledge and professional competence to contribute to a professional network meeting (case conference).
The ability to interpret the results of psychometric testing (NB this is included, as a psychologist on the course would already have this skill so it possibly needs inclusion?)	Demonstrate an underpinning knowledge of psychometric assessment and the potential significance of the results.
The ability to identify delay in speech and language.	Demonstrate a theoretical underpinning of language development. Demonstrate appropriate inclusion of Speech and Language therapy within a management plan. Know when to 'call in' a Speech and Language Therapist.
The ability to identify specific mental health problems associated with different age groups, e.g. psychosomatic, anorexia nervosa.	Demonstrate an in-depth knowledge of mental health problems more prevalent in the following groups, pre-school age child, school age child and adolescent. Demonstrate the ability to implement an appropriate intervention plan.
Identify and address areas of 'risk' within Practice.	Demonstrate and in-depth awareness of issues relating to clinical practice.

APPENDIX C

COMMUNITY HOSPITAL REPORT

August 2000

Report on the exploration of Trandisciplinary Practice in Neurological Disability at Claypond's Hospital

Gill Allen, Associate Lecturer and Project Manager
Andree le May*, formerly Deputy Head of Department
Department of Health Studies
Brunel University

Financial support from West London Consortium NMET monies
Administered by Hounslow and Spelthorne Community and Mental Health NHS Trust

Address for correspondence
School of Nursing and Midwifery, University of Southampton, The Nightingale Building,
Highfield, Southampton, SO17 1BJ

Background

The impetus for this project stemmed from the ongoing work of the Transdisciplinary Project Team (facilitated by Hounslow and Spelthorne Community and Mental Health NHS Trust) and Brunel University. Members of this team sought to determine the feasibility of an innovative approach to the care of people with a neurological disability (Transdisciplinary Practice) with a group of practitioners working locally within the specialism. To this end the manager and staff of Claypond's Hospital were approached and agreed to be part of this exploration.

Transdisciplinary practice

Transdisciplinary practice aims to improve the quality of the client experience by enabling individual practitioners, who are already expert in meeting some of the needs of a particular client group, to extend their range of competencies and scope of practice in order to meet significantly more of these needs. There is recognition that many people who access health and social services have needs which cannot be met fully by practitioners who have trained in a single clinical discipline. This alternative is not generic working rather an approach which builds on expertise rather than dilutes it. Trandisciplinary practice recognises that although a body of knowledge spanning all potential disciplines is too great to enable people to be trained in this way, there remains a need to increase specialisation within the framework of a particular client group - in this case the person with a neurological disability. Transdisciplinary practice is conceived as moving beyond multi-disciplinary working and the notion of genericism.

The aim of transdisciplinary practice

The aim of this innovative form of practice is to enable clients and their carers to experience care which meets their needs in a fully integrated way through the involvement of fewer people in this process; thus preventing fragmentation of care and unnecessary overlapping of services and information gathering.

Transdisciplinary practitioners

The key characteristics of transdisciplinary practitioners are:

- **expertise** within their own uniprofessional discipline with regard to the client group with whom they practice
- **extension of their expertise** through the acquisition of key skills and knowledge from the complementary disciplines traditionally involved in the client's care
- **extension** of their traditional, uniprofessional scope of practice
- **insight** into the practices and philosophies of colleagues in other disciplines
- **recognition** of their individual boundaries and an ability to call in other experts as needed
- **ability to practice safely and effectively** within a clear framework of protocols and guidelines

The exploratory project - design

Against this background an exploratory project was undertaken with a representative group of practitioners working at Claypond's Hospital in May 1999. This project comprised 3 phases.

Phase One - Gaining Access and Sample Identification

Access to a sample of practitioners (secured in March and May 1999 via the Care Group Leader [PAMs] and Specialist Rehabilitation Care Group Leader). A self selecting purposive sample was identified which included:

- 1 Consultant Medical Practitioner
- 1 Senior Nurse Manager
- 2 Staff Nurses
- 1 Physiotherapist (Therapy co-ordinator)
- 1 Occupational Therapist
- 1 Speech and Language Therapist.

All members of this group attended a preparatory meeting when the project was explained and a series of dates for further focus group meetings was agreed.

