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User involvement and improving quality of health and social care.

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User involvement and improving quality of health and social care

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Contents

1 Chesson R., Stephenson E., & McKay C. (1990) Motor/learning difficulties and the family, *Child; care, health and development* 16: 123-138.

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3 Chesson R. & Sutherland A. (1993) Self reported disability in six electoral districts in Grampian. *Health Bulletin.* 51, (3), 141 - 150.

4 Sutherland A. & Chesson R. (1994) The needs of physically disabled people aged 16-65 years and service usage. *British Journal of Occupational Therapy* 75 (5) 171-176.

5 Chesson R., Massie, S. and McLeod, M. (1996) Outcome measures used in therapy departments in Scotland. *Physiotherapy* 82, 12, 673-679 .

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7 Hart C. & Chesson R. (1998) Children as consumers. *British Medical Journal,* 316, 1600-1603.

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Abstract

The aims of the work presented have been to: i) extend knowledge of the social interactions which affect health and social care delivery; and ii) improve the quality of health and social care through an increased understanding of patients'/clients' needs and factors which influence professionals' practice. The main considerations in selecting the work presented include the desire to provide a representative sample of output and ensure the inclusion of the most significant work published to date. All the articles are within the parameters of health services research which is described in Section 1 and its relationship with the sociology of health is considered. An important aspect of the work presented is the development of appropriate methods of enquiry. In Section 2, the nature of my contribution to understanding of health and social care provision is discussed with particular reference to neurological disorders and therapy services; patient involvement in decision making; clinical practice; multi-disciplinary working and innovative service provision. Finally, the originality of the work is considered and identified as being with regard to: the research methods developed; the novel areas investigated; the emphasis placed on inter-agency and multi-disciplinary working; the development of socio-clinical research and methods of dissemination. Section 3 examines the impact of my research, not only on service provision but also the evolution of health services research. In addition, the impact of my published areas of work on recent research themes, such as patient knowledge and respite care, is discussed. In the concluding section, (Section 4), the consistency of my application to key themes is highlighted. Finally, the current status of health services research is reviewed and the current and future role of social scientists in contributing to health and social care improvement is examined.

Part A

Report

1 INTRODUCTION

The aims of the work presented have been to:

1) extend knowledge of the social interactions which affect health and social care delivery;

2) improve the quality of health and social care through an increased understanding of patients'/clients' needs and factors which influence professionals' practice.

1.1 Public output presented

The 10 papers and one chapter presented represent approximately 10% of all publications produced between 1990 and the year 2000. When the total output is considered including, for instance, conference presentations, this percentage is reduced further (Appendix 1). The main considerations in selecting the work presented were:

- to provide a representative sample of output;
- to ensure that a range of research designs and research populations were included;
- to present work completed across the entire 10 year time period;
- to include articles published in a range of journals;
- to ensure the inclusion of the most significant work published to date.

Main theme

The main focus of the work presented is on the needs of those with disabilities, especially service users, such as children, who are often excluded from consultation about health and social care. An integral part of the theme is the development of appropriate methods of enquiry which are acceptable to participants as well as the research community and which encompass quantitative and qualitative approaches. All articles are within the parameters of health services research.

1.2 Conceptual and theoretical context of health services research

1.2.1 Health Services Research

Health services research is the term applied to research relating to health and social care. It includes service delivery and organisation and policy issues, and the development and application of new health technologies, encompassing behavioural technologies, as well as interventional procedures, including pharmaceutical therapies. It is concerned also with the development, implementation and evaluation of new research, together with barriers to the implementation of evidence based practice. It covers primary, secondary and tertiary health care and the interface between them. With increasing emphasis on care in the community, aspects of social care are increasingly being subsumed into the research agenda. Thus, given the scope of activities incorporated within the term, it warrants further consideration.

1.2.2 The development of health services research in Britain

Health services research during its early years was closely allied to hospitals and Medical faculties. In fact, health services research has a history as long as clinical medicine in the University of Cambridge. At the inception of the Cambridge School of Clinical Medicine, a Health Services Research Group (HSRG) was planned and staff were in post in the School's first year. Reflecting a common trend, Cambridge's HSRG is part of a configuration that comprises the General Practice and Primary Care Research Unit in the Department of Community Medicine and is located within the Institute of Public Health. Today, the Group describes itself as undertaking ' applied social science research in the field of health and illness focusing specifically on medical treatments in their widest sense'. In order to achieve this, staff are drawn both from clinical areas such as medicine and nursing, but also include psychologists, economists and sociologists. Although economists became more influential during the Thatcherite years of the 1980s, both psychology and sociology have played a significant role in providing a conceptual underpinning for health services research. In particular, in recent years as qualitative research has become more commonly used by health services researchers (Black et al, 1998), sociology has had an increasingly important part to play.

1.2.3 The contribution of sociology to health services research

Sociology contributes to three main areas as follows:

(i) *Critical analysis of health care.* During the 1950s, both in Britain and the USA, medical sociology established itself as an academic discipline based on the methods and theories of mainstream sociology as applied to medicine (**30**). While in its early days the discipline by nature was sociology in medicine, within a remarkably short time it became the sociology *of* medicine. Indeed, the medical profession itself became the subject of investigation and American sociologists in particular examined critically the power of doctors (Zola, 1972) and pointed to the 'medicalisation of social life' (Illich, 1978). In less than two decades, sociologists developed their own research agenda published in new journals, which helped to establish their autonomy. In Britain, the Medical Research Council established a Sociology Unit. Incorporation within medicine, as a 'paramedical' profession has never occurred.

This autonomy has had important implications for the analysis of health care. Situated outside the system and educated apart, sociologists brought a new vision. Cherished assumptions were challenged and different questions were asked from those of professionals trained within the confines of a medical curriculum. From the subject's earliest days, medical sociologists opened up new and fruitful areas for investigation. For example, early sociological surveys helped to establish the importance of patients' views of treatment and care as well as the unintended consequences of health care (Goffman, 1963).

(ii) *The social context of health and illness.* Sociological work has consistently demonstrated that health and illness are socially constructed. Nowhere is this better illustrated than in the work of Brown and Harris (Brown & Harris, 1978) whose research on the social origins of depression continues to be influential in psychiatry today. Such a contribution may not have been possible without the utilisation of research methods associated with qualitative approaches.

(iii) *The development of research tools.* Qualitative methods have been described as having an 'enormous potential to illuminate the impact of care on patients'. (Fitzpatrick & Boulton, 1994) Health professionals may find qualitative methods more acceptable today compared with in the past, given that they have been exhorted to discover patients' existing knowledge, 'rather than treat them as empty vessels into which "appropriate" knowledge can be poured'. (Petchey & Murphey, 1992) Qualitative methods in medical and health publications are being promoted currently, 30 years after they were advocated in sociological journals. Their strength lies in their ability to establish 'meanings' achieved through the ability to view behaviour through the eyes of participants in social interaction. The fact the qualitative approaches are underpinned by decades of anthropological research provide them with a significant theoretical base. Therefore qualitative methods seek to establish or enhance understanding of social phenomena.

The book, *The Meaning of Disability*, (Blaxter, 1976) has had a major influence, for example, on disability research and subsequent work has confirmed that services need to be well co-ordinated (Beardshaw, 1988) and that continuity of care is crucial (Anderson, 1992). With care in the community, a common fear is that the quality of care will be compromised. Sociological research which showed that long stay care was dehumanising for patients through such practices as 'identity stripping' (Jones & Fowles, 1984) and 'batching' (Jones, 1972) has tended to be forgotten. High quality care, however, may be provided by family members in the community, who offer comfort, companionship, and respect dignity (Twigg & Atkin, 1994). Although early studies highlighted the strain on carers (Anderson, 1987) and the extent to which women were relied on (Finch & Groves, 1983), subsequent research has shown that caring can provide satisfaction (Qureski & Walker, 1989) and give purpose to life (Townsend & Davidson, 1982). Sociological theories and studies on the family and community - important foundations for the discipline - are vital in providing a framework for understanding and planning community care. Recent trends regarding care in the community show just how important it is to consider the social and organisational context of health and social care.

1.3 The social context of the research output

During the last decade, significant developments have taken place within British society and its health and social care systems. It is not possible within the confines of this report to examine in detail the relevant aspects. Therefore merely some of the key changes and trends most relevant to my work are outlined below:

(i) An increasing proportion of the population over 65 years and growing numbers of people with disabilities (Melzer et al, 1999).

(ii) Changes in government health and social care policy, most apparent in the change from a Conservative to Labour administration during the decade (Spurgeon, 1998).

(iii) Changes in health and social care provision and methods of service delivery, evident in the creation of the internal market, NHS Trusts and GP Funding Holding (Spurgeon, 1998).

(iv) Changes in social attitudes towards people with disabilities and changes in the expectations of those with disabilities (Oliver, 1990), reflected in passing of the Disability Discrimination Act in 1996.

(v) An increasing focus on social aspects of disability, emphasising disabling aspects of society (Oliver, 1998).

(vi) Trends towards a consumerist society, which has become manifest in health and social care (Spurgeon, 1998).

The published work presented (Box 1) is a product of the interaction between a changing environment and the research questions asked by the candidate. In Section 2, discussion focuses on how family, health and social care professionals and social relationships are affected by disability and the extent to which users' priorities shape care and treatment (aim 1). Section 3 considers how the selected publications have impacted on health and social care, especially in improving quality of care (aim 2). In section 4, the implications of the work are discussed, especially regarding social theories of disability.

Box 1 : Publications presented

1 Chesson R., Stephenson E., & McKay C. (1990) Motor/learning difficulties and the family, *Child; care, health and development* 16: 123-138.

2 Chesson R. & Sutherland A. (1992) General practice and the provision of information and services for physically disabled people aged 16 to 65 years. *British Journal of General Practice.* 42, 364, 473-476.

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2 CONTRIBUTION TO UNDERSTANDING OF HEALTH AND SOCIAL CARE DELIVERY

2.1 Health and social care provision

Developments in government policy regarding health and social care have been crucial to my work. The early papers presented on physical disability (**2, 3, 4**) were undertaken in the context of major changes occurring in health and social care following the implementation of the 1990 NHS and Community Care Act. Not only was there major reorganisation within the NHS, but also health care providers had to develop new ways of thinking and models of care (Spurgeon, 1998). Care in the community necessitated that greater attention was paid to marital and family relationships as these are crucial to independent living for people with disabilities. Family relationships and family life, in fact, were major elements in my early research and are reflected in later work regarding social support (24, 29, 33, 35, 52, 86, 94, 109). Work with children with motor learning difficulties demonstrated how their lack of co-ordination had a major influence, not only on family relationships, but also family routines and everyday life. Later, work with people with Parkinson's disease also highlighted that as levels of disability increased, family relationships became of greater significance, and patterns of social interaction were dislocated by disabilities and impacted on quality of life (**9**). Indeed, the people interviewed described how former social interests and activities had to be abandoned, not necessarily as a result of their own impairment, but because of other people's response who were embarrassed, for example, by their tremor.

Neurological disorders and therapy services

Over the years, my research on physical disabilities has become more disease specific and has increasingly focused on neurological disorders, especially Parkinson's disease and multiple sclerosis. By investigating the perspectives on quality of life held by people with Parkinson's disease, together with those of their therapists, new insights were obtained on the nature of therapeutic relationships. This work, in particular, highlighted that patients' central concerns may not be met by current health care provision; psychosocial problems, although acknowledged, may not be addressed by health professionals (**9**). Yet therapy, nevertheless, can serve important social functions for patients. Such research did not follow current paradigms of therapy research. In these, experimental and laboratory based research dominated, reflecting the fact the research agenda was set by professionals (usually by medical practitioners) with little consultation with health service users. This often reiterated the prevailing philosophy of patient care. This is well illustrated in the survey of Scottish therapy departments; treatment outcomes were based on professionals', rather than patients' perceptions (**5**). Indeed, even where patients' views were ascertained, this was seldom through any systematic means.

Patient involvement

During the 1990s, expert models of health care, which asserted that the professional knew best, increasingly were challenged by a growing disabled people's movement (Myers, 1996). However, research was lacking which presented 'the patient's view'. In this context, the Grampian survey of disabilities was significant because it was based on respondents' own perceptions of their health and disability (OPCS, 1988) and their own views on services and their current and future needs. It differed from many earlier surveys which used 'objective' criteria to establish disability and/or which, at best, merely assessed satisfaction with pre-existing provision. Similarly, the therapy service survey of use by people with Parkinson's disease focused on patients' own perceptions of therapy and broke new ground by exploring patients' views on benefit and outcome (**9**). Work in a child psychiatric unit extended this focus on patients' perspectives further by directly interviewing children, rather than depending on parents' views. Indeed, this study found incongruence in several respects between children's and parents' accounts (**6**). This project demonstrated that it was possible to involve children, even those with severe emotional and behavioural problems, although it highlighted some limitations of interviewing. Thus, concurrent research with children with learning disabilities and severe emotional and behavioural problems (**8**) was important in supporting and extending the child psychiatric study. It demonstrated that, indeed, it was feasible to achieve the participation of especially challenging patients if appropriate methods were used. This research, together with earlier studies with children, was influential in initiating a review of children's involvement in health care decision making. This highlighted why children should be consulted and the need for innovative methods for this to be achieved (**7**).

2.2 Development of research methods and procedures

While research methods have to be acceptable to participants, they require to withstand scrutiny. A notable strength of the research presented herein is that it has been accepted for publication in peer review journals, despite its often innovative nature. A key factor is that the work reported seeks to be inclusive in design, involving work with 'hard to reach' groups (**6, 8, 9**). Indeed, my projects have an important place in the development of methods appropriate for people with cognitive and perceptual difficulties. Collaborative research with clinicians, focusing on children and adults with learning disabilities, explored pictorial means of obtaining views on treatment (**8**). Initially, the research required the production of individualised photograph packs. Significantly, we found that the children were willing to participate and no photographs were destroyed. None of the children displayed challenging behaviour at interview, even with a person unknown to them. This pilot study, together with subsequent work, suggests photographs offer an excellent means of communication and recent projects have sought to refine this method further. This offers considerable potential for use with other care groups where communication is problematic, for example, stroke patients.

2.3 Informing clinical practice

A significant aspect of my work is its applied nature. Carried out in collaboration with practitioners, it addresses current and relevant issues for health and social care professionals (Table 1). A unique feature of my contribution is its relevancy for such a wide range of professionals. Paper co-authors, for example, include doctors, nurses, occupational therapists and physiotherapists working both in hospitals and the community. This has facilitated dissemination to large numbers of practitioners and has promoted awareness of research which otherwise might have been 'locked up' in profession specific journals.

The inter-professional collaboration in the projects reflects, moreover, the multi-faceted nature of disability and concomitantly the need for multi-disciplinary working.

Table 1 : Main findings of work presented

Paper	Main Findings
Motor/learning difficulties and the family (1990)	Child's difficulties impacted on all family members. Family routines/activities had to be adjusted to meet child's needs. Sibling relationships often seen to be problematic.
General practice and the provision of information and services for physically disabled people aged 16 to 65 years (1992)	GPs seen as main source of information by people with disabilities. GPs more than any other health/social professionals would be turned to for help with a problem. Needs of people with physical disabilities change over time.
Self reported disability in six electoral districts in Grampian (1993)	Established nature and extent of disabilities within population. Demonstrated variation in types and rates of disability in different parts of Grampian, especially evident regarding North and South Aberdeen. Identified and quantified households with two or more members with disabilities.
The needs of physically disabled people aged 16 to 65 years and service usage (1994)	Discovered low level of health and social service usage. Highlighted multi-dimensional nature of effects of disability and variable effects on individuals. Low service usage seen to relate to a number of factors, including low expectations, mis-perceptions of services, values of individual, especially those which stress self-sufficiency. Participants' views on service needs circumscribed by those currently in existence.

Paper	Main Findings
Outcome measures used in therapy departments in Scotland (1996)	Some confusion was apparent among therapists regarding term ‘outcome measure’. A minority of occupational therapy and physiotherapy departments in Scotland were using outcome measures. A minority of ‘users’ were applying validated measures. Patients’ views on outcome were seldom collected systematically.
Do parents and children have common perceptions of admission, treatment and outcome in a child psychiatric unit? (1997)	It proved feasible for children to express their views in an interview. Parents were willing to participate. A third of children had not been informed by parents about admission. Both parents and children had limited understanding of reason for admission. Parents seldom reported receiving professional help for themselves. Parents’ and children’s views on several issues were incongruent.
Children as consumers (1998)	National policy requires that children be consulted. Differences between parents’ and children’s views highlighted in literature. The voice of children is barely audible in health research. Children can express their opinions if appropriate methods are employed.
The use of photographs as a means of obtaining views of occupational therapy held by children with learning disabilities : a pilot study (1998)	Children with learning disabilities able to co-operate in the study, even though the interviewer was unknown to them. Children participated fully in viewing the photographs presented. Few negative responses were noted with regard to the photographs relating to therapy.

Paper	Main Findings
Quality of life with Parkinson's disease: Views of Scottish Consumers and Providers (1999)	Nearly 50% of respondents with Parkinson's disease had received therapy. Expectations of therapy were more likely to be met of occupational therapy than physiotherapy and speech and language therapy. 62% of respondents thought that they might need therapy services in the future. Approximately a quarter expressing future needs regarding physiotherapy earlier had reported that their expectations had not been met. Preference for home treatment was indicated by nearly half of respondents stating future therapy needs. Geriatricians rather than GPs and neurologists were the main source of referrals. 91% of managers thought that voluntary agencies should provide 'information about access to services' and, nearly a quarter, should provide therapy services. Only two therapists who participated in the quality of life study had used quality of life measures. 'Patients' had few difficulties in describing their quality of life; therapists experienced a greater problem and provided less comprehensive responses. Differences between patients' and therapists' views emerged regarding tremor and pain, and how these impacted on their quality of life. Therapists' main emphasis was on physical rather than psychosocial problems, despite those being seen as crucial to patients regarding quality of life. Patients with psychosocial problems commonly were referred to GPs.
More than a sympathetic ear? A report on the first year of a writer in residence in a unit for young, physically disabled people. (1999)	Patients describing wide-ranging benefits including improvements 'in mood' working with the writer in residence. The residency offered the patient the opportunity to be an individual with his or her own distinctive experiences and emotions. Members of the multi-disciplinary team in the unit identified benefits. In particular it was seen to address their own psychological needs.
Is this satisfaction survey satisfactory? - Some points to consider in planning and assessment (2000)	Exponential growth of satisfaction surveys in healthcare settings. Many surveys are poorly undertaken and previous advice on their execution does not appear to have been heeded. Satisfaction is rarely defined in surveys. Research is lacking on how satisfaction surveys have influenced service delivery

Multi-disciplinary working

A multi-disciplinary approach, while commonly advocated today, was not widely promoted in the 1980s and early 1990s. Boundaries were maintained and a premium placed on specialisation. A hierarchical model of care and treatment pervaded where doctors led and made the decisions regarding treatment. Even today, the British Society of Rehabilitation Medicine does not admit non-medical professions working within rehabilitation as members, even though this is the only clinical association in this specialty.

The overwhelming majority of disability research until the mid 1990s was within the medical model, undertaken by medical practitioners, and published in medical journals for medical colleagues. Experimentally based research dominated the research agenda and qualitative research was rarely funded by grant awarding bodies, especially medical charities.

While valuable work was carried out by medical sociologists, this tended to be published in social science journals to be read by other sociologists and social psychologists. A significant aspect of my work, therefore, is its contribution to building bridges between the social sciences (especially sociology) and clinical practice. Sociological concepts and theories underpin enquiries, although this is often implicit rather than explicit. In particular, individual experience is related to social processes and social structure. From early days, it has been my intention to increase clinicians' awareness of social aspects of disabilities and treatment. To this end, the majority of my publications have appeared in clinical journals, such as *The British Journal of General Practice, The British Journal of Occupational Therapy, The British Medical Journal, Clinical Rehabilitation* and *Physiotherapy* (Box 1).

Innovative service provision

A much neglected aspect of care, especially relevant for patients in hospital, is providing the opportunity for feelings to be expressed. This is often denied or discouraged within the discipline of a healthcare setting (Hughes, 2000). Thus, an important finding from interviews with patients and staff of a unit for young physically disabled people was that creative writing could serve the function of 'allowing' emotions to be expressed (**10**). The evaluation indicated also that staff could benefit from a writing residency, since it addresses psychological needs and may offer alternative ways of working. This research is significant in a number of respects including the following: (1) creative writing at the time of the study, had not been extensively explored as a therapeutic tool in rehabilitation, especially in the UK; (2) few, if any writing residencies in healthcare had been evaluated; (3) few, if any, previous evaluations of a hospital arts project had considered the potential benefits for staff. Yet, in medical education, the role of the arts in improving ethical awareness and communication has been recognised over the years (Calman et al, 1988; Rolfe et al, 1995; Calman & Downie, 1996). Perhaps, above all else, this research provides empirical support for Affirmative Models of Disability (Swain, French, 2000).

2.4 Originality

In reviewing the papers presented, it is evident that I have highlighted dimensions of disability and service delivery neglected hitherto by clinicians and researchers, but regarded by those with disabilities as important. However, this is not surprising, since user research in health and social care has been dominated by satisfaction surveys. The review paper co-authored with Bisset, well documents the limitations of many surveys (**11**).

Overall, my work consistently reflects innovation and is original in a number of respects:

1 *The research methods developed.* This is reflected, for example, in the use of individualised photographs with children with learning disabilities and the matched pairs of patients with Parkinson's disease and their therapists to establish commonality in perceptions of quality of life.

2 *The novel areas investigated.* I have asked new questions and pursued avenues of enquiry, often ignored by other researchers. Throughout the last decade, a priority has been to know and understand service users' views. This predates, to some considerable extent, current government interest. Work with challenging groups has led me to advocate the involvement of the 'hard to reach'.

3 *The emphasis placed on inter-agency and multi-disciplinary working.* This can be seen in both the topics selected for investigation, as well as the composition of research teams of which I have been part, where collaborators have been drawn from both health and social care.

4 *Development of socio-clinical research.* The embedding of social research within a clinical setting.

5 *Methods of dissemination.* The emphasis placed on dissemination to practitioners, by publication in clinical journals.

3 RESEARCH IMPACT

Impact can be demonstrated on both health and social care, encompassing both statutory and voluntary service providers. Table 2 shows how direct outcomes can be demonstrated regarding over half of the work presented. Impact can be shown also on the evolution of health services research during the decade, as well as on other strands of my research, not published in full, at the time of this submission.

3.1 Statutory service provision

The Grampian survey of disabilities (**2, 3, 4**) commenced as the Griffiths Report was published in 1989. The survey's timing was significant, since Griffiths' recommendations had far reaching implications for services for the physically disabled. Local social services authorities were required to 'assess the community care needs of their locality, set local priorities and service objectives and develop local plans in consultation with health authorities'. In addition, social services departments were 'to design packages of care best suited to enabling the consumer to live as normal a life as possible'. Our survey addressed both recommendations. Its robust design (a stratified random sample of 1 in 40 of the population, together with an 86.3% response rate to the postal questionnaire) provided a much needed evidence base for service planning. Many elements of a subsequent Action Plan were incorporated into the Regional Council's Community Care Plan. This was one of the first such documents in the UK, as Grampian was selected as a pilot area, prior to the implementation of the NHS and Community Care Act in 1993. Our survey's report was widely read; 2,000 copies were distributed following its publication. At the same time, the Council's Social Work Department (who had sponsored the research) worked closely with local health organisations as required in the post Griffiths era. Copies of the Report also were issued to all managers within Grampian Healthcare NHS Trust (currently Grampian Primary Care Trust). Subsequently, rehabilitation services were designed in the light of our findings and recommendations.

Table 2 : Impact of four projects on service provision and professional practice

Paper	Findings on practice	Impact
General practice and the provision of information and services for physically disabled people aged 16 to 65 years	▪ Evidence of patient reliance on GP as information provider ▪ Identified problems in GPs providing information on services and benefits	▪ Pilot project of information officer in GP practices in Aberdeen ▪ Information Officer (social worker) appointed as part of team at Community Hospital providing services for people with complex disabilities
Outcome measures used in therapy departments in Scotland	▪ Highlighted (1) outcome of treatment often unknown as not being assessed systematically in Scotland, (2) patients' views of therapy only obtained informally	▪ Co-author invited to join working party on outcome measures, set up by The Chartered Society of Physiotherapists ▪ Therapists in some departments introduced methods to incorporate patients' views
Quality of Life Chapter	▪ Main consultant referrals through geriatricians rather then neurologists ▪ Therapists not using any quality of life measures to evaluate outcome	▪ Parkinson's Disease Society developed strategy for increasing neurologists awareness of benefits of therapy ▪ Quality of life measures now more extensively used in therapy departments
More than a sympathetic ear? A report on the first year of a writer in residence in a unit for young, physically disabled people	▪ Contribution regarded by staff as valuable for themselves as well as patients ▪ Some patients saw writing as an opportunity to express emotions	▪ Staff formed own arts group ▪ Clinical psychologist re-appointed to unit ▪ Led to other arts initiatives within Grampian ▪ Health Board currently considering reintroduction of writer-in residence scheme

Of interest to note is that, recently, I have been approached by Aberdeen City Council to provide an updated survey in order to provide current statistics for planning purposes. During the intervening years, it is not known if, or how, the numbers of people with disabilities have grown and whether differing needs exist. There is evidence to suggest that there is an increasing prevalence of disability, since a recent longitudinal study of more than 10,000 people over 65 living in England and Wales, it was calculated that 1 in 10 men, and 1 in 5 women were disabled (Melzer et al, 1999). In the same study, over a third of people with limitations in daily living in private households were wholly or partly dependent on formal services for help.

Grampian Primary Care Trust also has renewed interest in my work on disabilities (**1-4**, **6-11**) because of the requirement to implement the Disability Discrimination Act (1996). The Act requires that from October 1999 service providers take 'reasonable steps to change practices, policies or procedures which make it impossible or unreasonably difficult for disabled people to use their service; provide auxiliary aids or services which would enable or facilitate disabled people to use a service; and overcome physical barriers by providing a service by a reasonably alternative method'. In order to respond to this, the Trust is at present developing a local strategy for equality of access to services, facilities and employment. I act as an adviser to the Strategy Steering Group. In addition, the model of service use developed from the 1990 disability survey (**3**) will be used to audit service use.

3.2 Voluntary service provision

Key findings on referral and patterns of therapy use by people with Parkinson's disease (**9**) were used by the Parkinson's Disease Society in developing its guidelines on best practice. The following Parkinson disease qualitative study played an important role in increasing awareness of the importance of 'quality of life' for people with Parkinson's disease and this became an issue for the Society. The same study also highlighted the significant role played by carers, as discussed further in Section 3.5.

3.3 Professional practice and multi-disciplinary working

The most enduring influence of my research has been regarding developments in occupational therapy and physiotherapy. My approach to care and service provision has been very different to that of many research therapists. However, through contact with therapists, including through teaching commitments (both undergraduate and postgraduate) joint research projects (as described in **1, 6, 7**), and conference presentations (Keynote Speaker at the Annual Congress of Physiotherapy in 1998) I have been able to set out my own ideas and contribute to a shift in the research agenda. In particular, I have sought to increase awareness of the need to include clients/patients in healthcare decision-making and recognise and respond to the psychosocial needs of service users.

Much of my research demonstrates the commonality between professions, be they working within child and family psychiatry (**6**) and departments of medicine for elderly (**9**) even though this can sometimes be obscured by territorial disputes. My own reporting of multi-disciplinary working preceded the current emphasis on team working as evident, for example, in *Our National Health* (Scottish Executive, 2000). During the 1990s, three main trends have become apparent: (i) a greater emphasis on teamworking in specialist areas not previously renowned for teamwork, for example in the area of radiological procedures, (Colyer, 1999) and general practice (Poulton, West 1999); (ii) more extensive differentiation between multi-disciplinary and inter-professional and trans-disciplinary working (Jackson, Davis, 1995); (iii) increasing recognition of the problems of teamworking and their impact on effectiveness.

Although the trans-disciplinary model, where services are co-ordinated as services across disciplines rather than isolated services within disciplines, is seen as the most desirable, it seldom occurs in practice. This is well demonstrated in several of my projects, including those not presented here (17, 50, 59, 83, 105). However, I have attempted through my own working practices to promote trans-disciplinary research reflecting my own philosophy. This places the patient or client in centre stage, whose needs should determine the configuration of care. The Health Services Research Group, which I set up in 1996 and which I now head, has played an important part in forwarding this approach. The Group is multi-disciplinary in composition and includes health services researchers and health professionals (nurses, physiotherapists and a radiographer) and has associated postgraduate students who are occupational therapists. In recent years, too, I have worked also with psychiatrists. This has been invaluable in extending my knowledge of psychological processes and therapies within psychiatry. While important in their own right, they are also applicable to people with physical disabilities, since a significant number have secondary psychological problems, such as depression.

User involvement: Much of the work undertaken has been developed through close working with service users. Commitment to joint working and user involvement has led to the formation of the Carers Research Partnership. This, I co-founded in 1999 with representatives from the Princess Royal Carers Trust, Aberdeen City Council Social Work Department, Grampian Primary Care NHS Trust and Aberdeen Association of Voluntary Organisations. The Carers Research Partnership is a good example of the manner in which my own involvement in research has had an impact on both local research infrastructure and user networks, as well as the research agenda.

Overall, my research indicates that if trans-disciplinary team working is to be achieved, changes will be required in traditional ways of thinking, including how patients are perceived. While lip service is paid to the patient, as part of the team, in reality full team membership is rarely awarded. If partnership with patients is to be achieved, previous models of patient/professional working will need to be discarded (**9**). Reflecting the extent to which my previous work addresses these issues, I have set up a project with Grampian Primary Care Trust specifically investigating professionals' perceptions of patient involvement. This is funded by Clinical Governance monies. A key element of the project is to develop educational and training strategies following data collection, thus providing an evidence base to training. The significance of this to the Trust may be gauged by the fact that the Steering Group is chaired by the Director of Human Resources. It provides further evidence of how my work is strongly related to quality of care and how it seeks to forge links between research, service planning and professional practice. It also provides a good working exemplar of research and development within the NHS.

Without doubt, my research has been inextricably linked with government strategies relating to user involvement. The Grampian disability survey (**2, 3, 4**) demonstrated that it was feasible to consult users, that information was a high priority need, and that consumer views were not necessarily congruent with service providers. Within health and social care, during the 1990s, it became widely recognised that there were considerable potential benefits arising from more formalised methods of patient consultation. *Designed to Care* (1997) was significant in reinforcing pre-existing, but often ad hoc, initiatives regarding user consultation: 'Our starting point is that every aspect of the planning and delivery of services should be designed from the perspective of patients. The role of patient information was also highlighted in this context since patients needed to be better informed if they were to be more actively involved in healthcare decision making' (Scottish Office, 1997).

Explicitly, in *Our National Health* (Scottish Executive, 2000), published three years after *Designed to Care*, the core aim was expressed of giving patients a stronger voice and involving people and communities in the design and delivery of health services. It is argued that involvement can and should take place at a number of different levels. Specifically, the role of information is highlighted: 'Information is crucial in determining people's access to healthcare and to ensuring that they can contribute as equal partners to decisions about their health'. My body of work on involvement, together with more recent investigations regarding patient information (85, 89, 102, 106, 107) are well placed to lead future research.

Taken as a whole, my research contribution has impacted on developments relating to the patient involvement agenda in three main respects: (1) identification of the need to involve service users through demonstration of its feasibility and benefits to consultation, and (2) the development of methods to involve users; and (3) recognition of the requirement to develop research methods to assess both the effectiveness of current involvement strategies and to evaluate the impact which user involvement may have on health and social care. Currently, my main focus is on the development of methods to assess involvement, since most of my attention to date has been on the former elements.

3.4 Contribution to health services research

During the last decade, there has been an increasing demand for health services research. In the years towards the end of the 1990s, quantitative research, in the form of randomised clinical trials (Smith, 1998), has been the prevailing research methodology, and represents the gold standard in effectiveness research. While qualitative research has existed alongside, often it is poorly regarded, reinforced by the Cochrane Collaboration categorising qualitative studies as a Grade IV level of evidence.

A feature of my research activities over the years has been to (a) undertake both quantitative and qualitative research, as appropriate; (b) ensure that quantitative work is as well scrutinised as qualitative research (**11**); (c) ensure wide dissemination of qualitative work (including publication in medically orientated journals, such as *Clinical Rehabilitation* - the journal of the British Society of Rehabilitation Medicine); (d) attempt to ensure that qualitative research is of the highest standard and is underpinned by a theoretical conceptual understanding of what it seeks to achieve, as well as sociological and anthropological theories upon which it rests. Currently, this is a major challenge, since all too often 'qualitative' research is undertaken by poorly trained researchers. Through several publications (for example **10**) I have sought to increase awareness of qualitative work among the medical community, and establish that specific, and often wide ranging skills, are required for such studies. I believe I have had an impact on developments in this respect, through not only my publications but also my work as a reviewer, reviewing papers for the *British Medical Journal, British Journal of Occupational Therapy, Clinical Rehabilitation* and *Quality in Health Care* and grant applications for the BMA, BUPA, Glasgow University Hospitals NHS Trust, Grampian University Hospitals NHS Trust, the Royal Hospital for Neuro-Disability and the Scottish Executive Health Department.

Qualitative research not only challenges prevailing experimental paradigms in medical research but research hierarchies as well which, traditionally, have been dominated by medical practitioners. Oliver (1998) contends that the new approaches to impairment and disability which arise from social theories of disabilities pose key questions for health care and research, such as who should be setting the research agenda and be in control of the research process. I have had the opportunity to influence the research agenda through both my membership of grant awarding committees and publications and presentations. It is worthy of note that the Health Services Research Group which I lead is not located within a medical school and, unusually, focuses on the interface between health and social care.

Oliver (1997) advocates the involvement of people with disability, not only in the design of research, but also its execution. However, it is only recently that this has been actively promoted by research funding agencies and health authorities, reinforced by government policy on patient involvement. Nevertheless, throughout my research career I have been an advocate for user participation in research, and the Carers Research Partnership will play an increasingly significant role in this respect.

3.5 Impact on the development of 'new' research areas

Two major areas of work which have evolved from the work presented relate to patients' knowledge of new radiological procedures and the provision and use of respite care.

Patient knowledge

Earlier work identified that information was a high priority of people with disabilities but that needs were seldom met (**2**, **9**). However, although information emerged as a key element in service provision, I had not investigated informational needs in their own right, until collaborative work with radiographers, commencing in 1999. The marrying of past research on patient involvement with earlier surveys with radiographers (for example on barium enemas), has led to a significant area of enquiry regarding patients' knowledge of new imaging techniques, such as ultrasound, computer assisted topography (CT) and magnetic resonance imaging (MRI). Funding from the Royal College of Radiologists has enabled us to complete a project which awaits journal publication.

This has highlighted patients' lack of basic knowledge regarding the procedure they were to receive and, indeed, found that misconceptions were commonplace. This investigation was timely, given the current government emphasis on patient information and indicates that the whole process of information-giving is far more complex than generally acknowledged (Dixon-Woods, 2001). From this work, we have made the case that information-giving must be considered within the context of the patient's social situation and care pathway. In addition, those providing informational materials need to recognise the emotional support which patients may require, since information may often provoke anxieties. Our approach to information is radically different to prevailing strategies, whereby technical aspects of presenting information are focused upon. Moreover, despite the growth of an information industry, there have been few, if any, attempts to establish what patients know and what they want. Both, we regard as precursors to information production. Most recently, reflecting these objectives, I have been part of a team investigating the informational needs of children with cystic fibrosis.

Respite Care

The Grampian survey of disabilities (**2, 3, 4**), together with my work on people with Parkinson's disease quality of life (**9**) indicated that respite or short breaks were important for carers and the people they cared for. However, even though I had undertaken previous research concerning carers (24, 35, 73, 78, 86, 94, 95), it was not until 1999 that I specifically initiated work on respite care.

While carers' need for respite was acknowledged in the Griffiths Report in 1989, currently respite care is often provided on an ad hoc basis and is difficult to access. At present, it is unknown how much respite care is provided in Scotland and who uses it. In order to create a database on respite, I have been instrumental in setting up research which addresses some of the key questions. A major project, which is funded by the National Lottery Charities Board, and jointly undertaken with Shared Care Scotland, is seeking to establish if people's needs for respite may be assessed through the use of standardised tools such as HADS and the NHP which measure, for example, anxiety, depression and quality of life. The project concentrates on a limited range of care groups - children with complex needs, adults with learning disabilities, people with MS, people with schizophrenia and frail elderly people - and this selection was strongly influenced by previous studies (**6, 8, 9**), as well as gaps in previous research, which focused on people with dementia. An important aspect of our current collaborative research is that both carer and cared for are included, in contrast to many earlier studies.

Our first project on respite, was significant in leading the way to further work. Currently, we are also investigating respite provision within the city of Aberdeen (funded by Aberdeen City Council). Our findings will be used by the Social Work Department to develop a respite strategy, including criteria for assessing people's needs. Most recently, the MS Society requested that I undertook an analysis of government policy on respite, together with a descriptive study of the two Society run Holiday Homes. This will be used to guide the Society's future strategy. These funded projects have enabled me to establish the Health Services Research Group as the main centre for respite research in Scotland.

4 OVERVIEW AND DISCUSSION

4.1 Overview

This thesis has provided the opportunity to explore the development of my own research and the relationship between different studies carried out at various points in time. Although there has been increased specialisation during the last decade, for instance regarding the focus on people with neurological disease, the key issues have remained constant, as outlined below:

(a) the challenge of developing appropriate methodologies and research procedures;
(b) the limited involvement of users in the design of services and determination of the outcome of interventions;
(c) the extent to which social relationships and quality of life are affected by chronic illness and disability;
(d) the failure of current health and social care services to meet users' and carers' psychosocial needs.