Phase Two - The Focus Groups - An Exploration of Trandisciplinary Practice (the practitioners)

Three two-hour focus groups were convened in May 1999 to explore:

1. Opportunities for and Barriers to Transdisciplinary Practice using the Nominal Group Technique (May 13th)
2. The feasibility of using Transdisciplinary Practice using discussion of case studies brought by participants (May 19th and May 25th).

Phase Three - Individual Client and Staff Interviews - An Exploration of Transdisciplinary Practice

A selection of consenting clients (n = 7) were asked to discuss, during semi-structured interviews, how they thought their care could have been altered through the instigation of transdisciplinary practice. The client interviews took place in 21st and 29th September 1999. To complement this data the staff providing care for these clients were also interviewed (where possible) using a semi-structured format. These interviews took place in October 1999.

The exploratory project - findings

Phase Two - The Focus Groups - An Exploration of Trandisciplinary Practice (the practitioners)

Opportunities for and Barriers to Transdisciplinary Practice

Seven participants took part in this exercise. Each was asked to note three key opportunities and three key barriers to transdisciplinary practice. A comprehensive list of these was then recorded and participants were asked to vote (4 votes were allocated per participant) against this list. Opportunities (Table 1) and barriers (Table 2) are detailed below.

Table 1: Opportunities for Transdisciplinary Practice

Rank	Opportunity	Number of votes allocated
1	Better communication and co-operation between practitioners and family	6
2	24 hour rehabilitation service	5
3	Person-led service	4
4	Focus on what is clinically important	3
5	Increased job satisfaction	2
6	Increased skills and knowledge	2
7	More time with patients	1
8	Potential for increased salary	1
9	Better interprofessional understanding	0
10	Faster management of disorders	0
11	Better for patients - seamless service	0

Table 2: Barriers to Transdisciplinary Practice

Rank	Barriers	Number of votes allocated
1	Jack of all trades	6
1	Professional jealousy	6
3	Acceptance by patients	5
4	Isolation	3
5	Knowledge and skills	4
6	Tradition	2

7	Resources and conditions of working	2
8	Publicity to others	1
9	Time management - quality	1
10	Responsibility for documentation	0

Discussion of case studies brought by participants

Four case studies were brought by each professional group (nursing, physiotherapy, occupational therapy and speech and language therapy) represented at the remaining two meetings. The potential of transdisciplinary practice was explored for clients with the following diagnoses:

- stroke (three case studies)
- Parkinson's disease (one case study).

Each is described below focussing on the potential for transdisciplinary practice in each.

Mrs H

History and resume of care:

Mrs H was an eighty two year old lady who suffered a stroke on 26.01.99. She was admitted to Ealing Hospital, transferred to Claypond on 10.02.99 and discharged to a nursing home on May 4th. She continues to attend Claypond as an outpatient. She previously lived alone and was independent in all of her activities of daily living. She has close family, was previously very outgoing and a keen and active gardener.

Her stroke left her with the following residual impairments:

- right hemiplegia
- expressive and receptive dysphasia
- memory problems
- incontinence.

Potential areas for skills transference:

- Skills related to the management of incontinence from the Nurse to the Speech and Language Therapist
- Skills related to the establishment of alternative communication strategies from the Speech and Language Therapist to the Nurse
- Skills related to mobility from the Physiotherapist to the Nurse
- Skills related to washing and dressing from the Occupational Therapist to the Nurse

Issues raised:

- Isolation and loneliness in relation to breaking away from the conventional multi-disciplinary team and all that is good about that

- Nothing left to do for individual specialist
- The stage at which transdisciplinary practice occurs - some merit in maintaining traditional practice during acute phase of illness and then moving to transdisciplinary model during the less acute, maintenance phase of the illness
- Which set of patients would benefit the most from this type of practice?

Mr S

History and resume of care:

Mr S is 93 years old. He was transferred from Ealing Hospital to Claypods 5 days after admission following a stroke. He lived with his wife and was fiercely independent in all his activities of daily living. Prior to hospitalisation he was able to drive, walk, garden and manage all his affairs.

Following his stroke he was left with the following residual impairments:

- right hemiplegia
- aphagia and PEG
- dysphasia
- depression
- stress incontinence
- constipation
- general lethargy, weakness and frailty

Potential areas for skills transference:

In this instance one person was thought able to provide most of the care required by Mr S through "extended roles". The key issue in this man's care was the need for one person to develop a strong link with him.

Issues raised:

A transdisciplinary practitioner was considered to have potential in this case since there was only one major difficulty to be addressed.