4.2 Discussion

4.2.1 Limitations of health services research

This review of my work has shown the significance of social factors to living with disabilities, managing disease and treatment outcomes. In so doing, the importance of the social sciences to health services research has been highlighted. However, in recent years, the contribution of social scientists to health services research has seldom been debated. Indeed, all too often health services research is atheoretical and health care 'problems' are presented in isolation, removed from their wider social context. Even though the findings of health services researchers often have considerable implications for health and social care policies, they are not necessarily brought to the attention of policy makers. This may be because of a number of factors, including: the diffuse nature of health services research; the manner in which health services research is funded, for example specific projects are commissioned on a 'one off' basis and the pragmatic nature of health services research itself. Health services researchers frequently have to be project focused, rather than committed to the investigation of a single health care problem. In addition, the tight deadlines imposed by funders, who require findings speedily so that services can be modified and/or developed, are not conducive to reflection on the long term implications of results.

It is not unexpected, therefore, that few health services researchers challenge the 'status quo'. In recent years there is little evidence of alliances developing between health services researchers and more radical commentators such as Oliver (1990) and French (1993) within the disabled people's movement. Therefore, it is important to note my own increasing contact with the voluntary sector, for example with the Parkinson's Disease Society. This can be seen, however, as part of a trend occurring within medical charities as they respond to a changing health milieu, whereby an increasing proportion of health care is provided in the community. In particular, the significant rise in the number of day surgery cases and emphasis on ambulatory and palliative care place new demands on family carers and primary care providers. Health support structures will need, increasingly, to be organised to meet their needs.

4.2.2 **Social support and social theories of disability**

Ultimately, the very feasibility of care in the community may depend on the quality of care provided by informal carers, and health professionals' ability to assess and harness that care. The *Black Report* (Townsend, Davidson, 1982), which stressed social factors in health, recommended long ago that statutory services should be seen to supplement, rather than substitute, family care (Townsend, 1957). If health is to be promoted, health services may need in some situations to perform functions, such as support, previously provided by family members (Gottlieb, 1985; Morgan et al, 1984). In the future, therefore, quality of health care is likely to become inextricably linked to interpersonal relations, the family, and neighbourhood networks. Social theories of disability are likely to obtain a wider audience, as increasing numbers of the population have a person with disability within their household or family.

Oliver, summarising social theories of disability, argues 'they move beyond the personal limitations that impaired individuals may face, to social restrictions imposed by an unthinking society' (Oliver, 1998; 1446). Attention therefore focuses on disabling barriers and how these may be removed rather than how people with disabilities can best 'be fit' into society. The Grampian survey of disability identified not only physical restrictions on access to services for people with disabilities (for example entry into GP surgeries and pharmacies) but also social attitudes which limited social participation. These were also important considerations for people with Parkinson's disease (**9**).

My work over the last 10 years has demonstrated how professionals too may be 'unthinking' in imposing their treatment on patients, rather than determining patients' priorities (**5, 9**). By contrast, the writer-in-residence, even though in a hospital setting, worked as a facilitator, enabling the patient to 'lead' (**10**). Our conclusion that the residency 'offered the patient the opportunity to be an individual . . . . It enabled anger to be expressed . . . .. It (helped) by making the person "feel whole again, a human being with a story to tell"' is of fundamental importance. Through our investigation, we were able to furnish research evidence to support the theory that frustration and anger can be collectively expressed through Disability Arts which challenges negative images of disability (Shakespeare et al 1990). Our own study reinforced the view that emotions should not be seen as 'personal problems to be resolved, say through counselling' (Swain and French, 2000), a key position within the Affirmative Model of Disability.

Nevertheless, the politicisation of disability has not occurred to any great extent in Britain. Indeed, some commentators equate the slow progress and limited scope of the Disability Discrimination Act (1996) as a reflection of the relative weakness of the Disability Rights movement. On the other hand, however, in Scotland there is increased political direction of health care. For example, in the year 2000, the Scottish Executive issued no fewer than 20 health related policy documents. Health services researchers, therefore, may need to pay increased attention to political processes and organisational dynamics.

4.2.3 **Implications of work presented**

The findings of the work presented have major implications both for workforce planning within the health and social care sectors, as well as the education and training of professionals. Previous emphasis on external intervention, 'curative' and ‘expert’ models of care, ‘negative’ images of people with disability (Shakespeare et al, 1990) and uni-professional working is no longer appropriate. In particular, radical changes will be required in attitudes to patients and healthcare delivery. This will not be achieved easily and may not be possible within pre-existing traditional structures both within the NHS and higher education. Social scientists with the expertise in research methods, including skills in quantitative and qualitative research, and understanding of family networks and social support gained from sociological studies on families and communities need to be in the forefront of developments.

Never has the need for research on disability, rehabilitation services and health and social care been greater. Social scientists are needed too in developing the agenda and contributing to developing a body of knowledge on both disability and care. While my own work has attempted to do both, there is a considerable distance to go. However, it must be ensured in future years that the relationship between research and service delivery, which has been a key concern for me, is strengthened and not lost sight of by other researchers. It is hoped that by synthesising numerous separate studies herein, it will increase their potential impact on health and social care and professional practice.

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Part B

Public Output

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Motor/learning difficulties and the family

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Summary The work reported here, which has as its central concern family dynamics and relationships, is part of a wider study of 31 children with motor/learning difficulties. All the children were attending an Occupational Therapy Department and had been assessed as having motor/learning difficulties. Descriptions of family background, structure and composition are provided and findings on conjugal, parent/child, sibling and extended family relationships presented. Characteristic patterns of family interaction are identified and factors affecting family cohesion discussed.

Medical, psychological and educational interest in 'clumsy' children has increased substantially in recent years. Despite the growing volume of publications a functional understanding of the disorder has yet to be achieved and types of motor disorder have still to be fully categorized (Hulme & Lord 1986). Work to date, however, suggests that the label 'clumsy' may be inaccurate (Henderson & Hall 1982) and unsatisfactory (Sugden & Waters 1983). Indeed, reflecting the difficulties of classification which abound, there is a lack of consensus regarding terminology although currently preference is being expressed for the term motor/learning difficulties (McKinlay 1987) and throughout the latter will be employed.

Research to date has focused on: neurological factors; the development and testing of screening instruments; and school performance especially regarding writing skills. The major concern, not unexpectedly, has been the recognition and characterization of the disorder (Hulme & Lord 1986). There have been few attempts to examine the

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affect motor/learning difficulties may have on the child, his or her family and student/teacher relationships and classroom practices. In so far as studies have reported on the family (Johnston & Crawford 1987), the interest would appear to lie in attempting to determine prevalence rather than describing the impact which the child may have on the family itself.

American work which places great emphasis on the parents' role as co-therapist in the treatment of motor/learning difficulties tends to isolate the child and parent (usually mother) in the therapeutic relationship from the everyday context of the family (Ayres 1979). There has been little investigation of how parents have coped with the distress of this disorder, although there have been a number of studies of the families of physically handicapped, terminally ill and Down's syndrome children. Yet, as Faerstein (1981) has written, within the context of learning disorders in North America 'we cannot fully help families . . . until we learn from them how they experience the problem at home, in the community and within the medical setting'.

If, as has been asserted (Gordon & McKinlay 1980), these children usually receive less sympathy and understanding, often because of the subtle nature of motor/learning difficulties and the concomitant problems of identification — and indeed some professionals maintain that there is no evidence that the syndrome is a definable entity (Hall 1988) — then parental problems may even be greater than those, for example, with children having major brain dysfunction. Less support from family and friends may be forthcoming and few, if any, services may be available. The mother whose child is behaviourally disturbed in public places may be in receipt of criticism rather than compassion.

In Britain, it has been contended that '. . . a clumsy child, reacting to frustration and disappointment may show conduct which threatens the relationship with family and teachers' (McKinlay 1980), but there is little empirical work to support this. One of the questions this paper addresses is whether in the case of motor/learning difficulties there is: a decrease in family cohesion; a disruption of routines; an increase in distance between family members; and a higher rate of marital separation and divorce — all factors which have been found to be associated with disorder in the family (Orford 1987).

The work reported here, which has as its central concern family dynamics and relationships, is part of a wider study of children with motor/learning difficulties. Key issues investigated include child developmental profiles; processes by which motor/learning difficulties were identified; educational achievement and school performance; and parental evaluation of remediation. A major objective of the research was to obtain a broadly based perspective and give prominence to social rather than physiological/neurological factors. It was intended that such an approach might avoid the shortcomings of some studies which tend to present the child as a passive recipient of attention rather than as an active member of society, constructing his or her social world and influencing, as well as being influenced by, family and school life. Both the latter were therefore important foci of interest, although consideration in this paper is restricted to the former.

THE STUDY

The study, which is based on children receiving occupational therapy at the Royal Aberdeen Children's Hospital, was stimulated both by the therapist's own desire to have a more comprehensive knowledge base from which to work and parents' own quest for more detailed information on motor/learning difficulties. In fact, the research began as attempts were being made to establish a Parents' Support Group. Currently, not only is this well established, but also it is playing an active part in increasing understanding of the disorder in the community. An information booklet has been produced as a guide for parents and teachers and this research has latterly been supported by funds raised by the group. Parents have shown a high level of interest in the study's findings, and the first feedback meeting was well attended. At parents' request further sessions on the research conclusions are planned. For a detailed account of the group's development see Stephenson & McKay (1989).

METHODS

Over a 2-year period from 1985–1987 parents of children assessed as having motor/learning difficulties attending the Occupational Therapy Department were requested to participate in the study. Only in one instance did parents decline to take part thus providing the opportunity to include 32 families in this investigation. However, during data analysis material on one child had to be abandoned and she was excluded from the study. Adoption precluded information on preschool years being available and the family dynamics were considered to be different and more complex.

One parent (and where possible both) was interviewed on at least one occasion. Interviews were semi-structured and parents were given as much scope as possible in talking about their experiences and defining what was important to them. Interview data were supplemented by material from clinical notes and records, and information collected through informal contact with parents and meetings of the support group. A detailed account of the methods and techniques can be found in an earlier paper (Stephenson *et al.* 1990).

It should be noted that 12 joint interviews (where both partners were present), representing over one-third of the total number, were held. These were regarded as important as they provided an opportunity to ascertain the extent of agreement between partners regarding, for instance, perceptions of their child, philosophies and methods of parenting and descriptions of family life. They ensured that total reliance was not placed on mothers' reports and fathers' involvement and views did not consequently have to be inferred. These interviews, in addition, served to alert us to the limitations of the one-parent interviews (19 with mothers and one with a father). Although contact with other family members would have been valuable, it was beyond the resources of this study. Moreover, the undesirability of focusing further attention on the study–child precluded direct questioning of siblings.

The joint interviews provided a source of very high quality data. Issues were explored in some depth and detail and often the sessions were of considerable intensity with some issues and points of information being contested. The presence of a partner appeared to promote reflection and self-analysis and on occasions sensitive questions were posed by a spouse which the interviewer in all probability would not have raised. Contrary to expectation, wives did not dominate the discussion (Cunningham–Burley 1987). Despite attempts to achieve a higher number of joint interviews this did not prove possible, often because of the difficulty of these being arranged during the working day, although some fathers were reluctant to attend. The desirability of relating interview data to that obtained from other sources was highlighted by the receipt of a letter from a mother subsequent to her formal interview. She wrote:

> At the end of a busy holiday with a very relaxed and happy Colin, I may have

> created a rather 'rosier' picture of him than is true the other day . . . I think I underestimated some of the problems he's had . . . I definitely underestimated the effect he's had on me — feelings of failure, inadequacy . . . I said he hadn't really affected my relationship with James (his brother) but I think he has . . . you may be able to add some of these comments to the questionnaire. (Mrs Addison)

The interview is the principal source of comments used in the text. Where possible, parents who participated in our investigation speak for themselves. As Bradley *et al.* (1983) have argued, 'The use of illustrative quotations offers evidence in a way that is more direct and self evident in its implications than the narration of observed incidents or second hand opinions'. In order to protect families, all names have been changed in the text.

RESULTS

A profile on the children

Only two of the 31 children were girls. The youngest child attending the department was aged 5 years and 10 months and the eldest was 11 years and 9 months (average age was 9 years and 1 month). All IQ scores fell within the normal range, with over half being between 80 and 100. Discrepancy between verbal and performance scores was not widespread. Thirty children were attending primary schools (one alone was a secondary school student) and with one exception all were receiving education in the public sector. Four were placed within language units of local primary schools and only one child was a special school pupil and his placement was temporary. (For a more wide-ranging description of the children see Stephenson *et al.* (1990).)

Family background and composition

The mother's age at the time of the child's birth ranged from 20 to 33 years, the mean age being 25 years and 9 months. Maternal age therefore reflected Scottish age/birth norms. For example, in 1981 the maternal age groups which contributed the greatest numbers of live births in Scotland were groups aged 25–29 and 20–24 (Registrar General Scotland 1982a). The mean age groups of the mothers and fathers at the time of the interview were 34·6 and 36·7 respectively. The majority of grandparents were still living although 14 grandfathers and two grandmothers were now dead. Contact with two grandparents had been lost subsequent to their marital separation.

All the fathers were in full-time employment and their social class distribution closely resembled that of the region as a whole; 38·8% of fathers were employed in non-manual occupations (Registrar General's classes I, II, IInm) and 61·2% in manual jobs (classes IIIm, IV, V). Approximately one-third of all mothers were in either part-time or full-time paid employment and of those the majority were in professional and executive-type occupations, including five nurses and two teachers. Of those not currently doing paid work, one was studying for a university degree and another working as a voluntary playgroup leader. In addition, two had formerly worked within the caring professions, one as a speech therapist, the other as a teacher. Nearly one-half of all parents had received further or higher education but although the majority of mothers had proceeded to full-time education following school leaving, only four fathers had done so. Most had undertaken vocational training on a part-time basis, under the aegis of their employers.

Overall, 12 mothers and 15 fathers regarded themselves as having experienced learning difficulties and these were not confined to those with fewest educational qualifications and least formal education.

Thirty of the children were from two-parent homes and 29 at the time of the study had at least one sibling. The majority (19) were members of two-child families as is shown in Table 1. Two of the three families with four children had occurred through remarriage. Position within the family was variable; just over half (17) were first born.

The ages of siblings ranged from 10 months to 21 years. In two-child families brothers outnumbered sisters by 12 to eight respectively but in the three-child families, gender distribution was symmetrical (each study-child having one sister and one brother). Speech and/or language difficulties were experienced by approximately a quarter of the siblings of school age or under (10 of 37).

TABLE 1. Family size

Number of children per family	Number in study
'Only'	2
Two	17
Three	9
Four	3
Total	31

Marital relationships

A high degree of marital stability was evident within the group. Only three parents were divorced: in one case, prior to the study-child's birth; in another, it was said to be unrelated to the disorder; and in the third, their son's difficulties were regarded as a major causal factor. Although there were no additional instances of separation, a small group of parents reported marital crises: '(we came) close to separation' (Mrs Laird); '. . . nearly divorced . . . argued constantly . . . I walked out . . .' (Mrs Donaldson). In all, parents of 10 children stated explicitly that their marriage had been affected adversely. Others, while recalling marital problems in the past, now felt that these had been overcome, especially since a diagnosis had been obtained for their child and therapy commenced. Some mothers, however, considered that they had been instrumental in sustaining the relationship: 'I worked at not letting my marriage suffer too much' (Mrs Farquhar).

Even where no major or long lasting repercussions were described, relationships could be subject to particular stresses, sometimes acute. One father (Mr Godfrey), for example, said he was 'fed up' because he doesn't sleep with his wife since his daughter needs to sleep with her and 'be actually in contact'. The two most frequently reported sources of marital strain were: (i) factors associated with the identification and acknowledgement of the child's problems; and (ii) approaches to child handling and management.

(i) Identification and acknowledgement of the problem

Seventeen mothers initially suspected 'something' was wrong with their child before professional confirmation and prior to spouse recognition. Only one father (a nurse) described himself as the first to detect difficulties. In six cases both partners reached similar conclusions around the same time.

Where wives had difficulty persuading their husbands that a problem existed, and/or medical assessment was necessary, tensions were described as becoming severe. Fathers, both from their own and mother's accounts, tended to: define any perceived abnormality as of minor concern; provide explanation by reference to late development; and counsel mothers to wait before seeking professional help. When wives continued to pursue further investigations after a thorough examination had failed to yield cause for concern, relationships were said to become particularly difficult. Some mothers who were diagnosed by their GPs as 'over-anxious' and 'neurotic' reported distress not only at this, but also at their husband's seemingly wholehearted support for this explanation of the situation.

In the only case where marital breakdown was attributed to the child's motor/learning difficulties, it was stated specifically that 'my marriage broke up because my husband refused to acknowledge the fact that our son had a problem' (Mrs Addison). It was common for mothers to say at single rather than joint interviews that their husbands had still to acknowledge their child's problems, even where this had been confirmed some time previously. Fathers' own contributions suggested, however, that rather than denying difficulties they possessed a narrowly circumscribed view of the nature and extent of the disorder. Husbands were more likely than wives to report difficulty in understanding the concept of motor/learning difficulties and tended to minimize effects. Lack of motivation was identified as a major explanation for poor performance. One father maintained that his daughter who had severe generalized problems 'avoids homework by pretending she's unable to do it' (Mr Innes), but this view was strongly contended by the mother.

(ii) Approaches to child handling and management

Parents' views on this subject were often at variance, reflecting the existence of frequently conflicting expectations and perceptions of the child. Behaviour associated with lack of control gave rise to greatest parental concern. Fathers appeared most exasperated by developmentally late lack of bladder or bowel control, while mothers frequently had greatest difficulties coping with disturbed or socially disruptive behaviour in public places. Mothers, with only a few exceptions, regarded themselves as better at child management than their husbands. For example, as one mother (Mrs Jennings) said to her spouse at interview, 'You don't understand the way to work Alistair like I do'. A common criticism of fathers was that their strategies were *ad hoc* or short-term. 'Bribes', although often regarded by mothers as being inappropriate, were used frequently by fathers in an attempt to modify behaviour.

In conclusion, regarding conjugal relationships, it should be noted that a small minority of mothers felt that the experience of coping with a child's disability had had a positive effect on their relationship and had even strengthened it. 'My husband balances my anxiety . . . so in a way we feel closer' (Mrs Shaw).

Parent/child relationships

Very few of the children were described negatively at interview and indeed mother/son relationships were described as particularly strong. This was seen related to providing constant help and support and sometimes the husband's rejection of the child. Problems and inadequacies while recognized did not dominate accounts and many parents (close agreement was evident, in fact, at joint interviews) spoke warmly of their offspring — 'I'm a happy dad, I'm fine pleased with him' (Mr Jennings). The following mother summarized well parental views in general when she said:

> Loveable and likeable. Problems with self control in all areas — very short fuse. Guileless, unable to deceive and never occurs to him . . . knows what is socially acceptable but isn't always able to do it. Gets upset if mistakenly blamed — feels he gets blamed for lots — feels blame unfair if something is an accident . . . will be a very decent sort of person . . . (Mrs Urquhart).

Asked to identify their child's strengths, two-thirds of parents placed great emphasis on personality traits, with frequent reference made to their child being 'determined', 'lively' and 'caring'. In the remaining nine cases, specific intellectual aptitudes (such as ability to memorize information) or sporting abilities were stressed. Only one parent failed to pinpoint any particular strength and this child had severe generalized problems.