Mr SS

History and resume of care:

Mr SS is a 73 year old man who was admitted to Ealing Hospital on June 29th 1998, he was transferred to Claypods on August 24th and discharged to his own home in the 28th January 1999. He lives with his wife and brother. Previously independent in all his activities of daily living he enjoyed driving and visiting friends and family.

Following his stroke he was left with residual disabilities related to:

- left hemiplegia
- dysphagia and PEG feeding
- cognition and problem solving

- emotional lability

Potential areas for skills transference:

The Speech and Language Therapist was the identified key worker in this man's care and the group identified that is certain skills were transferred this practitioner could have moved towards transdisciplinary practice.

- Skills related to seating, posture and transfer from the Physiotherapist and Occupational Therapist to the Speech and Language Therapist
- Skills related to chest physiotherapy from the Physiotherapist to the Speech and Language Therapist
- Skills related to PEG management from the Nurse to the Speech and Language Therapist

Issues raised:

- Inefficient dealings with social services regarding housing. This could have been enhanced if a single practitioner had been involved
- Discussion of plateau reached after each individual practitioner has "finished" their part in the rehabilitation process - would a transdisciplinary practitioner minimise deterioration during the period prior to discharge - or hasten discharge if they could move through to provide some care in the community

Mrs C

History and resume of care:

Mrs C is a seventy five year old lady who was admitted to Ealing Hospital on 29.01.99 due to poorly controlled Parkinson's Disease and falls. She was transferred to Clayponds on March 9th 1999.

Following admission she retained the following residual impairments:

- general stiffness
- depression
- moderate dysarthria

Potential areas for skills transference:

- Skills related to swallowing from the Speech and Language Therapist to all other members of the team
- Skills related to home adaptation from the Occupational Therapist to all other members of the team
- Skills related to the identification of depression from the Doctor, Psychologist, Nurse to all other members of the team

Issues raised:

- Complex situation linked to inability to provide the right package of care to Mrs H and her aunt who lived with her. Community focussed transdisciplinary practitioner may have been able to facilitate this.

General discussion

Several key issues arose from the general discussion which followed the completion of each case and the exercise as a whole. These are detailed below:

- The need to have one Transdisciplinary Practitioner for each specific client group (e.g. stroke, Parkinson's disease, multiple sclerosis)
- The stage at which transdisciplinary practice occurs - some merit in maintaining traditional practice during acute phase of illness and then moving to transdisciplinary
- The gap between health and social services which led to:
    - time wasting
    - duplication related to assessments
    - overspending on hospital focussed provision
    - difficulties in adjustment between hospital and home.

Phase Three - Individual Client and Staff Interviews - An Exploration of Transdisciplinary Practice

Seven clients from Clayponds Hospital consented to be interviewed. They were asked to discuss their experiences of care and ways in which the instigation of transdisciplinary practice may alter their care. The clients' comments are documented as recorded during interviews.

Each client had a designated named nurse and key worker. Their grade and discipline are detailed in Table 3

Table 3 **Grade and discipline of named nurse and key worker**

	Named Nurse	Key Worker
Mr B	Staff Nurse	Staff Nurse
Mrs M	Staff Nurse	Staff Nurse
Mr W	Staff Nurse	Occupational Therapist
Mrs C	Staff Nurse	Physiotherapist
Miss B	Staff Nurse	Occupational Therapist
Mrs E	Staff Nurse	Occupational Therapist
Mr S	Enrolled Nurse	Enrolled Nurse

Mr S's story of his stroke

How has it been so far...?

"Got from home to the A and E pretty quick but then spent from 1930-1530 the following day on a trolley in the corridor, that was awful and oh, the noise! Spent a week in that hospital, the nurses looked after me and I saw the physio, one a day, every day, Monday to Friday. Then, of course, here to Clayponds. Been here six weeks now.

I had my stroke the day before getting my new dentures, so I haven't had any teeth until a couple of days ago. Eating hasn't been easy. Haven't had much of an appetite though. I've asked everyone, 'why me?' Why did I have a stroke? What was the cause? I mean, I want to know, in case there is anything I can do to stop me having another one. No one can tell me. Me, I reckon, it could be the smoking. I promise to give it up soon. The wife is worried too. No one has told her why I had a stroke either. I'm on some extra tablets now. Keep asking what they're for, but no one can tell me. But the staff know best, so if they say I must take them, then so be it.