The overwhelming majority of parents believed that they responded differently to the study-child compared with other siblings. Only four parents felt their behaviour was unaltered. The main differences were: more expressed anger and frustration; greater protectiveness; and the making of more allowances, including (although less frequently reported) the tendency to give greater praise and encouragement than to siblings. The major and most common differential response was that of frustration. As one mother said, 'I try not to lose my temper when he can't cope with seemingly simple things but this is hard' (Mrs Wallace).

Many parents stressed that expectations of the study-child were different from those held for brothers or sisters. Some mothers feared that they had, as Mrs Innes said, put too much into the child and had, as a consequence, neglected other offspring. A small group of mothers stressed that they believed the whole family had been adversely affected as is evident in the following comments: 'The rest of us have had to pay for stabilizing Alistair' (Mrs Jennings); 'Been a strain on the family — on everyone, brother, sister, mother and father' (Mrs Taylor).

Sibling relationships

Patterns of sibling interaction were diverse; both close loving relationships and ones of seemingly total rejection were reported. Approximately half of all parents felt that relationships were either satisfactory and did not give cause for concern — 'Underneath there's a great deal of family feeling. They play together and fight normally' (Mrs McDonald) — or good, 'His sister thinks he's wonderful!' (Mrs Sinclair). Of the parents, however, 45% indicated poor relationships existed. Brothers (less usually sisters) were variously reported as ignoring, resenting, being embarrassed by and sometimes jealous of a sibling with motor/learning difficulties. Negative feelings of considerable hostility were said on occasions to be expressed. An elder son, for example, asked of his brother, 'Why don't you put him away?' Mr and Mrs Watson reported at a joint interview.

Sibling embarrassment was reported and was particularly acute where the same school was attended. The behaviour of one child was said to rebound on the other, affecting both peer and teacher relationships. Resentment was seen to be caused by the disproportionate amount of parental attention received and the extent to which family routines and activities were tailored to the needs of the study-child. It was believed that some siblings felt that they had 'missed out' — 'His brother has had it explained to him that we can't do things because of Angus' (Mrs Greig) — and yet were required to be especially tolerant and understanding — 'The hardest thing I ever have to do is be nice to my brother' (Jane) — whatever the provocation. Interference with and breakage of sibling possessions was an oft cited irritant: 'If I want to keep anything whole, I've got to hide it' (George). Problems were, in fact, more likely to exist where siblings were older, as Table 2 demonstrates. Only four of the 16 families

TABLE 2. Nature of sibling relationship and position in family

Study child	Regarded as problematic	Fair or good	Total
Older/eldest	4	12	16
Younger/youngest	9	4	13
Total	13	16	29*

*Study included 2 'only' children

where the child with motor/learning difficulties was first born reported that sibling relationships were problematic.

Extended family relationships

Reference to grandparents and wider kin was, as might be expected, limited. Mention at interview tended to be made when discussion focused on: (1) the process of identification of motor/learning difficulties; (2) general understanding and appreciation of the problem by wider kin; and (3) family activities and outings. Grandparents (including one grandmother who was a health visitor) tended not to have seen any cause for concern prior to identification, even where developmental delay was evident. Once motor/learning difficulties had been diagnosed grandparents were reported as often having difficulty understanding the nature of the disorder. Tensions relating to a grandchild's problem were seen to arise, viz: '(Paternal) grandparents can't cope for long — nor can other family members who find Michael overwhelming — they like a tidy, ordered existence — can't cope with chaos' (Mrs Urquhart).

Although more negative than positive responses were attributed to wider kin, some grandparents were cited as providing practical help and being supportive.

Family life

Approximately two-thirds of parents (22) saw family life as being affected in a major way by their child's disorder. Only a small number felt, however, that the child's influence was all pervasive: 'Family life revolves around him' (Mrs Strachan). In general, it was reported that family activities, both daily and occasional, had to be geared to the special needs of the study-child. Everyday living routines, in particular, had to be arranged so as to accommodate the slower pace of this child, often creating frustration and friction between family members. Bedtimes and morning routines, entailing problems with dressing, together with mealtimes and concomitant difficulties with cutlery, were often described as being fraught, not least for mothers. Early evening was singled out by parents writing for the booklet as an 'extremely trying time of day' with 'a meal to prepare, homework to supervise and other children to cope with before dad comes home' (Department of Occupational Therapy 1988). It is perhaps not surprising, therefore, that one father should have said, 'I would work late to avoid coming home at teatime and walking in on rows, hoping things would be calmer later' (Mr McLennan).

In half of all the interviews, parents were not able to identify anything specific which was difficult for the family as a whole to do. Yet many of these said that they tended to avoid those activities which were likely to present problems: 'Angus' problems don't prevent the family doing things, but we do tend to do things he can cope with, for example, swimming' (Mrs Greig). Parents who stated that difficulties, sometimes pronounced, existed frequently mentioned family outings and holidays in this context: 'It is the first year that all the family are going to the panto — (we) can't go roller skating, etc. Holidays are very restricted in the things that could be done together, although it's getting easier' (Mrs Godfrey). Several parents said that they had to take into account their child's reluctance to visit new places and do new things. In such circumstances, children had to be cajoled into participation, resulting sometimes in reduced enjoyment and pleasure for other family members: 'He never totally disrupted family life, though at times his negative attitude would put a blight on the day' (Mrs McDonald).

When visits to friends or relatives were considered, choice was restricted generally to those who were likely to be sympathetic to the child. Interestingly, a father suggested at a Parents' Support Group meeting that limitations on choice could be a positive advantage; potential for conflict was reduced as boundaries were well established.

At interview, when parents were asked to name the activities enjoyed by the family as a whole, a limited number, restricted in range, were identified. Most often mentioned (by over two-thirds of parents) were family outings, including car drives, visits to the beach, trips to the park, walks and visits to castles. Swimming was by far the most popular sport (favoured by over half the families); the second most popular, football, lagged far behind. Four parents were unable to suggest any activity at all, though fathers' working hours were seen largely to be responsible.

The study-child was seen by many parents as functioning best in the family setting and in the home in particular. Family life was seen as being 'safe and secure' and a source of compensation when problems were met, for instance, at school. Siblings were regarded as often providing the companionship, albeit reluctantly, which could not be achieved with peers, even where there was a wide age difference. Affection too often was not fully reciprocated.

From parents' accounts, it was evident that while some saw patterns of family interaction as influenced profoundly by their child's disorder, others saw the family as a whole as minimally affected, and perceived the problem to be restricted to one family member. However, help in varying degrees related to emotional and behavioural difficulties had been, or was being, provided for eight children and their families, mainly by child and family psychiatry. This usually was provided prior to and soon after occupational therapy had commenced. On the whole, parents considered that tensions within the family had tended to reduce once contact with the therapist had been established.

DISCUSSION

Marital separation and divorce has, of course, not only far-ranging effects on the conjugal couple but also alters radically and permanently family structure and family life. Divorce, therefore, as has been well recognized, provides an indication of both marital breakdown and family disruption. Given the difficulty of reliably assessing family cohesion — one of the main concerns of this paper — divorce and separation rates are of particular significance. It is noteworthy that only three of the 31 children had parents who were divorced. Even when the age and class structure of the study parents is taken into account, together with region and place of residence, the numbers remain lower than might be expected (Registrar General Scotland 1982b).

Moreover, while there was only a single case of a one-parent family in this investigation, among children under 16 years of age living in Aberdeen city in 1981, 7% lived in households consisting of only one person aged 16 and over and one or more children under 16 (Registrar General Scotland 1982b). This is all the more surprising in the light of research on families of the chronically sick (Eiser 1987) and handicapped children. While overall the evidence is unclear, the higher incidence of separation and divorce has been reported frequently both in Britain (McConchie 1982) and the United States of America (Faerstein 1981).

Of special interest is Leidermann's observation (1974) of an increase in the rate of divorce and separation after the birth of a baby nursed in a special-care unit. Over one-third (12) of the children included in this study had been placed in a neonatal intensive care unit following their birth (Stephenson *et al.* 1990). Why have the marriages of study-parents endured? Why such apparent family stability?

There is, however, a growing volume of research which emphasizes that marital breakdown is not an inevitable consequence of the additional strain that a child's disorder may produce. Gath (1978) concluded in the case of children with Down's syndrome that the marital state prior to the child's birth was of crucial importance and it has been argued that the very stresses which childhood disorder may create may even strengthen rather than weaken a marriage provided that the existing relationship is not a poor one (Lansdown 1980). Voysey (1975), for example, has suggested that experiencing abnormal events together may increase feelings of solidarity, while Wishart *et al.* (1981) contend that parents may be brought closer together by being more likely than otherwise to talk through matters of child rearing and future plans. Common to this approach is that much depends on the emotional strength of partners, their resources and nature of their pre-existing relationship.

To demonstrate that marital relationships have endured is not to contend that they were unproblematic and not subject to tensions. Fathers' reluctance to acknowledge motor/learning difficulties was, for example, a major source of strain. This threatened relationships not only for reasons of self-image and esteem but also because it made dissension more likely over the child's handling and management.

That there was no one consistent pattern of sibling response was to be expected given the diversity of sibling ages and, as Pahl & Quine (1987) have pointed out in the context of mentally handicapped children, the practical and psychological consequences for siblings may well be different depending on whether other children in the family are older or younger. Certainly, here more problems were reported where siblings were born first. However, they were much older, suggesting the difficulties may relate to age rather than birth order. Many parents were concerned that siblings were placed at a disadvantage by their brother's or sister's disorder. Family life was seen often as geared to the study-child's needs with the consequence that other children's requirements went unrecognized and/or unmet. Frequently, other children's lives were reported as being restricted. Extended family members were seen to be affected, too. Orford's (1988) conclusion that 'The impact of coping with disorder in the family is not, of course, confined to the principal carer or the 'key' relative. Ripples occur through the family . . .' would seem equally applicable in the case of families of children with motor/learning difficulties.

It is striking that despite the stresses to which the families had been subjected the overwhelming majority of those included in this study had survived intact. Although the process had been lengthy, help and support finally had been forthcoming. It appeared that adjustments had been made, new norms established and differing expectations of family members and lifestyle developed. It needs to be emphasized, however, that our study-parents were a highly selected group: all their children had been formally identified as having motor/learning difficulties and all were receiving treatment. Such parents are unlikely to be representative, and may well possess such characteristics as persistence and perseverance (as demonstrated by insistence on an assessment; Henderson & Hall 1982) which may well affect family cohesion. In addition, a contributory factor may have been that approximately a third of the study-mothers were (or had been) employed in the caring professions. Resources to cope, moreover, are likely to have increased by access to an occupational therapist, psychiatrist and latterly a Parents' Support Group. A controlled study of families without recourse to these is needed. It would seem likely that parents who have received the worst services or rejected intervention may be most at risk of marital and family breakdown.

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General practice and the provision of information and services for physically disabled people aged 16 to 65 years

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SUMMARY. The study reported here was part of a larger survey investigating the nature and extent of disability in the Grampian region. Interviews with 212 people aged between 16 and 65 years who had a wide range of physical disabilities elicited perceptions of current and past service provision. Respondents expressed a strong need for information on disability services and reported difficulty in knowing whom to approach for this. General practitioners were the most commonly reported source of such information and low usage of the Department of Social Security, social work departments and voluntary organizations was identified. No significant relationship was found between degree of disability and frequency of consultation with a general practitioner. However, the more severe the disability the more likely it was that the general practitioner initiated contact rather than the patient. Although in general those interviewed were satisfied with medical information given regarding their diagnosis, they were more critical of information provided in relation to coping with the disorder, including that concerning benefits and services. The study confirmed the pivotal role of the general practitioner in the care of physically disabled people in the community aged between 16 and 65 years. The need to re-evaluate the role of the general practitioner in the provision of information and services is discussed.

Keywords: physically handicapped; information sources; patient needs; patient information.

Introduction

IN 1989 Grampian Regional Council social work committee undertook a survey of people with disabilities to establish a local database. This represented the first large scale investigation of this group in the north east of Scotland. The region has a distinctive character — a low population density, low levels of social deprivation, low numbers of people in ethnic minority groups and low levels of unemployment. This suggests that it may not be possible to use the findings of the survey of disability carried out by the Office of Population Censuses and Surveys in 1988[1] or other more recently completed regional surveys[2,3] as a basis for service planning.

The part of the study presented here aimed to obtain an in-depth understanding of the perceptions of people aged between 16 and 65 years with physical disabilities (excluding purely sensory disorders), regarding current and past service provision.

The use of general practice by people with physical disabilities is of interest, given the controversy surrounding the three-yearly health checks[4] and the role of the general practitioner in the assessment of health needs and the provision of community care.

Method

Main survey

To determine the nature and extent of disability in the region and to identify those with disabilities, for subsequent interviewing, a sample survey was carried out. In total, 5042 people were sent a questionnaire in May 1989 (a random sample of approximately one in 40 households in Grampian). The questionnaire was a shortened and simplified version of the Office of Population Censuses and Surveys postal screening questionnaire, and was returned by 4213 people, a response rate of 83.6%.

From the questionnaires, and in particular from individuals' self definitions, it was concluded that 1289 households had at least one person with a disability, disability being defined as someone who is disadvantaged or restricted in his or her daily life as a result of a health problem or disability.[5] While the majority of households reporting disability contained only one disabled person, households with two and three disabled people accounted for 25.9% of all households with disability.

Interview survey

Of the respondents with a disability, 59.3% were willing to be interviewed, as intimated by their response to the final question of the questionnaire. Only 55.1% of those aged 45 years and under were willing to be interviewed compared with 63.6% and 67.2% of those aged between 46 and 65 years and over 65 years, respectively. Since the interview survey was to relate only to younger physically disabled people, respondents over 65 years together with those under 16 years and those not suffering from a physical disability were excluded from the pool of potential interviewees. Of the 765 respondents willing to be interviewed approximately half (371) were eligible for the study.

Of the 371 respondents, a purposive sample of 250 was selected. A major objective was to ensure that people with differing experiences of the impact of physical disability, regardless of whether these were of social, psychological or physiological origin, were included. Two hundred and twelve interviews were carried out between October 1989 and January 1990, including one partial interview. For a variety of reasons it was not possible to complete interviews with 38 people.

Interviews were carried out by 15 experienced interviewers. Both open and closed questions were asked and responses recorded on interview schedules. The main topics covered included the nature of disability; employment status, benefits and allowances; receipt of medical information; sources of information on disability services; and contact with general practitioners. At the same time a self completion questionnaire for carers was distributed, to be returned to the interviewer.

Assessment of disability level

In order to analyse the data it was necessary to distinguish between different levels of disability. The aim was for interviewees to determine their own levels of ability and to elucidate their

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own motivations and attitudes to their disability. It was therefore considered inappropriate to use a scale such as the Barthel index of physical dependence[6] since it depends on an external assessor. While both Arber and colleagues'[7] and Townsend's[8] self reporting disability scales were given careful consideration, both were rejected because they focused on a narrow range of activities.

As no measurement scales met the requirements of the study, it was decided to develop and pilot a battery of self report measures, which would yield an assistance score.[9,10] This was based only on the respondents' assessments of the assistance they required in everyday life. Respondents were scored on the basis of their replies to three questions regarding help with mobility, household tasks and self care, which contained seven, eight and 18 items respectively. For each item, where people said they required help a single point was awarded, up to a maximum of 33. To avoid a subjective judgement regarding which problems caused greater disability to any given individual no weighting was placed on different aspects. In effect, however, self care was weighted more heavily since there were over twice as many items. On account of the unique experience of wheelchair users they were considered as a separate group.

Analysis

Data were analysed using *dbase 3*. Chi square tests were used to test the association between variables.

Results

Profile of the interviewees

Of the 212 interviewees, 117 were women; 55 women were aged between 56 and 65 years and 16 were aged between 16 and 35 years. Ten of the 95 men were aged between 16 and 35 years and 52 between 56 and 65 years. Despite attempts to increase the representation of younger age groups, 50.5% of all interviewees were aged over 55 years. Only 24 (11.3%) interviewees were in single person households. Over three quarters of the study group (163, 76.9%) were married, with a higher proportion of women being single or widowed than men (24.8% versus 16.8%). A total of 29.7% were in paid employment, 22.2% being in full time work.

The majority of the interviewees (140) reported having a musculoskeletal disorder. The other most commonly reported disorders were of the circulatory system (85), the respiratory system (48) and the nervous system (42). A total of 119 people had two or more disorders. The majority of those interviewed (156) had at least one health disorder which had been present for five or more years. A further 13 had a congenital disease including one person with Huntington's chorea and three people with spina bifida.

Assistance scores

The assistance scores of the interviewees and their reported economic status are shown in Table 1. Less than half (95) had assistance scores below seven while 44 had a score above 15 or were wheelchair users. There appeared to be a relationship between interviewees' economic activity, receipt of mobility allowance and/or attendance allowance and their assistance score, a greater percentage of those with lower scores having employment.

Table 1. Assistance scores and economic status of the 212 interviewees.

Economic status	% of people with assistance scores:[a]				% of wheelchair users ($n = 13$)
	0–7 ($n = 95$)	8–15 ($n = 73$)	16–23 ($n = 22$)	24–33 ($n = 9$)	
Economically active	41	22	23	11	15
Receiving mobility allowance	2	15	18	25	92
Receiving attendance allowance	0	0	9	56	46

n = number of interviewees in group. [a] Assistance required with mobility, self care and household tasks.

Communicating medical information

A total of 80.2% of interviewees believed that they had been given appropriate information on their condition when a firm diagnosis had been made, most commonly in the hospital setting and were, moreover, satisfied with the timing and nature of the information conveyed. However, 19.8% of interviewees felt that either there was an unacceptable delay in communicating the diagnosis or that this had never been given directly to them. Five interviewees reported that they had learned inadvertently of their condition. For example, one interviewee said she discovered she had multiple sclerosis while taking part in a drug trial and in another case the diagnosis had been found out on assessment for registration as a disabled person. Criticism was also voiced concerning the occasion on which information was conveyed. One young person said that she was told that she had epilepsy when accompanying her mother who was on a routine visit to her general practitioner's surgery.

Most satisfaction was expressed by interviewees who had been given their diagnosis in a straightforward informative way with a realistic picture being presented of the prognosis. Nine interviewees considered that the worst possible outcome for their particular disability had been described to them at diagnosis. Although in general interviewees were satisfied with information regarding their diagnosis, they were more critical of that given in relation to coping in the future. At the time of diagnosis only 11 interviewees (5.2%) said that advice had been forthcoming on potentially useful services and contacts. Nine respondents were especially distressed when told there was no cure without being given information on how the disorder could be managed and how they could help themselves. In the words of one interviewee, it was like being 'left in thin air, there was a void'. On reviewing interviews as a whole, only 13.2% of interviewees did not at some point express the need for information on services and benefits.

Sources of information

General practitioners were the most commonly reported source of information on disability services (Table 2). Over 10.0% of respondents, including three wheelchair users, had never used any standard sources of information and a further 10.4% had used only one service. Relatives, friends and the media were more frequently used to gain information than statutory services. The Department of Social Security was more frequently used on an occasional basis for information than social work departments, and health visitors were more commonly approached than district nurses. A wide range of information was sought on topics such as housing, benefits and transport.

Little use was made of voluntary organizations as information providers, reflecting low levels of membership (22.2% of

Table 2. Sources of information on disability services reported by 211 interviewees, and their frequency of use.

	No. of patients receiving information:		
Souce of information	Regularly[a]	Occasionally[b]	Never
General practitioner	32	77	102
TV/radio	14	58	139
Booklets	14	52	145
Newspapers	12	51	148
Relatives	10	43	158
Friends	8	49	154
Department of Social Security	4	41	166
Social work department	4	27	180
Library	4	25	182
Health visitor	4	16	191
Voluntary organizations	4	15	192
District nurse	4	6	201
Information/advice office	3	5	203
Citizens advice bureau	2	9	200
Other	10	19	182

[a] Used more than than once or recurrently. [b] Used on a one-off basis.

Table 3. Initiation of contact, and frequency of contact with general practitioner, by severity of disability.

	% of people with assistance scores:				% of wheelchair users
	0–7	8–15	16–23	24–31	
Initiation of contact with GP	*(n = 72)*	*(n = 62)*	*(n = 20)*	*(n = 8)*	*(n = 9)*
Self initiated	*78*	*68*	*65*	*38*	*44*
GP initiated	*18*	*19*	*30*	*25*	*33*
Other[a]	*4*	*13*	*5*	*38*	*22*
Frequency of contact with GP[b]	*(n = 95)*	*(n = 73)*	*(n = 22)*	*(n = 9)*	*(n = 13)*
0	*24*	*15*	*9*	*11*	*31*
1–3	*47*	*37*	*64*	*33*	*46*
4–5	*7*	*7*	*5*	*0*	*0*
6 +	*21*	*41*	*18*	*56*	*23*

n = number of respondents. [a] Mutually arranged contacts and appointments. [b] Over previous six months.

interviewees). The groups with the highest number of study members were the Arthritis and Rheumatism Council and the Multiple Sclerosis Society (eight and seven respectively). Only 11 members attended meetings although two interviewees had attempted to attend those of the Arthritis and Rheumatism Council but for one there were 'too many stairs' and for the other transport was stopped.

Contact with general practitioners

Of the respondents, 80.7% had seen their general practitioner in the previous six months. Approximately half (108), had had frequent contact (four or more visits) during this period. For 160 interviewees (75.5%) general practitioner consultation time represented their only contact with community health care services, including chiropody but excluding dentistry. Current visits from a health visitor were received by 16 interviewees, from an occupational therapist by 10 and from a district nurse by eight. Only seven interviewees were having home help.

No relationship was found between degree of disability and frequency of general practitioner consultation. Those with less severe disability were just as likely to have contact as those with severe disability (Table 3). The greater the degree of disability, however, the more likely it was that general practitioners initiated contact rather than the patient. It appeared that those with similar levels of disability could receive very different levels of service from their general practitioner; a wheelchair user with multiple sclerosis in south Aberdeenshire had not seen her general practitioner for eight years (her husband collected repeat prescriptions from the surgery) whereas a similar patient living north of Aberdeen was visited monthly.

Data on access to community facilities revealed that 11.3% of respondents (24) had problems in visiting the general practitioner's surgery. While this mainly related to factors associated with transport, in six cases there were difficulties in gaining physical access to the surgery. None of the latter respondents were patients at the same practice.

Communication and psychological problems, such as depression and withdrawal, also created difficulties over contact with the general practitioner. As a consequence carers were depended on to seek a home visit when appropriate if the general practitioner was not in the habit of calling. Of the interviewees 32 (15.1%) had no telephone, four of whom lived alone; 25 respondents said that they needed help with using a telephone.

When carers were asked, 'If things get difficult who do you turn to?', 40.0% of the 35 carers who completed the form stated that this would be to the general practitioner, the same proportion as indicated a relative. By contrast, only 11.4% and 5.7% respectively said they would turn to a district nurse or health visitor, or minister of religion.

Although respondents' level of satisfaction with primary health care was not explored specifically, 24 interviewees volunteered their opinions. Thirteen were negative and 11 positive. From this, albeit self selecting group, it was apparent that the two main aspects of general practice stimulating comment were those of willingness to make home visits and ability to communicate effectively.

Discussion

An unexpected outcome of this study was the relatively high proportion of respondents with disability who indicated on the postal questionnaire that they did not wish to be interviewed. It is unlikely that this can be explained by reference to sponsorship of the study by Grampian Regional Council. A response rate of 83.6% had been obtained for the questionnaire, the distribution of which coincided with the first community charge demands. It is difficult to find studies which have asked people in advance if they were willing to be interviewed and response to this option gives rise to speculation regarding reluctance to participate. Given that the 1990 National Health Service and community care act calls for a needs led rather than a service led approach to provision of care, the above finding has considerable implications. The opinions of the vocal and willing may not necessarily be those of the total population. In addition, some individuals may choose not to receive services or be reluctant to seek assistance. The data highlight the complexity of assessing need.

The Grampian study confirmed the pivotal role of the general practitioner in the care of physically disabled people aged between 16 and 65 years in the community. Despite the changes which have occurred in health and social services in the 1980s the survey indicates that general practitioners continue to have more contact with physically disabled people than any other professional or agency. The frequency of contact found here is congruent with both the findings of the 1988 Office of Population Censuses and Surveys disability survey and those of Patrick and colleagues,[11] and regional surveys such as that carried out in Gloucestershire.[12] In the light of these results, it is perhaps surprising that those within general practice have not had greater involvement in developing systems of case management and needs assessment. Certainly general practitioners have had a long tradition of care in the community and many would see their role as care managers. The findings indicate that this was the expectation of patients too since general practitioners were often expected to meet social as well as medical needs, as reflected in their request for information on such topics as housing, benefits and so on.

Respondents were more likely to use their general practitioner as a source of information on benefits and services than the Department of Social Security or social work department. However, the strong emphasis among those interviewed on stressing the need for more information on services, together with the low uptake of services, and other findings that not all benefits to which individuals were entitled were being claimed[9] would suggest that a less than comprehensive service was being offered by practices in this respect. Broadly based research on physically disabled people,[13] young physically disabled people[14] and more narrowly focused work on multiple sclerosis patients[15] would indicate that doctors may not be well informed regarding either application/referral procedures for benefits and services or eligibility criteria. The complexity of these processes and lack of coordination between social and medical services have been well documented.[16] Further changes will occur with the implementation of the remainder of the National Health Service and community care act 1990 in April 1993, with social services having a bigger role to play.

It has been argued that general practitioners should become better acquainted with the benefits and services available and more knowledgeable regarding application procedures.[13] This cannot be achieved easily. Despite recent simplifications of some benefits, eligibility is seldom a straightforward case. The changing nature of benefits and services also make it difficult to be confident that information is sufficiently up to date and reliable. Even the most conscientious may have problems keeping abreast of current developments following the 1990 National Health Service and community care act. Pressures on consultation time may also make it difficult to allocate sufficient time for the communication of often complex information. General practitioners may be reluctant to award a priority to such tasks even though Buckle suggested that help in obtaining a benefit may be cost effective since improving the patient's financial position may reduce the number of future consultations.[13] Greater recourse could be made to information-giving databases at practice level. These offer the opportunity for both the general practitioner and the patient to improve knowledge of services and benefits available. Indeed direct patient access could reduce the general practitioner's workload in this respect. However, it may be argued that such information giving is a role for social work and other health care staff rather than general practitioners.

It would seem that at practice level an instrument for assessing patient need especially regarding services could be of use. A self completion assistance questionnaire could be sent to patients with conditions likely to cause disability. The information from this, including the assistance score, could be retained as part of the patient's records and also entered into a database. While further testing for reliability and validity is required for the assistance scale used in this study, it can be seen that there was a strong internal consistency between interviewees' economic activity, receipt of mobility and/or attendance allowance and their assistance score. Patients with high scores could be offered information on potentially useful services and facilities. The information could be updated on a regular basis, for example annually, to monitor change and the need for general practitioner intervention or to offer further information. This would provide a longitudinal picture of the changing nature of an individual's situation. The assistance score could be used in a variety of ways. Different degrees of disability could be identified by bandings within the score. Specific problem areas could be identified, such as mobility, self care and difficulties with household tasks, and information or appropriate interventions could be offered accordingly. Non-respondents would need to be investigated.

The national disability information project has recently been set up in England, aiming to improve the quality and accessibility of information services for disabled people, their carers and service providers, and to develop a national framework for the coordination of disability information services.[17] It would seem timely to evaluate the role of the general practitioner in the provision of information and services.

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Self Reported Disability in Six Electoral Districts in Grampian

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Summary

Following the Office of Population Censuses and Surveys (1988) Survey on disability, a survey was carried out in Grampian in 1989, initiated by the Social Work Department of Grampian Regional Council. From 5,042 mail questionnaires a response rate of 83.6% was obtained. Twelve and 88% of those with health disorders were considered as having impairments and disabilities respectively, when the categories of the World Health Organisation's International Classification of Impairments, Disabilities and Handicaps (1980) were applied. Thirty-two per cent of survey households considered that they had at least one person with a disability. Of the 1,289 households with disability 23% and 3% had two, and three or more people with a disability. Six disorders accounted for 86.9% of all disability, and asthma accounted for nearly half of all reported disability among Grampian's population under 16 years of age. The nature and extent of disability was found to vary considerably within Grampian.

Introduction

In April 1989 a survey of disability in Grampian[1] was initiated and sponsored by the Regional Council's Social Work Department.

The need for a local data base was apparent and the work was in large part in response to:

(1) The Chronically Sick and Disabled Persons Act (Scotland) 1972, reinforced by the Disabled Persons (Services, Consultation and Representation) Act 1986, by which local authorities are required to know the numbers of disabled people and the extent of service needs within their area.
(2) The Griffiths Report on Community Care[2] which proposed that local social services authorities should 'assess the community care needs of their locality, set local

priorities and service objectives, and develop local plans in consultation with health authorities in particular ... for delivering those objectives'.

(3) The OPCS survey of disability[3] which indicated that the prevalence of disability was greater than that formerly estimated, and the surveys of Heiser et al[4] and Bell *et al*,[5] for example, which found that many disabled people's service needs were unmet.

The two main aims of the Grampian investigation were:

(i) to present the regional picture of disability, distinguishing the latter from impairment as conceptualised in the WHO's International Classification of Impairment, Disabilities and Handicaps.[6] Impairment was taken to be a permanent or transitory psychological, physiological or anatomical loss of abnormality of structure or function, whereas disability was viewed as a restriction or prevention of the performance of an activity resulting from an impairment; and

(ii) to determine perceptions of people aged 16–65 with physical disabilities (excluding purely sensory disorders) regarding current and past service provision so that service development could be responsive to need.

The work reported here relates solely to the first aim stated above.

Methods

In order to meet the first aim of the study a sample survey of the population of Grampian was carried out to identify those with long term health problems or a disability. Using current estimates of prevalence it was calculated that approximately one in 40 households would need to be selected, if adequate numbers of people with disabilities were to be included so as to permit continuance of the survey onto its second interview stage relating to perceptions of services. Since variation between districts could occur, in the number of disabled people and in service provision, it was considered necessary to stratify the region by electoral constituency prior to sampling. Subsequently a random sample from each of the six constituencies was taken. Sample size ranged from 771 in Aberdeen South to 988 in Gordon District.

The 5,042 households in the sample were sent a modified (shortened and simplified) version of the OPCS[3] postal screening questionnaire. The section relating to health disorders was phrased as far as possible in lay terms, in order to (a) improve the reliability of self reporting and (b) encourage completion of the form. A major consideration in questionnaire design was that respondents' reports of their disorders, perceptions of their health states and descriptions of their difficulties with activities of daily living were to be used to decide whether or not they had a disability. The decision was made not to attempt to administer a rating scale such as the Barthel,[7] because it was considered that people's perceptions of their health state and possible consequent problems were more likely than a scale to indicate their need for service provision.

Overall 83.6% of questionnaires were returned after one postal reminder and one telephone reminder to 10% of the remaining non-respondents. The response varied between constituencies and ranged from 79.7% in Aberdeen North to 86.3% in Moray.

The OPCS Classification of Diseases (a modified form of the WHO International Classification of Diseases)[6] was used to categorise health disorders, although it was decided to separate the OPCS combined category of mental illness and handicap, and to collapse ear and eye conditions into a single group. The Grampian Regional mid year age structure estimates for 1989 were used in calculating the age related prevalence figures for disability in Banff and Buchan and Moray. As age related data were not collected on the questionnaire for those without disability, reliance had to be placed on the regional estimates, which however are presented by district rather than by electoral area, so that they could not be used to calculate age related prevalence for Aberdeen, Gordon and Kincardine and Deeside, where districts and constituencies are not identical.

Findings

The Regional Picture. Although responses were received from 4,213 households, a final figure of 3,978 was obtained, as in 235 households those to whom the questionnaire had been addressed had either moved away or died. 1,092 of the respondents reported that one or more persons within the household had 'a long term health problem or disability'. Eighty-two people did not complete this question, although their subsequent responses indicated that they had health disorder(s) and difficulties. It was considered more appropriate therefore to include them together with those indicating disability. In addition, 115 of the 2,779 people reporting no disability (4.1%) gave subsequent answers which led us to conclude that a more accurate picture would be obtained by including them within the disabled category. Eighty-eight per cent and 12% of respondents reporting disorders were regarded as having a disability and impairment respectively. Overall 32% (1,289) of the survey households were identified as having at least one person with a disability (SE = 0.72%—see Appendix 1). However when the number of people per household is taken into account, and over 90% of respondents did supply information concerning the total number of people with disability living within the household, a figure of 1,660 people with disability is obtained. Using the OPCS[3] formula the following estimates of prevalence were made within 90% confidence limits: 17% ±0.6% of the Grampian population would have health disorders; 13.4% ±0.6% would have a disability.

Although a wide range of disorders were reported, six disorders accounted for 86.9% of all reported disability. The main problems experienced in the households were: musculoskeletal (54%); circulatory (35%); respiratory (33%); eye and ear (24%); endocrine and metabolic (17%); and mental illness (14%), as is evident from Table I. It should be borne in mind that the figures include individuals with more than one disorder, and households with more than one individual with a health disorder. While the majority of households (64%) did in fact contain solely one disabled person, no less than 23% and 3% of households respectively had two and three or more people with a disability. Such households included those with both mental and physical disorders and those with a high level of dependency, as reflected in the two following examples:

> Household X—male aged 56–65 with depression; female aged 46–55 with diabetes; female aged 16–25 with partial sight and hearing;
>
> Household Y—female aged 26–35 with multiple sclerosis; female aged under 16 with asthma; male aged under 16 with mental handicap.

Table I: Distribution of Self Reported Health Disorders in Grampian

Disorder	*Number of households*	*Of households with health disorder %*
Infectious	10	1
Neoplasms (cancers)	12	1
Endocrine and Metabolic	220	17
Blood	12	1
Mental illness	175	14
Mental handicap	52	4
Nervous system	126	10
Eye and Ear	315	24
Circulatory	454	35
Respiratory	420	33
Digestive	53	4
Genito-urinary	16	1
Skin	10	1
Musculoskeletal	702	54
Congenital	11	1
Other and vague	42	3

Table II shows that among those reporting disability there is a predominance of older people, and that while boys outnumbered girls up to 16 years of age, in all subsequent age groups a greater number of females than males was found. Of those reporting endocrine and metabolic disorders the overwhelming majority were women, as was also the case regarding mental illness and musculo-skeletal conditions, as can be seen from Table III. It is important to note that nearly a third (32.4%) of all reported asthma was found among children aged under 16 years. Asthma, in fact, accounted for nearly half (49.2%) of all reported disability among Grampian's population under 16 years of age. By way of comparison, proportionally the second and third largest categories of childhood disability were mental handicap (12.9%) and eye and ear conditions (12.1%).

Disability in the Six Districts. An association was found between the proportion of responding households having a member with a disability and geographical district. Variation was mainly explained by reference on the one hand to the higher proportion of disabled households in Aberdeen North, and on the other hand the lower proportion in Gordon (see Table IV). Moray had the highest proportion of disabled households with two *or* more people with a disability, as shown in Table V. However when a chi-squared test was applied there was no significant association between district and number of disabled persons per household.

Among those with reported disability it can be seen from Table VI that there was a lower level of mental illness in Moray, and high rates of musculoskeletal and respiratory conditions in Aberdeen North (the latter being nearly double that for Moray). Overall Gordon had the lowest levels of four of the six main conditions (endocrine and metabolic, eye and ear, circulatory, and musculoskeletal), while Aberdeen North had the highest, for three of the main conditions.

Table II: Age and Gender of People with Disability

Age	*Males*	*Females*	*No information*	*Total*
	No. (%)	*No. (%)*	*No. (%)*	*No. (%)*
Up to 16	59 (58)	43 (42)	—	102 (100)
16–25	32 (44)	40 (56)	—	72 (100)
26–35	41 (40)	61 (60)	—	102 (100)
36–45	46 (39)	71 (61)	—	117 (100)
46–55	87 (45)	105 (55)	—	192 (100)
56–65	148 (47)	169 (63)	—	317 (100)
66–75	160 (48)	170 (52)	—	330 (100)
76–85	84 (39)	130 (61)	1 (0)	215 (100)
Over 85	13 (24)	39 (72)	2 (4)	54 (100)
No information	11 (7)	17 (11)	131 (82)	159 (100)
Total	681 (41)	845 (51)	134 (8)	1,660 (100)

Table III: Main Disorders by Gender

Condition	*Males*	*Females*	*No Information*	*Total*
	No. (%)	*No. (%)*	*No. (%)*	*No. (%)*
Endocrine and Metabolic	64 (32.3)	133 (67.2)	1 (0.5)	198 (100)
Mental illness	56 (35.9)	96 (61.5)	4 (2.6)	156 (100)
Eye and Ear	119 (43.1)	154 (55.8)	3 (1.1)	276 (100)
Circulatory:				
Cardiac	114 (53.0)	101 (46.9)	—	215 (100)
Other	94 (40.5)	136 (58.6)	2 (0.9)	232 (100)
Respiratory:				
Asthma	87 (46.3)	101 (53.7)	—	188 (100)
Other	134 (58.5)	95 (41.5)	—	229 (100)
Musculo-skeletal (excluding amputee)	246 (38.3)	393 (61.2)	3 (0.5)	642 (100)

Table IV: Proportion of Households with Disability by District

District	*Households with disability*
	No. (%)
Aberdeen North	229 (38.2)
Aberdeen South	180 (32.1)
Banff and Buchan	223 (34.5)
Gordon	216 (26.8)
Kincardine/Deeside	213 (31.9)
Moray	228 (33.5)

Table V: Number of People per Household with Disability

	3 people per household	*2 people per household*	*1 person per household*	*Unknown number per household*	*Total number of disabled households*
Aberdeen North	5	53	152	19	229
Aberdeen South	5	37	119	19	180
Banff/Buchan	4	49	146	24	223
Gordon	9	50	137	20	216
Kincardine/Deeside	7	50	141	15	213
Moray	6	60	134	28	228
Total	36	299	829	125	1,289
(%)	(2.8)	(23.2)	(64.3)	(9.7)	(100)

Table VI: Proportion of Disabled Population Reporting Main Disorders by District

Condition	*AN (N=292) (%)*	*AS (N=227) (%)*	*B & B (N=280) (%)*	*G (N=284) (%)*	*K & D (N=277) (%)*	*M (N=300) (%)*
Endocrine and Metabolic	10.3	12.3	13.6	10.2	15.2	10.3
Mental illness	10.9	12.3	9.6	8.1	11.6	4.7
Eye and Ear	17.1	19.8	16.8	15.5	15.5	15.7
Circulatory	31.8	31.7	27.9	22.2	26.3	22.7
Respiratory	31.8	19.8	25.3	29.6	23.8	19.3
Musculo-skeletal	44.9	39.6	37.5	36.9	37.5	39.0
Others	17.1	19.8	18.2	17.6	20.9	23.0

Gordon's age/disability profile is distinct, as can be seen from Table VII. Moreover a third of children had more than one condition, with asthma affecting 59%. By contrast nearly half (47.1%) of all Aberdeen South's disability was concentrated within the population over 65 years of age, and in the case of women in this group, over two thirds (65.5%) were aged over 75 years. Differences were apparent between Banff and Buchan and Moray regarding age related prevalence of disability. Notable was Banff and Buchan's higher prevalence in males aged 46–65 and females aged 26–45, as can be seen in Tables VIII(a) and (b).