The O.T. is sorting things out at home, getting rails and things to help me. Haven't been home yet. Going next week to see how I get on."

How it could have been...?

"So many people involved, perhaps if one person, don't know who that would best be, but someone who you knew, knew everything that was going on, or could find out anyhow. Like why I had the stroke? What those new tablets are for? To let my GP know, cos when a nurse eventually did contact my dentist about getting my dentures over to the hospital, the dentist phoned my GP to check if it was OK and my GP said he didn't know I was in hospital, let alone had a stroke. Perhaps if the GP had of known, he might have popped round to see the wife and keep an eye on her and her nerves."

Unable to interview named nurse/key worker.

Mrs E had had a stroke and was also very deaf

How has it been so far...?

"Had the stroke. I knew what it was. Got taken to hospital, not here. Stayed in bed for two days, then got moved here. Much better here. Can move about as you please, for a start. Can't fault anything here. Everything is excellent. The whole team work well together. The food is good, ward is clean and tidy, you know. I'm a bit worried as to why I'm on an Aspirin a day though, that's the only thing."

How it could have been...?

"Nothing different really, sorry I can't say any more"

Comments from the Staff Nurse & Occupational Therapist (named nurse and key

worker)

“We don't have a S/W at the moment, so just so much time is taken up with sorting out what he/she should be doing, especially around housing issues. Keeping the family informed and up to date as well. Sorting out the benefits too; it's all very frustrating because we don't really know enough about it all, so it takes us longer.”

“Mrs E's morale is dropping now. She has plateaued as regards her functional recovery. So now she is just waiting and waiting to have her housing issues sorted out. This is not good, wasting time and money.”

Miss B’s story of her stroke

How has it been so far...?

“I was in the other hospital for six weeks before I came here, like it better here. I really enjoy the physio best of all, but you don't get any on a Saturday or Sunday; in fact you don't do anything then and it's boring. Sitting in a chair all day, I get a sore bottom. Apparently I had high blood pressure and that was the cause of my stroke as they say. I'm on extra tablets now. My GP didn't know I was in here to begin with, no one had let him know.”

How it could have been...?

“Physio every day, weekends shouldn't be any different, that's all.”

No comments from the Staff Nurse and Occupational Therapist (named nurse and key worker)

Miss B has suffered two further strokes since the interview and is now semi conscious. Her care plan has now completely changed, at present she is medically unstable. After her second stroke (this occurred when the SALT was not on duty) a S/N who had been taught by the SALT how to perform a swallowing assessment, was able to carry this out, otherwise there may have been a considerable time delay, until after the weekend when the SALT came back.

Mr W’s story of his stroke

How has it been so far...?

“I can remember everything, all the dates. In the first hospital from 12th August until 24th August. Since then I've been here and boredom is what is killing me, not the stroke. The boredom, do you get that, boredom? The patronising is foul and not good diplomacy. I'm not stupid. I can reason. Just because I can't speak very well, doesn't mean that I can't think, in fact all I do is think.

Why they don't tell you things, I don't know. It's killing me this no explanation business. They must all be truthful with me. My father had a stroke and coped for ten years from 1958 to 1968 until he died. Don't tell me there isn't any connection between the two of us both having strokes in our 40s.

To me, a holistic approach means not just the physical but the mind and soul as well. The physical is very important of course, I realise this, but my soul needs to be included with the programme. My soul is my thinking part, part of my individuality and now part of my stroke."

How it could have been...?

"If they want to increase throughput and decrease unnecessary waiting time here (when it isn't necessary), then they need to increase the ratio of staff to patients, quite simple, the staff each have too much to do, they end up not doing their jobs well anyway. Most patients need a 1:1 with a social worker. The O.T. in my case is doing the best she can to chase things up, I live in Bedfordshire, just to complicate things, you know, different areas, more red tape, more referrals. It's all you hear about, more paperwork. Some person needs to be able to press the button for everything to work all in synchronisation, instead we get segmentalisation and so much time wasting and duplication."

Comments from the Occupational Therapist (keyworker)

"So much of my time has been spent doing the social worker's role (we don't have one on the ward at the moment). As Mr W lives in Bedfordshire, I have to liaise and refer to the S/W, OT, etc there, it isn't easy. It's not that I mind really, it is just the time factor which means that I can't spend my OT time with him thinking about his occupation and his activities of daily living. The Transdisciplinary Practitioner role would be great, at the moment, we're trying to do both, but with our original size case load and it simply can't be done.

I hope there won't be much duplication in assessments, but I somehow fear that there will be, so as soon as Mr W gets to Bedfordshire, everyone will ignore my work and just assess all over again."

Mr B's story of his stroke

How has it been so far...?

"I had my stroke on 27th August 1999. I'm not surprised, I've been feeling giddy for over a year now and I put it down to all the stress and strain of caring for the wife.

They concentrate on my walking a lot, well that's their job, isn't it, to get me walking again, but all I'm concerned about is how am I going to cope when I get home. Just what is going to happen? Why can't someone tell me that?

My wife has now been admitted to the hospital where I was, I've asked if she can't come here, so that we can be together, but it is all too complicated or something. She hasn't had a stroke, something wrong with her waterworks. She wasn't drinking properly, so they say, dehydrated

I suppose. Anyway, she can't come here and I can't go there. All I want to do is just see her.

There are such long gaps in the day when you're not walking, so other patients either eat or sleep, but I can't do much of either. I just want to be with my wife. We've never been apart all our married life.

I don't know how I'm going to cope, no one can tell me. How am I going to go shopping and cook the food. I have a stair rail at home, but I'll need more help than that. If she can't hold her water anymore, then I'll never cope with all the washing.

I'm due to go to Moorfields Hospital to have my other cataract op, but I won't be able to have that done now, I don't suppose."

How it could have been...?

"Someone to help my son sort out getting us both into a home down in Sussex, near to him and the grandchildren. I can't cope with this stress anymore. There isn't a Social Worker, so they say."

Comments from Staff Nurse (named nurse and key worker)

"The absence of a social worker is really crucial for Mr B. Further assessments are needed before he and his wife can be considered for a Nursing Home. So more money, keeping him in hospital and more money on more assessments. I would like to do more for his family especially, they have a right to have access to information about why their Dad had a stroke, teaching them about the risk factors, etc. There needs to be more follow up for the 'at risk' elderly in the community. Perhaps neither Mr or Mrs B would be in hospital now if an appropriate care package had been in situ, who knows?

So long as I don't loose my speciality as a nurse, then I think the idea of a Transdisciplinary Practitioner is great.

It took some time to organise, but I did manage to get Mr W to see his wife, three times now, so that felt good. Weekends would be ideal, but we have so much extra duties/tasks to do then and you might be the only qualified member of staff on."

Mrs C has Parkinson's Disease as a result of a fall, she has broken her right head of humerus and right neck of femur

How has it been so far...?

"It's such a long story, where do you want me to start? Because I was in Poole on holiday, when I had the fall. The nurses made sure I had a bed by the window so I could see the view, that was a nice thought. They were very good, kind and caring about my pain, I was so helpless. What with broken bones and the Parkinson's; I was on a gynae ward for a few weeks as they didn't have any beds anywhere else, so I didn't get any 'special care' for my fractures or my Parkinson's, but they all did the best they could.

Then I came back here. I see a physio to help me with my walking, the OT helps me with getting washed and dressed. I'd like to see Lynne the Parkinson's nurse. I know she'd visit me if she knew I was here, but it's all to do with communication here and getting people to know. My GP didn't know about my fall until very recently, Poole didn't let him know."

How it could have been...?

"I just want to get back home and look after my elderly Aunt again (she is still down in Poole in a nursing home, waiting for me to get better).

Someone to coordinate and organise everything. You know what I mean? The house, getting my Aunt back, getting me home and obviously Social Services will have to come in to begin with."

Comments from the Staff Nurse and Physiotherapist (named nurse and key worker)

Mrs C needs much support, supervision and confidence to get her back to where she was prior to her fall.

Without a S/W it is difficult pulling everything together, trying to get carers to look after Mrs C and her elderly Aunt instead of two separate teams of carers, all very frustrating. We're trying our hardest to work as a team, but social services are a big piece of the jigsaw missing. It's a pity there isn't more time to do more rehab with her at the weekend, but we just are so busy, but definitely there isn't enough happening for patients at the weekends.

Mrs M's story of her stroke

How has it been so far...?