Discussion

Grampian's estimated number of people with disability living in private households (13.4%) is within the range of recent surveys. The OPCS[3] estimated that nationally 14% of adults in the population are disabled. In North Tyneside[5] and Camden[4] 12% and 16% respectively of adults and children estimated to have disabilities.

When Grampian's health profile is compared with that of other surveys (see Table IX) many respiratory, circulatory and endocrine and metabolic disorders are evident, whereas levels of musculo-skeletal and neurological conditions are broadly similar to

Table VII: Age Distribution of People Reporting Disability by Electoral District

Age	*AN (N=272) (%)*	*AS (N=206) (%)*	*B & B (N=254) (%)*	*G (N=263) (%)*	*K & D (N=260) (%)*	*M (N=271) (%)*
Up to 16	7.0	1.5	7.1	12.2	5.8	5.5
16–25	4.8	4.4	5.1	4.2	5.4	4.4
26–45	15.0	10.7	13.4	21.3	14.2	10.7
46–65	33.5	33.5	35.0	26.6	35.0	36.5
Over 65	40.0	47.1	38.2	33.0	38.5	40.2
No information	0.7	2.9	1.1	2.6	2.1	2.6
Total	101.0	100.1	99.9	99.9	101.0	99.9

Table VIII: Prevalence of Disability by Age/Gender* and District

(a) **Males**

	Banff and Buchan	*Moray*
<16	5.0	3.6
16–25	3.3	4.7
26–45	6.5	4.6
46–65	20.2	8.2
>65	43.1	48.7
All ages	12.4	9.7

(b) **Females**

	Banff and Buchan	*Moray*
<16	4.2	4.3
16–25	5.4	3.5
26–45	14.2	6.6
46–65	26.4	23.1
>65	40.0	42.8
All ages	15.3	15.0

* Excluding those whose age/gender was unknown.

those of other areas. Despite some minor differences in procedures between surveys, it is not believed that the distinctive pattern found within Grampian can be explained by reference to methodology. The high level of, for instance, circulatory and endocrine and metabolic conditions is consistent with a body of research which shows that Scotland has the highest rate of coronary heart disease in the world,[8] and that Grampian has one of the highest levels of diabetes mellitus in Scotland and the world.[9, 10] Less expected was the relatively high number of households with two or more disabled members. Both of these findings clearly have implications for health and social services and carers.

The differences between the districts with regard to the nature and extent of disability are likely to be related to a complex interaction of demographic, environmental and

Table IX: Major Disorders Reported by Four Disability Survey Populations*

Disorder	*Percentage of Disabled with Disorder*			
	Grampian	*O.P.C.S.*	*North Tyneside*	*Camden*
Endocrine and Metabolic	10	2	4	3
Mental illness	12	11	8†	17
Eye	—	22	13	8
Ear	20	38	13	14
Circulatory	33	20	26	15
Respiratory	25	13	19	19
Musculo-skeletal	47	46	42	21
Nervous system	10	8	9	8

* Do not sum to 100% as more than one disorder per person reported.
† Includes mental handicap.

socio-economic factors. Indeed, as can be seen from Table X, Aberdeen North had higher levels of unemployment, those on low incomes and households without cars than, for example, Aberdeen South and Gordon. Particularly notable was the significantly higher percentage of those in Aberdeen North living in Local Authority housing (65%) compared with those in Aberdeen South (19%), Gordon (20%) and Kincardine and Deeside (24%).

Acknowledgement

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Table X: Social Characteristics of Constituencies Within Grampian Region

Constituency	*% of households with disability*	*% over 65 years**	*% of households without access to a car*	*% in local authority housing*	*% unemployed*	*% without professional or vocational qualifications*	*% in low income groups*
Aberdeen North	38	22†	56	65	6.2	94	40
Aberdeen South	32		51	19	4.7	83	29
Banff and Buchan	34	21	36	33	5.8	92	36
Gordon	27	18	24	20	2.7	86	28
Kincardine and Deeside	32	19	38	24	3.0	86	27
Moray	33	21	37	29	6.3	92	34

* Local Government districts.

† Only combined figure available for Aberdeen North and South.

Source: Grampian Regional Council Planning Department (1990).

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Appendix 1

Standard error of a proportion in a stratified random sample.

$$SE = \sqrt{\frac{\Sigma n_i\, p_i(1-p_i)}{n^2}}$$

n_i = sample number in i^{th} strata
p_i = proportion of sample in i^{th} stratum possessing this attribute
n = total sample size

$n_1 = 633$	$p_1 = 0.38$	$n_1\, p_1\, (1-p_1) = 149.135$
$n_2 = 631$	$p_2 = 0.32$	$n_2\, p_2\, (1-p_2) = 137.3056$
$n_3 = 684$	$p_3 = 0.34$	$n_3\, p_3\, (1-p_3) = 153.4896$
$n_4 = 843$	$p_4 = 0.27$	$n_4\, p_4\, (1-p_4) = 166.1553$
$n_5 = 704$	$p_5 = 0.32$	$n_5\, p_5\, (1-p_5) = 153.1904$
$n_6 = 709$	$p_6 = 0.33$	$n_6\, p_6\, (1-p_6) = 156.7599$
$n = 4{,}204$		916.0358

(n_1–n_6) calculated by multiplying response rate by number sent out to each division.

$$\text{Sample Error} = \frac{916.0358}{4{,}204^2} = 0.0072$$

i.e. 0.72% sample error of proportion of households in Grampian which are disabled.

The Needs of Physically Disabled People Aged 16-65 Years and Service Usage in Grampian

Anne Sutherland and Rosemary Chesson

The work reported here forms part of a two-phase investigation of disability sponsored by Grampian Regional Council Social Work Committee. Following a questionnaire survey of about one in 40 of the region's households, 212 people with physical disabilities aged 16-65 were interviewed during 1989/90 to obtain an in-depth understanding of their perceptions of current and past service provision. Two-thirds of all those interviewed required some help with self-care across a wide range of activities. Sixty-six (31%) interviewees were found to use 150 items to help with self-care and a further 45 (21%) indicated that they would like equipment. Forty-one per cent of all self-care aids had been self-purchased. Minimal service use was discovered, the most common being dentistry and chiropody. Despite the level of disability, only seven respondents currently had a home help and 10 were in receipt of community occupational therapy. Very low involvement in voluntary organisations was found.

Less than half of interviewees (45%) reported 'going out' every day and sedentary leisure activities were more common than visits to clubs or friends. The main reason given for non-participation in other leisure activities was physical difficulty. Only 13 people took part in social activities organised either wholly or partly for people with physical disabilities. In general, those interviewed sought better opportunities for integration into the life of their community. Two case studies are presented in an appendix, which illustrate the multifaceted nature of interviewees' problems and the nature and extent of formal and informal care within two survey households.

Introduction

In 1989, Grampian Regional Council Social Work Committee initiated a survey of people with disabilities which represented the first large-scale investigation of this group in the North East of Scotland. The study had two broad aims, namely:

1. To present an overall picture of disability in the region, which would include people of all ages with any condition, be it physical or sensory disability, learning difficulties or mental illness
2. To obtain an in-depth understanding of the perceptions of people aged 16-65 with physical disabilities (excluding purely sensory disorder) regarding current and past service provision.

The need for a local data base was apparent and the work was in large part in response to:

1. The Chronically Sick and Disabled Persons Act (Scotland) 1972, reinforced by the Disabled Persons (Services, Consultation and Representation) Act 1986, by which local authorities are required to know the numbers of disabled people and the extent of service needs within their area
2. The Griffiths Report on Community Care,[1] which proposed that local social services authorities should 'assess the community care needs of their locality, set local priorities and service objectives, and develop local plans in consultation with health authorities in particular ... for delivering those objectives'
3. The Office of Population Censuses and Surveys (OPCS) survey of disability,[2] which indicated that the prevalence of disability was greater than that formerly estimated, and the surveys of Heiser et al[3] and Bell et al,[4] for example, which found that many disabled people's service needs were unmet.

Methods

Main survey

A sample survey was the starting point for the whole study because, in addition to determining the nature and extent of disability in the region, it was necessary to identify those with disabilities for subsequent interviewing. A sample of Grampian's households was selected after the region had been stratified by electoral constituency. This was deemed necessary since variation between districts was thought likely to occur both regarding the number of disabled people and in service provision. A random sample of approximately one in 40 households was selected from the electoral register through the use of a computerised random number generation programme. In total, 5042 people were sent a questionnaire which was a modified (shortened and simplified) version of the OPCS postal screening questionnaire.[2] The response rate achieved of 83.6% (4213) compared favourably with other disability surveys and was higher than expected, given that the mailing coincided with the introduction of the collection of the community charge by Grampian Regional Council.

From the questionnaires, and in particular individuals' own self-definitions, it was concluded that 32% of households (1289) had at least one person with a disability. While the majority of households reporting disability contained only one

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disabled person, two and three person households were not uncommon and accounted for 25.9% (335) of all households with disability. Grampian's estimated number of people with disability living in private households (13.4%) was within the range of surveys such as that of the OPCS[2] and those of Bell et al[4] and Heiser et al.[3]

Interview survey

Of the respondents with a disability, 59.3% (765) were willing to be interviewed, as intimated by their response to the final question of the questionnaire. Since the interview survey was to relate only to younger physically disabled people, respondents over 65 years together with those under 16 years and those not having a physical disability were excluded from the pool of potential interviewees. Of the 765 respondents willing to be interviewed, a purposive sample was selected: a major objective was to ensure that people with differing experiences of the impact of physical disability, regardless of whether these were of social, psychological or physiological origin, were included (see Sutherland and Chesson[5] for a detailed account of how people were selected). Two hundred and twelve interviews were carried out between October 1989 and January 1990, including one partial interview.

Interviews were carried out by interviewers residing within each of the districts in the region. All had had previous experience in the area of disability. Seven were occupational therapists and four social workers while, in addition, there was a physiotherapist, a nurse and two others with health care related experience. However, interviewers were requested not to disclose their professional background in order to avoid response bias. Interviews lasted on average for 90 minutes, although in some instances they took up to 2 hours to complete. Both open and closed questions were asked and responses recorded on interview schedules. Interviews were far-ranging and the main topics covered included the nature and extent of disability; employment status; benefits; allowances and family finance; information received on disability services; service usage; housing; leisure activities; transport and access; and the provision of informal care and help.

Assistance scores

A review of existing scales indicated that no existing tool met the study requirements. As interviewees were required to determine their own levels of ability and elucidate their own motivations and attitudes to disability, no pre-existing tool met these criteria. It was considered inappropriate, for example, to use a scale such as the Barthel Index of physical dependence[6] since it depends on an external assessor and, while both Arber and colleagues'[7] and Townsend's[8] self-reporting disability scales were given careful consideration, both were rejected because they focused on a narrow range of activities. It was decided to develop and pilot a battery of self-report measures which would yield an assistance score (AS). This was based solely on respondents' assessment of the assistance they required in everyday life.

Respondents were scored on the basis of their replies to three interview questions regarding help with mobility, household tasks and self-care, which contained 7, 8 and 17 items respectively. For each item where people said they required help a single point was awarded, up to a maximum of 32. No weighting was placed on different aspects because the researchers wanted to avoid a subjective judgement regarding which problems cause greater disability to any given individual. In effect, however, self-care was weighted since there were over twice as many items in this area. On account of the unique experience of wheelchair users, they were considered as a separate group even though their assistance scores ranged between 12 and 28. For further details of the scale and methods used, see Sutherland and Chesson.[5,9]

Findings

Given the comprehensive nature of the survey, it is not possible to report here on all aspects of it. Since issues relating to the role of general practitioners[10] and housing[11] have already been described, the focus of this particular article is findings relevant to occupational therapy.

A profile of the interviewees

Table 1 shows the age and gender of those interviewed. Despite attempts to increase the representation of younger age-groups, over half of all interviewees were over 55 years of age. The overwhelming majority of people interviewed were living with at least one other adult; only 11% (24) formed single-person households. Over three-quarters of the study group were married (163), with a slightly higher proportion of women being single or widowed. Thirty per cent (70) were in paid employment, although only 22.2% (47) were in full-time work.

Table 1. Age and gender of interviewees

	Gender		
Age	**Male**	**Female**	**Total**
16-25	1	5	6
26-35	9	11	20
36-45	11	17	28
46-55	22	29	51
56-65	52	55	107
Total	95	117	212

The majority of the interviewees (140) reported having a musculoskeletal disorder. The other most commonly reported disorders were of the circulatory system (85), the respiratory system (48) and the nervous system (42). A total of 119 people had two or more disorders. The majority of those interviewed (156) had at least one health disorder which had been present for 5 or more years. A further 13 had a congenital disease, including one person with Huntington's chorea and three people with spina bifida. Less than half (95) had an AS below 7 while 44 had an AS above 15 or were wheelchair users.

The majority of interviewees, 60% (127), required help in all three areas of mobility, household tasks and self-care, with 23% (49) and 10% (21) requiring help in two areas and one area respectively; 7% (15) required no assistance. As expected, the higher the assistance score the more likely help was to be required in all three areas; for example, all those with a score of AS 12 or over were so categorised. Of the 33% (70) requiring help in only one or two areas, assistance was required with household tasks and mobility significantly more often than with self-care.

Self-care

Two-thirds of all people interviewed (140) required some help with self-care, either on a regular or an irregular basis. Assistance was needed across a wide range of activities of daily living, including help with eating and drinking, managing medication and reading a book or newspaper. Help required ranged from 1-16 aspects of self-care, with 44% of people needing help with 1-4 aspects, 12% with 5-8 and 11% with 9 and over.

The main areas of difficulty where help was required were bathing/showering, footcare and dressing/undressing, as shown in Table 2. A significant amount of help was also need-

Table 2. Assistance with self-care

Activity	Help required (n=212) Always	Help required (n=212) Sometimes	% Requiring help	Help received (n=212) Always	Help received (n=212) Sometimes	% Receiving help	% Gap between requiring/ receiving help
In/out bed	9	26	17	8	22	14	2.4
Dressing/undressing	28	34	29	23	31	25	3.8
Washing/grooming	10	25	17	10	16	12	4.2
Bathing/showering	38	28	31	32	22	25	5.7
Footcare	41	22	30	36	17	25	4.7
In/out chair	12	34	22	10	24	16	5.7
Eating/drinking	5	13	8	3	11	7	1.9
Getting to/using toilet	8	15	11	6	10	8	3.3
Bladder management	7	6	6	4	4	4	2.4
Bowel management	4	8	6	3	4	3	2.4
Managing medication	11	15	12	11	14	12	0.5
Holding pen/writing	19	27	22	9	18	13	9.0
Reading newspaper/book	14	19	16	3	8	5	10.4
Using telephone	11	14	12	9	8	8	3.8
Understanding speech	2	6	4	1	2	1	2.4
Expressing self	9	6	7	5	2	3	3.8
Seeking emergency help	44	15	28	39	10	23	4.7

ed with seeking help in emergencies, transferring to and from a chair, and holding a pen and writing. No less than 12% of interviewees reported needing assistance in using a telephone and 11% in getting to and using a toilet. Where needs were met, this was usually related to the presence of an informal carer in the household. As would be expected, the discrepancy between help required and received was more common in single rather than in two-person households.

Use of equipment related to self-care

In the light of respondents' stated requirements regarding help and the pattern of assistance provided, it was to be expected that equipment would most frequently be used to help with bathing/showering and dressing/undressing. Over one-third of all items of equipment relating to self-care were used in these two areas alone. Two additional aspects of daily living – chair transference and toilet use – accounted for nearly a further third (29%) of equipment (see Table 3). Equipment requirements too were most frequently reported to be related to bathing/showering.

Sixty-six (31%) interviewees were found to use 150 items of equipment to help with self-care and a further 45 (21%) indicated that they would like equipment. Approximately half of all those interviewed who had equipment used only one item, with 27% using two and three pieces and 18% four or more. Two people used at least eight items of equipment. As was the case with mobility, over half the interviewees (55%, 117) considered the equipment to be essential, a further 17% (36) found it useful and 3% queried its use; the remainder did not express any views on level of satisfaction. In addition, a number of items of mobility equipment were also used to assist with self-care. For example, a walking stick was used to help with dressing/undressing and a walking frame employed to transfer from a chair to a standing position.

Considering the high number of those interviewed who would have difficulty seeking emergency help, it was surprising to find that 32 people (15%) had no telephone, 18 of these having a score of AS 8 or over. Four lived alone, one having a score of AS 20.

When respondents were asked about the provision of equipment used in self-care, 54 of the 66 people with such items were able to supply information regarding its provision. However, 26% (14) thought that it had been provided by the NHS (although it seems likely that, if NHS staff were involved, they were more likely to be instigators of provision rather than providers). Thirty-one per cent reported equipment to be provided by the Social Work Department, as would be expected, although most commonly equipment had been self-purchased in 41% of all cases.

Table 3. Use of self-care equipment

Activity	Equipment used (n=66) No.	Equipment used (n=66) %	Equipment required (n=45) No.	Equipment required (n=45) %
In/out bed	6	9	3	7
Dressing/undressing	21	32	5	11
Washing/grooming	3	5	1	2
Bathing/showering	35	53	24	53
Footcare (excluding chiropody)	1	2	6	13
In/out chair	23	35	9	20
Eating/drinking	8	12	5	11
Getting to/using toilet	20	30	2	4
Bladder management	8	12	–	–
Bowel management	5	8	1	2
Managing medication	1	2	6	13
Holding pen/writing	6	9	4	9
Reading newspaper/book	3	5	3	7
Using telephone	4	6	7	16
Understanding speech	1	2	1	2
Seeking emergency help	5	8	8	18

Service use

Despite the level of disability found, minimal service use was discovered, as is apparent from Table 4. Only seven respondents currently had a home help and only one instance of current use of residential respite care was found. Only 10 people were in receipt of community occupational therapy, with a further nine reporting contact in the previous 3 years. The most commonly used services were dentistry and chiropody.