"When I had my stroke, I was in the first hospital for six weeks, didn't do much there. They make you work so much harder here, but it is good for you I suppose. Sometimes, I feel as if they're treating me like a kid, like I'm 'dopey' or something. But I'm not. I do sleep a lot, but only because I'm bored, especially at the weekends, all there is is TV and football is on all the time.

I'm worried about my husband. He's not eating properly, when he comes into see me, we have nothing to talk about now, we used to talk all day long when we were at home together."

How it could have been...?

"Someone surely can sort things out so that my husband can be helped to look after me... and if I could do the cooking again to make sure he is eating properly."

Comments from the Staff Nurse (named nurse and key worker)

Sadly, I feel that Mrs M is deteriorating and has developed incontinence problems. She reached her potential and was then just waiting for Social Services. Her husband now feels that he won't be able to cope with his wife at home. If there hadn't have been this delay, may be, they would have been at home together, too much valuable time lost.

Key issues for further consideration

From the clients' perspective:

- Lack of information about diagnosis
- Not being given knowledge about medication
- Unacceptable time delay in social services 'producing the goods'
- Too boring at weekends, not enough 'therapy'
- Staff can at times patronise
- Too many assessments, too much repetition and duplication

From the staff's perspective:

- Not enough trust between professions to accept each other's assessments
- Too much time delay by all segments of the "system"; not getting their act(s) together (health and social services)
- Emphasis on one patient:one practitioner - continuity of care and service provision

In general:

- Skills, knowledge, attitudes and expertise are essential
- A deeper understanding of where each profession is coming from ... and going to ... is required
- Enhanced awareness of carers who become patients and the impact of providing care is required
- The substitution of the notion of "calling in" rather than "referring out" to specific expertise should be considered
- Increased user and carer involvement in the rehabilitation programme is recommended ensuring partnership with one professional wherever possible
- Any reduction in the paperwork and administration would be welcomed

APPENDIX D

CONFERENCE SLIDES
CONFERENCE PROGRAMME

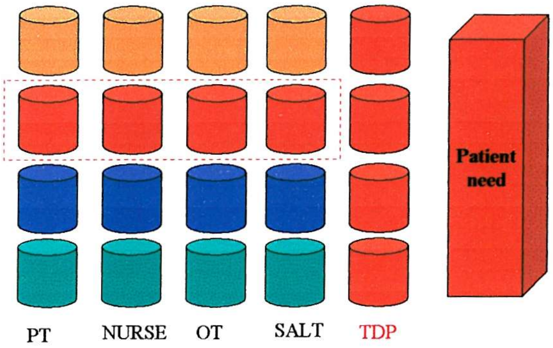
Welcome

Transdisciplinary Practice Conference

We aim to improve

- The experience of patients and their families.
- The career development of clinicians.
- The cost-effectiveness of healthcare.

Re-assembling expertise



What we build on

- Shared expertise
  - Anatomy and physiology.
  - Clinical problem solving.
- Client group knowledge and experience.
- Working with patients and families.
- Recognising limitations.
- Accessing other expertise.

What we transfer

- Clinical skills.
- Underpinning knowledge.
- Paradigms and mental models.
- Values and beliefs.
- Quality standards.
- Notions of safe practice.

What we add

- Multiple perspectives.
- Insight into other professions.
- Care management skills.
- Patient partnership skills.
- Research skills.
- Evidence based practice.
- Service management skills.

An enabling framework

- Evidence-based packages of care.
- Consultant opinion and expertise.
- Clinical supervision.
- Extended scope of practice.
- New authority.
- Reduced case loads.
- A transdisciplinary team.

An educational framework

- Mastery.
- Learning exchange.
- Problem-based learning.
- Clinical competence framework.
- Client group specific learning.
- Common modules.

For patients and families

- A practitioner who can meet most of their needs.
- Fewer different people providing care.
- Properly integrated and managed care.
- A truly holistic approach.
- An expert partner.

For clinicians

- A longer career ladder.
- Valuing of their current expertise.
- Developing new expertise.
- Being able to meet more of the needs of their patients.
- Having the power to make things happen.
- Less time wasting.

For “jugglers”

- Lower cost per case.
- Fewer bottlenecks.
- Retaining clinical staff.
- Sensible workforce planning.
- Ways of measuring outcomes.
- Less lost time.
- Happier patients and families.

The Modules

- Client centred practice.
- Service Management.
- Clinical effectiveness.
- Research skills.
- Specialist clinical 1
- Specialist clinical 2
- Dissertation.

Transdisciplinary Practice Conference

Aim

To enable participants to evaluate the potential relevance and usefulness of a programme to develop practitioners with a range of competences which cross over traditional professional boundaries.

Target audience

Lead clinicians.
Directors of Nursing.
Directors of Therapy Services.
Service commissioners in Health Authorities or PCGs.
Chairs or Chief Executives of Education Consortia.
Directors of Human Resources.

Programme

09.30 - 10.00	Registration and coffee.	
10.00 - 10.30	Linking service need and education - a strategy for a modern workforce.	
10.30 - 11.15	The principles and potential benefits of transdisciplinary practice.	
11.15 - 11.30	Coffee.	
11.30 - 12.00	Opportunities and concerns - small group discussion to identify immediate reactions to the ideas in the programme.	
12.00 - 12.45	Sharing our views on opportunities and concerns.	
12.45 - 13.30	LUNCH	
13.30 - 14.00	Benefits for patients - a case study presentation.	Gill Allen and colleagues from Clayponds Hospital.
14.00 - 14.30	Practical issues for clinicians and patients.	Small group work with clinicians who have been involved in the project.
14.30 - 15.00	Creating a career path for clinicians.	
15.00 - 15.15	Tea.	
15.15 - 16.00	Questions and answer forum.	
16.00 - 16.30	Moving forward - the next steps	

List of references

Argyris C (1993) *Knowledge for Action: A Guide to Overcoming Barriers to Organizational Change.* San Francisco CA. Jossey-Bass.

Argyris C and Schon DA (1974) *Organizational Learning: Theory of Action Perspective.* Reading MA. Addison-Wesley.

Argyris C, Putnam R, and Smith D (1985) *Action Science: Concepts, Methods, and Skills for Research and Intervention.* San Francisco, CA. Jossey Press.

Argyris C (1982) *Reasoning, Learning and Action: Individual and Organisational.* San Francisco. Jossey-Bass.

Argyris C (1992) *On Organisational Learning.* Oxford. Blackwell.

Argyris C and Schon DA (1996) *Organizational Learning 11: Theory, Method and Practice.* Reading MA. Addison Wesley MA.

Bloor M (1977) '*Professional autonomy and client exclusion: a study in ENT clinics*', in Wadsworth M and Robinson D *Studies in Everyday Life.* London:Martin Robinson.

Bruner J (1960) *The Process of Education.* Cambridge Mass. Harvard University Press.

Buzan A (1993) *The Mind Map Book.* London. BBC Books.

Dale B and Copper C (1992) *Total Quality and Human Resources.* Oxford. Blackwell.

Davis A and Horobin g (eds) (1977) *Medical Encounters: The Experience of Illness and Treatment.* London. Croom Helm.

Delbecq, Andrew L, Van de Ven, Andrew H, and Gustafson, David H (1975) *Group Techniques for Program Planning, a Guide to Nominal Group Technique and Delphi Processes.* Scott Foreman.

Dennett DC (1995). *Darwin's Dangerous Idea: Evolution and the Meanings of Life.* London, UK Penguin.

Department of Health (DOH) (2000) *The NHS Plan.* London. The Stationery Office.

Department of Health (DOH) (2001) *Shifting the Balance of Power within the NHS – Securing Delivery.* London. The Stationery Office.

Department of Health (DOH) (2000) *The Cancer Plan.* London. The Stationery Office.

Department of Health (DOH) (2001) *The Expert Patient*. London. The Stationery Office.

Department of Health (DOH) (1998) *A First Class Service: Quality in the new NHS*. London . The Stationery Office.

de Raeve L (ed) (1997) *Nursing Research: An ethical and legal appraisal*. London. Bailliere Tindall.

Dewey J (1933) *Logic: The Theory of Inquiry*. New York. Holt, Rinehart & Winston.

Eraut M (1994) *Developing Professional Knowledge and Competence*. London. Falmer Press.

Exploring Clinical Practice (2001) London. West London Workforce Development Confederation.

Friedman VJ (1998) as cited in Handbook of Action Research 2001

Friedson E (1983) '*Theory of the professions: the state of the art*' in Dingwall R and Lewis P. *The Sociology of the Professions*. London. Macmillan.

Foucault M (1980) '*The eye of power*' in Gordon C (ed) *Power/Knowledge*. Brighton. Harvester.