Table 4. Use of services

	Current use (n=212)		Used in past 3 years (n=212)	
Service	**No.**	**%**	**No.**	**%**
Dentist	63	30	27	13
Chiropodist	37	17	12	6
Health visitor	16	8	11	5
Community occupational therapist	10	5	9	4
District nurse	8	4	14	7
Home help	7	3	4	2
Community alarm	7	3	–	–
Social worker	6	3	10	5
*Community physiotherapist	4	2	26	12
Community speech therapist	1	0.5	2	1
Respite/residential care	1	0.5	2	1
Meals on wheels	–	–	2	1
Home care service	–	–	–	–
Crossroads care attendant scheme	–	–	–	–

* Includes instances of hospital outpatient treatment.

Some interviewees were unsure of the role of some services and were given information about any with which they were unfamiliar. Confusion was also apparent between some services, in particular between social workers and community occupational therapists and also to some extent between district nurses and health visitors. A degree of mismatching of services was also apparent in that individuals applied for services which were declined and services were offered to others who turned them down For example, eight respondents declined home help, four meals on wheels and three other services. Three unsuccessfully requested home help, two physiotherapy and three a shower through Social Work Department occupational therapists. Eight other interviewees responded that they would like a home help, two wished for meals on wheels and two wanted a community alarm.

Contact with voluntary organisations

Very low involvement in voluntary organisations was found and even lower active participation. Twenty-two per cent of interviewees (47) were members of a voluntary organisation with two having membership of more than one. The highest membership numbers were with respect to the Arthritis and Rheumatism Council and the Multiple Sclerosis Society (which had eight and seven members respectively), followed by the British Diabetic Association and the Chest, Heart and Stroke Association which had five members each.

Interestingly, only a minority of members participated in activities involving social contact with other members; the single most frequently used service, referred to by 19 members, was the provision of information and news, commonly via newsletters and magazines. Merely 11 attended meetings (representing 5% of the 212 people interviewed). Of attenders, although the majority enjoyed the social contact, others wanted sessions to be informative and geared to self-help rather than social events. Two interviewees tried to attend meetings for the Arthritis and Rheumatism Council but for one there were too many stairs and for the other transport was stopped. Two other interviewees attended one meeting of a voluntary organisation and did not return, one because she found people 'so unhelpful' and the other because 'there was a wrangle about Committee members'.

Only four interviewees had ever taken advantage of holidays provided or subsidised by a voluntary organisation, while as few as three respondents reported receiving help from an organisation with regard to transport or financial problems; the same number, in fact, stated that they had had assistance with treatment, the provision of physiotherapy and hyperbaric oxygen being mentioned in this context.

Reference was made by some interviewees, including members and non-members, to avoiding such groups because they were perceived to be distressing, especially for recently diagnosed people.

Social and leisure activities

Less than half (95, 45%) of interviewees reported 'going out' every day, 41% went out weekly and 4% monthly. The remaining 10% reported going out either two or three times per week or less frequently than monthly. 'Going out' could mean anything from a short walk near home to going to the theatre. A number of people indicated the value of having their own transport in maintaining social contact.

Table 5 shows the leisure activities enjoyed by interviewees. As might be anticipated, sedentary activities were reported more commonly than visits to friends or clubs.

Over half of all interviewees (114, 54%), however, indicated that there were other activities that they would like to pursue but could not. These mostly related to sports, outdoor pursuits, hobbies and clubs (Table 6). In addition, a variety of other activities was mentioned, ranging from those requiring excellent physical function such as rock climbing, aerobics and horse jumping to very modest ambitions such as visiting friends, reading and taking the children swimming. A number of interviewees reported that the nature of their participation in leisure activities had changed; for example, from going to football matches to watching games on television, from fishing alone to fishing only when accompanied. They expressed distress and regret at these changes, as did the interviewees who had been forced to abandon enjoyed leisure activities through increasing disability.

Table 5. Leisure activities pursued

	Interviewees (n=212)	
Activity	**No.**	**%**
TV, radio, listening to music	179	84
Visits (for example, pub, clubs, church and theatre)	124	58
Reading	112	53
Visiting friends and relatives	106	50
Sports and outdoor pursuits	64	30
Knitting, sewing, arts, crafts	44	21
Games, puzzles, crosswords (including Bingo)	22	10
Walking	15	7
Making music (piano, singing)	14	7
Gardening	13	6
Care of pets	11	5
Others (for example, car drives and dancing)	18	8

Table 6. Desired participation in leisure activities

	Interviewees (n=212)	
Activity	**No.**	**%**
Sports	66	31
Outdoor pursuits	39	18
Hobbies and clubs	18	8
Other activities	29	14

The main reason for interviewees being unable to participate in leisure activities was, as expected, physical difficulty (34%), although cost, the need for assistance and lack of transport were also factors, as shown in Table 7.

Table 7. Reasons for non-participation in leisure activities

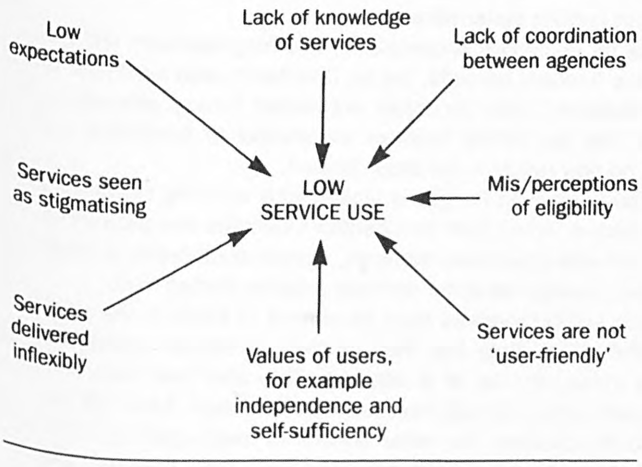
	Interviewees (n=212)	
Activity	**No.**	**%**
Physical difficulties	72	34
Too expensive	19	9
Would need a helper	12	6
Lack of transport	12	6
Facilities unsuitable	9	4
Not available	5	2
Other	5	2

Only 13 (6%) interviewees took part in social activities organised either wholly or partly for people with disabilities. Five attended a sports club, the remaining going to social activities arranged by disability-specific organisations.

Discussion

The findings presented here are of significance in the context of the 1990 National Health Service and Community Care Act. The ability of disabled people to live in the community (and their quality of life) will depend, as is well known, on the types of formal and informal support networks which exist. The interview data would indicate that service uptake is a complex process in which a number of factors interact. In Fig.1, some of the major influences have been identified. While low service use may, in part, be explained by reference to confusion or ignorance regarding access and mode of service delivery, social and psychological considerations need to be taken into account, yet are often overlooked. A request for service input is likely to have implications for those already providing informal care; feelings of failure or inadequacy may be felt and/or articulated. Social values that stress self-sufficiency may also deter service use, as may perceptions of formal care as 'charity'. Service use may underscore an unwanted and/or unaccepted identity as a disabled person with special needs.

Fig.1. Factors contributing to low service use.



From the survey, it was evident that people did not want to be passive recipients of services. Many interviewees were prepared to commit finances (often scarce) to make daily life less difficult or improve the quality of their lives, as instanced in their willingness to pay for housing adaptations.

A factor common to all interviewed was the restrictions on life experience. The survey demonstrated that often these restrictions may be unnoticed by members of the general public since they appear minor or are not clearly visible, yet they may have a profound effect on an individual's life. Notably, over 100 people interviewed stated that there were recreational activities that they would like to pursue but were not able to do so. Further work, it would appear, is needed in identifying obstacles and facilitating participation; some activities may well be possible given a reliable helper and possible modification to facilities. Those interviewed clearly preferred to have a place in mainstream life rather than experience segregated services and use facilities specifically for people with disability. In general, the respondents sought better opportunities for integration into the life of the community.

Finally, two case studies are provided (see Appendix 1) since, with survey reporting, people's lives become fragmented and sight of the individual's total experience is often lost. The case studies well illustrate how different elements within respondents' lives interact and contribute to perceptions of service needs.

Despite the differences in the situations of the two individuals and their lifestyles, it is evident that commonalities in experience emerge. For example:

1. High reliance on informal support was apparent
2. Household resources clearly were of importance in enabling difficulties to be overcome
3. Frustration and sometimes anger were apparent regarding the attitudes of able-bodied people.

The case studies suggest that the recent emphasis in the UK on empowerment will require major attitudinal change in society as a whole.

Conclusion

Overall, it emerged very clearly from the interview data that people had developed a keen sense of their capabilities and their requirements. Most welcomed the opportunities that the interview created to reflect on difficulties and communicated satisfactions and dissatisfactions with services to date. Despite often many years of disability, it was found that most people had not become resigned to the limitations that their conditions imposed.

There are obvious implications from this study for hospital and community-based staff, including occupational therapists, regarding how needs are identified and met. However, with resource restrictions and, frequently, a service-led approach to provision, the specific needs of the individual may not be met appropriately. It is to be hoped that the full introduction of care management, which took place in April 1993, is more likely to facilitate the development of a needs-led approach to service planning and delivery.

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Appendix 1. Case studies

In order to protect the anonymity of the people concerned, names have been changed and minor modifications made to personal and biographical data.

Miss Duncan (Assistance Score 8)

Miss Duncan is a 53-year-old woman who lives with her elderly mother of 79 in a local authority house in Aberdeen. She had congenital hip dislocation leading to progressive osteoarthritis throughout adult life. She had a hip joint replacement in her early twenties and the other joint replaced over 20 years later. She has pain and restricted movement of hip and knee joints and wears a raised shoe and supporting knee brace to correct a shortened leg. She falls occasionally and is unable to get up without help. Miss Duncan also has a problem with bladder and bowel incontinence and has had psychiatric treatment from time to time for depression.

Miss Duncan's elderly mother is also in poor health with 'circulation problems', diabetes and restricted mobility. She does, however, give her daughter daily help with dressing and with footcare when required, but is not able to help with Miss Duncan's mobility problems, especially when she has a fall. A neighbour has to be called in when this occurs.

Until she was persuaded by her psychiatrist to learn to drive at the age of 51, Miss Duncan had led a very restricted, isolated life. She had never been in open employment because she was 'regarded as disabled from birth' due to her medical problems and inability to walk any distance. (She was employed for a short period as a packer in a sheltered workshop but disliked the routine nature of the work.) In addition, she was unable use public transport because of the high step on buses. Driving 'opened up life altogether' for her. She now goes out daily in her automatic car and enjoys the independence this provides.

Miss Duncan and her mother live in a mobility standard purpose-built flat which they were allocated when her father retired because all three had medical problems. While generally very satisfied with the accommodation, she finds it too far from the nearest shops. There is a 'call button' with a help light outside the door and she also has a community alarm. She is able to carry out the majority of household tasks without help, apart from maintenance and decorating.

Miss Duncan attended a day centre for a time, enjoying the craftwork and the social aspects in particular, but found the hours too long and some of the 'work' physically tiring. She would still like to go to a club once a week, where she could meet people and pursue her interest in craftwork and knitting. She knits for various charities and also enjoys reading, but still feels isolated to a certain extent.

Miss Duncan found the Department of Social Security very helpful with her benefits entitlement and receives severe disablement allowance, mobility allowance and income support. She considers that she has many extra expenses because of her disability, such as additional heating, special furniture and special clothing/shoes, as well as having to employ tradesmen for all household repairs.

As far as services are concerned, Miss Duncan uses a community alarm, has occasional visits from a health visitor and visits her GP monthly. She also uses NHS chiropody but supplements this privately because it is too infrequent for her needs. She uses various pieces of equipment, namely a walking stick, raised shoe and brace, kitchen trolley, high chair, toilet frame and incontinence pads. She bought some of the equipment herself; the rest comes from statutory sources.

She considers that her accommodation, her car, regular chiropody and her special equipment are the most important elements in helping her to remain independent.

Mr Charlton (Assistance Score 23)

Mr Charlton is a married man of 43 who lives in a privately owned house in Morayshire with his wife and younger daughter of 15. He was involved in a road traffic accident in 1980 in which he sustained a head injury causing hemiplegia and short-term memory loss. He uses a wheelchair much of the time but can walk short distances with a walking frame.

Mr Charlton was not able to continue his former employment as a plumber and, in fact, has not worked since the accident. Mrs Charlton had to change to part-time work to fit in with her husband's needs. She also feels that becoming a carer has dramatically changed her lifestyle. In addition, she reported that their elder daughter left home at 17 because she could not come to terms with her father's disability. Mr Charlton now finds people assume he has a mental handicap and is adamant that he is not 'brain dead', although disabled.

The family have not moved house since the accident but have had their ground floor adapted by the Social Work Department to improve internal and external access and the bathroom facilities. They still find the area noisy, too far from family and friends and too hilly for satisfactory wheelchair use.

Mrs Charlton gives her husband a great deal of help with all aspects of mobility and self-care, spending up to 4 hours a day caring, with occasional additional help at night. She feels that her husband 'has to be considered all the time'. In addition, she runs the household and does her part-time job.

Although Mr Charlton has not worked since the accident, he considers himself available for work and would like employment even if it were 'sheltered'. He attended a day centre for over 2 years hoping for an improvement in his abilities. He was not generally satisfied with the regime of the centre or the attitude of the staff, but was offered counselling through the centre which he found helpful. He is interested in sheltered and voluntary work and offered himself for voluntary typing but nothing materialised.

As far as leisure is concerned, watching television and typing are frequent pursuits, but Mr Charlton is also a member of a philatelists' club. He enjoys occasional fishing, although he finds that few fishing facilities are wheelchair accessible and that he now needs to be accompanied.

The household budget is limited with resulting restrictions on lifestyle. Apart from Mr Charlton's benefits and allowances and his wife's part-time earnings, a small contribution is made by their younger daughter who has recently started work.

The family members have no relative or friend in the vicinity who offers help but they receive occasional assistance from those who live at a distance. They also have daily contact with a helpful neighbour and the GP makes 3-monthly visits to Mr Charlton. No other service is used apart from 3-4 weeks' residential respite care per year. Both husband and wife attend Headway groups.

Mrs Charlton feels that the vast majority of the burden of caring is borne by her, although her younger daughter sits with her husband for two evenings a week to give her a break. She finds it difficult to admit that she needs a complete break and appreciates the respite she gets when her husband is in residential care. She misses the social side of life, particularly going dancing, and says that friends now stay away. She is anxious about the future, although she considers their situation to be reasonably stable at present.

RESEARCH REPORT

Outcome Measures Used in Therapy Departments in Scotland

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Key Words

Outcome measures, standardised instruments, occupational therapy, physiotherapy.

Summary

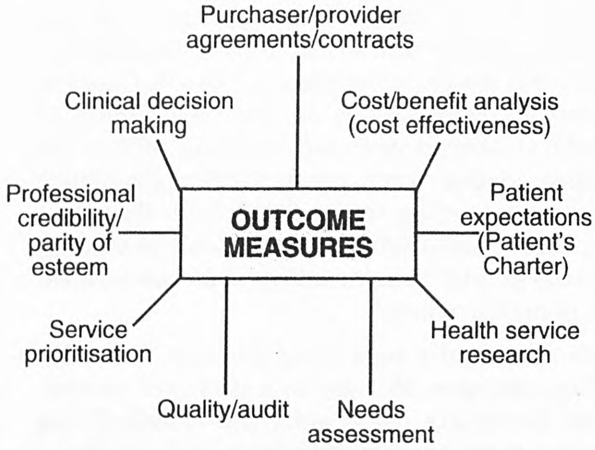
Occupational and physiotherapy departments in Scotland were surveyed to establish the extent to which outcome measures, and especially standardised measures, were used. A two-phase investigation was carried out; respondents indicating use in the first questionnaire survey were the subject of a second survey designed to provide more detailed information on measures. A total of 247 questionnaires were mailed to senior therapists (108 physiotherapists and 139 occupational therapists). A 74% response rate was achieved and a significantly higher proportion of physiotherapists than occupational therapists responded.

The questionnaires indicated that outcome measures were used in 72 departments, representing 39.1% of all departments responding to the first questionnaire. Wide variation was found between geographical areas of Scotland regarding both response rate and use of outcome measures. When the 72 departments were contacted for further details, 86% responded. Of the 62 therapists who responded, 46 confirmed that measures were in use (others reported measures were at the planning stage or use had been discontinued).

The majority of outcome measures had been introduced in the 1990s and standardised measures were used in 17 departments. Patients' views on outcome, while sought in approximately half of all departments, were seldom collected systematically in a structured format. The majority of respondents regarded outcome measurement favourably, and more positive than negative views were expressed. Outcome data were used in departments for a wide range of purposes.

Introduction

Many of the factors relating to use of outcome measures are linked inextricably to recent changes within the health service (see figure). In particular, as contracting has become embedded, increasing emphasis has been placed on outcome measurement (Orchard, 1994); whereas health commissioners use evidence on effectiveness to choose what to purchase, they use evidence on achieved outcomes to choose where to purchase (Long, 1994). Thus service providers able to demonstrate the effectiveness of care through improving patient outcome will be better placed to compete for purchaser funding (Garratt *et al*, 1993). Outcome measures have been defined as 'the results (effects) of processes. They are that part of the situation pertaining after a process which can be attributed to the process' (UK Clearing House on Health Outcomes, 1993) although the term may mean different things to different people (Austin and Clark, 1993).



Major influences on outcome measure use in therapy departments

Outcome studies to date have focused mainly on measuring medical outcome of care with little consideration of the contribution made by other health professionals (Higgins *et al*, 1992); a working party in 1993 concluded that there was 'little information' regarding the outcomes of care given by nurses and professions allied to medicine (Hopkins, 1993). However, there may be significant benefits for therapists of measuring outcome relating to clinical work since it can help to determine the impact of an overall treatment programme on an individual; the impact of a specific treatment approach on an individual; the overall impact of care on all clients within a programme; relative outcomes in a group of individuals in order to identify those who benefit most and least from the services provided; and productivity (Cole *et al*, 1995). The use of outcome measures in providing a means of measuring, demonstrating and monitoring therapy will help to establish credibility, not only with other professionals (Fricke, 1993), but also with clients, the community and governments (Department of National Health and Welfare / Canadian Association of Occupational Therapy, 1987).

Currently we do not know how many therapists are using outcome measures or what is in use; a survey of British therapy departments seems long overdue. Of particular interest is likely to be the extent to which usage involves standardised measures, that is 'a published measurement tool, designed for a specified purpose in a given population, with detailed instructions provided as to when and how it is to be administered and scored, interpretation of the scores and results of investigations of reliability and validity' (Cole *et al*, 1995). In addition to having greater validity and reliability, standardised measures permit comparisons between provider units, and promote consistency of measures as patients transfer between primary and secondary sectors (Zinober, 1995). Yet the early database of the UK Clearing House for Information on the Assessment of Health Outcomes revealed that over 50% of the studies logged were using locally developed measures, leading to the conclusion that 'this is not an encouraging result if one is looking towards greater comparability and standardisation of measurement'.

More specifically regarding therapy, a similar picture emerges. McAvoy in a survey of occupational therapists' use of activities of daily living measurement tools in Northern Ireland found that none of the departments surveyed were using a standardised index. Where assessment forms were in use they had been developed within departments (McAvoy, 1991).