Gardner H (1984, 1985) *The Mind's New Science*. New York. Basic Books.

Glaser B and Strauss A (1966) *The Discovery of Grounded Theory* .Strategies for Qualitative Research. Chicago.

Goffman, E. (1968) *Stigma:Notes on the management of spoiled identity*. London. Penguin.

Heron P and Reason P (1991) *Participatory Action Research*. London Sage Publications.

Heron J (1981) '*Philosophical basis for a new paradigm*', in Reason P and Rowan J (eds) *Human Inquiry: a Sourcebook of New Paradigm Research*. Chichester. Wiley.

Heron J (1996) *Co-operative Inquiry: Research into the Human Condition*. London. Sage Publications.

Hoerr J and Pollock MA (1986) *Management discovers the human side of automation*. Business Week. Washington.

Holloway I and Wheeler S (1995) *Qualitative Research for Nurses*. Blackwell Oxford.

Josselson R (ed) (1996) *The Narrative Study of Lives- narrative psychology*. London. Sage Publications.

Josselson R (ed) (1996) *The Narrative Study of Lives-lived experience.* London. Sage Publications.

Kember D (2000) *Action Learning and Action Research.* London. Kogan Page.

Kimball Fischer (2000) *Leading self-directed work teams.* New York. McGraw Hill.

Leathard A (1994) *Going Inter-professional: Working Together for Health and Welfare.* London. Routledge.

Leslie H and McAllister M (2002) '*The benefits of being a nurse in critical social research practice*' Qualitative Health Research. Vol 12. No 5.

Lewin K (1946) *Action Research and minority problems.* Journal of Social Issues.

Lewin K (1951) *Resolving Social Conflicts.* New York. Harper & Row.
Lippit GL (1973) *Visualising Change.* California. University Associates.

Mazijoglou M and Scrivener SAR (1998) '*The rich picture of design activity*', *Automation in Construction.* Elsevier Science, Vol 7.

Morgan G (1998) *Images of Organisation.* London. Sage Publications.

Morgan G (1997) *Imaginization: New Mindsets for Seeing, Organizing and Managing.* San Francisco. Berrett-Koehler.

Morgan DL (1988) *Focus Groups as Qualitative Research.* London Sage

Moss Kanter R (1989) *When Giants Learn to Dance.* London International. Thompson Business Press.

National Co-ordinating Centre for NHS Service Delivery and Organisation Research and Development (NCCSDO) (2001) *Continuity of Care.*

National Co-ordinating Centre for NHS Service Delivery and Organisation Research and Development (NCCSDO) (2000) *National Listening Exercise : Report on Findings.*

Paris R and Bradley CL (2001) *Qualitative Health Research.* Vol 11, No 5.

Psathas G (1995) *Conversation Analysis: the study of talk-in-interaction.* London. Sage Publications.

Reason P (ed) (1994) *Participation in Human Inquiry.* London.Sage Publications.

Reason P and Bradbury H (eds) (2001) *Handbook of Action Research – Participative Inquiry and Practice.* London. Sage Publications.

Reissman CK (1993) *Narrative Analysis.* London. Sage Publications.

Royal College of Nursing (RCN) (1998) *Research Ethics*. London RCN.

Schon DA (1974) *Theory in Practice*. Jossey Press.

Senge PM (1993) *The Fifth Discipline*: the Art and Practice of the Learning Organization. London. Century Business.

Stacey RD (2001) *Complex Responsive Processes in Organisations*. London Routledge.

Sykes JB (ed) (1982) *The Concise Oxford Dictionary*. Oxford. Clarendon Press.

The Audit Commission (2000) *The Way To Go Home: rehabilitation and remedial services for older people*. London. Audit Commission.

UKCC (1992) *The Scope of Professional Practice for Registered Nurses, Midwives and Health Visitors.*

Vezeau T M (1994) Qualitative Health Research Vol 11, No 5, Sept 2001

Wenger E (1998) *Communities of Practice: Learning, Meaning and Identity.* New York. Cambridge University Press.

Wenger E , McDermott R and Snyder WM (2002) *Cultivating Communities of Practice*. Boston. Harvard Business School Press.

Wenger E and Snyder WM .(Jan-Feb 2000 p 139-145) ‘Communities of Practice: The Organizational Frontier’. Harvard Business Review.