It was decided therefore to carry out a survey of Scottish therapists in order to start to discover answers to some of the questions posed. Further, one of the authors (SM) was intending to introduce outcome measurement in her service and believed that a knowledge of other departments' use might help to indicate the most appropriate measures.

Survey Objectives

The main objectives were to :

- Establish the number of therapy departments in Scotland using outcome measures and when they were first introduced.
- Identify the characteristics of departments using outcome measures.
- Determine the nature of measures and specifically the extent to which standardised measures were used.
- Delineate the main methods of recording outcome measures.
- Obtain an evaluation of outcome measure use from identified users.

Methods

Early discussions with colleagues suggested that it would be advantageous to include both occupational and physiotherapy departments since both professions had to overcome similar problems in measurement, often because of a common patient population. It was decided also to approach departmental heads, rather than all therapists, since it was believed that the former would know of staff's use of outcome measures and could report on behalf of the department.

Given the national scale of the project a questionnaire survey was regarded as the only feasible method of data collection. A form was developed but in its pilot stages it became apparent that the lengthy questionnaire needed to provide detailed and comprehensive information on use would discourage response. Therefore a two-phased survey was undertaken. In the first phase departments using outcome measures would be identified and these would be followed up in a second questionnaire survey, in order to obtain more specific and detailed information on usage.

First Survey

A list was compiled of all hospital and community based departments, whether or not they were NHS or local authority administered. An initial problem was to establish contact names and addresses as no pre-existing list was sufficiently comprehensive with regard to the two professions and provided coverage of both community and hospital based therapists. The final mailing list was based on a number of sources including names provided by professional bodies; area advisers; special interest groups; and local senior managers. Some considerable effort was made to ensure that all departments were covered, and that duplicate reporting was avoided.

In November 1992 a total of 247 questionnaires were mailed to senior therapists employed in Scotland comprising 108 superintendent physiotherapists and 139 head occupational therapists, including their equivalent grade in the community. The questionnaires were short, simply worded, and included largely pre-coded items.

Non-respondents were subsequently contacted by letter and telephone.

Second Survey

A follow-up survey of all therapy departments in Scotland where outcome measures had been reported as in use was undertaken during December 1992 and January 1993.

Findings

First Survey

Response and Use

Initially 33% of therapists replied to the first questionnaire. Telephone calls made to non-respondents indicated three main reasons for the questionnaires not being returned:

1. Confusion surrounding the term 'outcome measure'.

Table 1: Use of outcome measures by profession and region (first survey)

Area	Questionnaires							Departments using outcome measures			
	OT departments		Physiotherapy departments		Total		Response rate (%)	Occupational therapy	Physiotherapy	Total	
	Sent	Returned	Sent	Returned	Sent	Returned				No	%
Argyll & Clyde	11	9	5	5	16	14	87.5	5	4	9	64.3
Ayrshire & Arran	3	3	4	3	7	6	85.7	–	2	2	33.3
Border	3	1	4	4	7	5	71.4	–	3	3	60.0
Dumfries & Galloway	3	4	1	1	6	5	83.3	1	1	2	40.0
Fife	17	12	8	7	25	19	76.0	4	–	4	21.1
Forth Valley	5	3	6	4	11	7	63.6	2	2	4	57.1
Grampian	18	14	7	6	25	20	80.0	4	1	5	25.0
Greater Glasgow	32	21	27	23	59	44	74.6	7	9	16	36.4
Highlands & Islands	9	5	11	9	20	14	70.0	1	3	4	28.6
Lanarkshire	7	2	6	4	13	6	46.2	1	–	1	16.7
Lothian	8	6	18	11	26	17	65.4	4	7	11	64.7
Tayside	21	18	11	9	32	27	84.4	5	6	11	40.7
Total	139	98	108	86	247	184	74.0	34	38	72	39.1

2. Little or no activity regarding outcome measurement.

3. Low priority awarded the form, because of demands relating to the health reforms and the introduction of community care.

Following contact with departments and reminders being sent, a 74% response rate was achieved. Of the 274 questionnaires mailed to therapy departments as part of the first survey, 184 were returned, of which 98 and 86 were from occupational therapy and physiotherapy departments, representing a 70.5% and 79.6% response rate respectively. When the Mann Whitney U-test (Wilcoxon rank sum W-test) was applied, a significant difference (at 10% significance level) was found between the two professions.

Overall 72 (39%) of respondents reported that measures were in use (44% in physiotherapy and 35% in occupational therapy departments). Variation was found between geographical areas regarding response rates, and the proportion of departments using measures, ranging from 16.7% in Lanarkshire to 64.7% in Lothian (table 1). In two-thirds of the areas (eight of the 12) less than 40% of respondents indicated usage in their departments.

Second Survey

Response and Use

Of the 72 questionnaires mailed 62 were returned, providing a 86.1% response rate. Although questionnaires were sent exclusively to therapists reporting outcome measures in the first questionnaire, of the 62 respondents, 16 (25.8%) indicated that measures were not in use. Overall 46 departments confirmed use, comprising 26 physiotherapy and 20 occupational therapy departments representing 68% and 58% respectively of respondents initially indicating usage. Five of the therapists who provided an explanation for the difference between the two responses commented that measures had yet to be implemented and were currently at the planning stage. In two further instances measures were reported as no longer in use, in one case because of 'inadequate funding'.

Introduction of Measures

The overwhelming majority of outcome measures (75%) had been introduced into departments in the 1990s; but six were introduced prior to 1986. Nine measures were described as being first used in 1988, 17 in 1991 and 34 in 1992. Paediatric occupational therapists provided the three earliest instances of measures in use, dating from 1974. The first reported use of the Barthel Index was by an occupational therapist in 1980.

Specialty

Data relating to the use of measures within specialties were not easy to interpret for a number of reasons: variation in organisational structure between care settings; the existence of specialist units such as stroke units in some but not all hospitals; and differential interpretation of the term 'specialty', ranging from a high degree of specificity to very broad categorisation. In addition, measures were reported as in use in more than one specialty and seven respondents reported that outcome measures were used across all specialties, although details were not provided regarding their nature or number. Additionally, information was not provided on all the measures listed by respondents, particularly where a number were in use. Outcome measures were reported in 12 specialties: care of the elderly, paediatrics, general medicine, general surgery, mental health, gynaecology, rheumatology, amputees, orthopaedics, stroke, out-patients, and neurology. Care of the elderly was the single most frequently mentioned specialty (referred to by nearly a quarter of respondents), followed by stroke and out-patients. Equal numbers of occupational therapists and physiotherapists described usage in care of the elderly and stroke rehabilitation, while physiotherapists reported outcome measures in use in out-patient departments.

Number of Measures Used

The mean number of outcome measures in use per department was 1.97 (range 1 – 10). Approximately half of all respondents (46) were using one outcome measure, as is shown in table 2. The maximum number of outcome measures in use was found in an occupational therapy department, where nine of the ten measures described were, in fact, standardised.

Table 2: Numbers of departments using standardised measures (2nd survey)

Measure	*Occupational therapy departments*	*Physiotherapy departments*	*Total*
Standardised only	5	5	10
Standard and non-standardised	3	4	7
Non-standardised only	12	17	29
Total	20	26	46

Use of Standardised / Non-standardised Measures

Approximately one quarter of departments (10/46) were reported as using standardised measures exclusively (table 3). Sixteen respondents (representing over one-third of departments) stated that either the Functional Independence Measure (FIM) or the Barthel Index was used (equal numbers cited each measure). The FIM was most common in physiotherapy departments and the Barthel Index in occupational therapy departments. The latter tended to be used most frequently in stroke rehabilitation and the former in care of the elderly. The other main measures used included the Chessington Neurological Assessment Battery, the Rivermead Assessment, and the Clifton Assessment Procedure for the Elderly. Specialist measures included the Jebsen and Maberg used by occupational therapists for assessing hands and the Russek reported by physiotherapists working with amputees.

Table 3: Numbers of outcome measures used by profession (2nd survey)

No of measures per department	*Occupational therapy*	*Physiotherapy*	*Total*
1	10	16	26
2	3	4	7
3	5	3	8
4+	2	3	5
Total	20	26	46

A wide range of activities and methods of data collection were regarded by respondents as non-standardised outcome measures. Discharge outcome codes specifically were most mentioned in this context, referred to by 12 of the 36 non-standardised measure users. Patient satisfaction questionnaires were described by a minority of therapists and the use of goal attainment was reported by three physiotherapists. The majority of non-standardised measure users (26) had been involved in their development. Few therapists stated that measures had been introduced by multi-professional teamwork but physiotherapists most frequently referred to collaboration with medical colleagues, and occupational therapists to joint working with physiotherapists.

Outcome Measures and Patients' View of Treatment

When asked specifically if patients' opinions of outcome were sought, 26 respondents said that this occurred. The form that this took varied considerably. Although there were no reported cases of validated questionnaires, in seven departments patients were given questionnaires (or forms) to complete.

Three therapists (all from paediatric departments) stated that parents / carers were involved in discussions relating to progress and treatment planning.

Multi-professional Usage

The majority of respondents reported measures as having uni-professional usage although 31% of respondents indicated use by more than one member of the multi-disciplinary team.

Use of Computers

Ten respondents reported using computers to collect and collate outcome data. No single database package was used across departments and mention was made of a limited number of software packages.

Training

Nearly three-quarters of departments indicated that training was provided regarding outcome measures, but this was variable (see table 4). Eight occupational therapists and two physiotherapists reported that no training was offered.

Table 4: Provision of training and use of outcome measures (2nd survey)

Type of provision	*No*	*%*
Included in induction	12	26.1
Initial explanation to new staff	7	15.2
Use of video*	7	15.2
One-to-one training	5	10.9
On-going workshops/training	2	4.3
No training	13	28.3
Total	46	100

*FIM training video

Users' Evaluation of Outcome Measures

When therapists were asked the main reasons for using outcome measures answers closely corresponded with their use of outcome data (see tables 5 and 6).

Table 5: Main reasons for using outcome measures given by therapists (2nd survey)

Reason	*No (N = 46)**
Assessment/improve effectiveness of treatment	22
Monitor patients/standardise measurement	18
To carry out audit/quality	8
Evaluate service/identify good practice	6
For service agreements/contracts/resource usage	5
Patient satisfaction/Patient's Charter/accountability	3
Other (research, communication between team)	6

*More than one reason given

Table 6: Main use of outcome data collected in user departments (2nd survey)

Use	*No (N = 46)**
Evaluate effectiveness of treatment/service	20
Audit/quality	22
Identify patients' progress	26
Predict treatment length/planning	10
Improve patient management/discharge decisions	8
For managers/marketing	6
Staff performance/time usage/training needs	5
Other (eg patient satisfaction)	6

*More than one reason given

Overall, more positive than negative comments were made by users and 62% of all views were favourable. The three main areas of which therapists commented positively were regarding the opportunity provided by measures for patient involvement; the value of having evidence of the effectiveness of treatment; and the ease of implementation and application of outcome measures. By contrast, outcome measures were regarded as time-consuming and demanding for staff by 25% of therapists expressing negative views. The second most frequently selected area for critical comment was with respect to the validity and reliability of measures, described as being too basic, insensitive, or subjective. Choice of measure was seen also as restricted by availability and this was seen as a particular problem by paediatric therapists. In general, negative views tended to relate to technical difficulties in outcome measurement, although very few questioned its value.

It was widely recognised that outcome data collected could be used for a range of different purposes, including personal learning; motivating patients; and aiding decision-making on patient discharge. Indeed, a small but significant number of therapists expressed the view that outcome measures helped to focus a therapist on the most appropriate form of treatment for a patient. Three therapists commented that such data were used to assess staff competency, two mentioned their use in research and another in making inter-departmental comparisons. Replies indicated extensive use when outcome data were collected.

Discussion

While differences were found between occupational therapists and physiotherapists regarding rates of response, extent of use, and type of measure employed, of greater significance appeared to be the wide variation between geographical areas. For example very low rates of usage were reported by occupational therapists and physiotherapists in Lanarkshire. This may suggest that there are local factors such as hospital, trust and board management practices and policies which may influence usage. Staff recruitment, turnover, and participation rates in continuing education could also be implicated.

Our findings regarding an initially low response rate to our first questionnaire are of interest in the light of a parallel 1992 Canadian study. Pilot work revealed that not all Canadian physical therapists and directors had been exposed to the term 'outcome measures' and did not know to what the researchers were referring (Cole *et al*, 1995). Thus in their main study respondents were asked about 'tools used to document clients' progress' and 'published measurement scales'. The latter were equated with 'standardised outcome measures'. It seems likely that at least some of the differences found between responses to our first and second questionnaire may have been related to understanding of terms. Users' comments also suggested considerable variation in the way in which the terms were used and understood. Indeed the term is likely to mean different things to different people (Austin and Clark, 1993).

Of the 46 departments who responded to the second questionnaire, 37% reported using standardised measures. This closely compares with 41% of physiotherapy staff in Canada who thought that published measurement scales were being used in their departments (Cole *et al*, 1995).

The high usage of non-standardised instruments must give rise to concern since use of unreliable assessments is likely to 'seriously diminish the credibility of the profession' (Eakin, 1989). Indeed it has been asserted that 'most therapeutic techniques used by physiotherapists are based on assessment processes which themselves have not yet been fully standardised'. Dobkin (1989) in a review of stroke rehabilitation found that two-thirds of the studies investigating predictors of outcome used measures untested for reliability and validity. Writing on behalf of the Australian Quality Assurance Committee, Nosworthy *et al* (1989) put forward the view that by producing standardised forms, therapists would greatly enhance their ability to evaluate outcome, and hence ensure a high quality of care.

In addition it may not be 'sensible' for clinical physiotherapists to devise their own outcome measures, since developing a standardised scale or measure is a long and time-consuming process, which cannot be achieved without appropriate research supervision or funding (Lennon, 1995). Commenting with regard to neurology, Lennon suggests that rather than devising new assessments, clinicians should concentrate on evaluating the standardised scales already published. Unless physiotherapists are willing to use valid and reliable tools for evaluating the efficacy of physiotherapy Lennon believes they will fail to gain resources for patient care.

Contrary to expectations outcome measures were more commonly used in care of the elderly rather than any other speciality. But as McAvoy (1991) has argued: 'Outcomes are intangible and nowhere more elusive than with the elderly who bring with them a lifetime's accumulation of physical, social and psychological events, any of which may have contributed to their presenting condition and require resolution'. Although it may be particularly difficult to define the most appropriate measure for this patient group (Green, 1992) and the Royal College of Physicians / British Geriatrics Society (RCP/BGS) concluded in 1992 that in general there was no consensus regarding outcome measures, we found that just two measures (FIM and the Barthel Index) were widely used in this specialty. Therefore it would be interesting to know whether the assessment package recommended by the RCP/BGS and advocated for use by physiotherapists (Simpson and Forster, 1993) has been widely used. A further confounding factor – namely treatment by the multi-disciplinary team – has also been highlighted (Green, 1992) but despite the increasing prevalence of teamwork most measures in this study were applied on a uni-professional basis.

While we found about half of all respondents incorporated patients' views into outcome measures, only six were using systematic methods (for example a questionnaire). This would reflect an American observation that patients' oral descriptions of their illness are rarely quantified and stated formally within assessments, although therapists are said to place an importance on them (Delitto, 1989). Current emphasis on patient-defined outcomes (Ross Davies, 1994) would highlight the need for increasing attention to be given to how patients' assessments of treatment may be reliably and routinely collected and how impact on health status may be measured. Departments, for example, may find it useful to adopt the approach of Enderby who has used the WHO classification of impairment, disability and handicap in attempting to assess the impact of physiotherapy on different client groups (Enderby and Kew, 1995). The relationship between what is being measured, and its relevance to patients may need also to be considered; Southgate (1988) contends that patients evaluate the success of treatment against their own yardsticks such as pain, fear, and stigma, as well as loss of function.

Our respondents' information on the date of the introduction of measures, however, illustrates the extent to which departmental activities are fast developing and reflect the changing ethos of the NHS. The survey demonstrated an exponential growth in outcome measure usage in the 1990s; over half of all the measures reported by users had been introduced in the previous three years. Measures are likely also to have come into use since then, as suggested by the publication of a symposium of papers on outcome and audit in *Physiotherapy* in April 1995.

In the years between our initial survey and this publication, therefore, changes are likely to have occurred. In particular there has been discussion and debate relating to the use of standardised measures (Smith, 1993; Mawson, 1995). Considerably more by way of support and advice is now available to therapists. The CSP offers the following information to members: a factsheet of references on outcome measures; details of the UK network of physiotherapists looking at outcome measures; a copy of the Clearing House database list of physiotherapists using outcome measures; lists giving names and addresses of relevant organisations, and relevant journals (Romain, 1993). Clearly there are increasing expectations that outcome measures will be used, given the current emphasis on research and the production of clinical guidelines (Romain, 1994). We hope to replicate this survey in the future and extend it to England and Wales in order to provide data on the current situation. Anecdotal evidence suggests that outcome measure usage is far more widespread now than in 1993.

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Copies of the full report (including questionnaires used) may be obtained from Susan Massie, Physiotherapy Department, Woodend Hospital, Aberdeen.

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Do Parents and Children Have Common Perceptions of Admission, Treatment and Outcome in a Child Psychiatric Unit?

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ABSTRACT

This investigation sought to establish how both child and parent from the same family viewed psychiatric input, its functioning and effects, and whether they shared similar perceptions. It was intended to redress the balance regarding an earlier study which focused on how staff attitudes, education, training, values and philosophies might affect therapeutic relationships in a child psychiatric unit (Chesson, 1996). A survey of children attending the inpatient psychiatric unit at the Royal Aberdeen Children's Hospital, as well as of their parents, was carried out over an 18-month period. Interviews were held prior to hospitalization and during inpatient stay, and took place on at least one occasion in the children's homes. Main findings were that a third of the children had not been informed by parents about admission (a view supported by parental comments), only two children saw the unit as a hospital, and that parents and children were not able to provide a clear reason for admission. Limited understanding of treatment and the work of the multidisciplinary team was evident, and parents seldom reported receiving any professional help themselves. A graduation emerged from younger/less intelligent children having a less accurate perception of reasons for inpatient stay to older/more intelligent children having one of greater accuracy. Children's satisfaction appeared related to outcome as measured by parental perception, but not scores on the Rutter's (1967) Child Behavioural Questionnaire. Parents' and children's views on several issues were incongruent, and it is suggested that this has significant implications for treatment.

KEYWORDS

child psychiatric units, children, consumers' views, parents' perceptions

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RESEARCHERS have concentrated on the effects of hospitalization on children with physical disease and the ways in which they conceptualize health and disease, as reflected, for instance, in the work of Bibace and Walsh (1980). Children's and their parents' understanding of psychiatric hospitalization has been little studied and investigations which have been taking place have been in the USA, where child psychiatric units have existed since the 1920s. By contrast in the UK the first psychiatric ward for children was established in 1947 at the Maudsley Hospital (Cameron, 1949) and the first opened in Scotland in 1951 at the Crighton Royal Hospital, Dumfries (Rogers, 1954).

Units increased in number as it became more evident that they could offer unique advantages in care, an essential part of which remains the supportive environment or milieu that specially trained nursing staff can provide (Wolkind & Gent, 1987). The relationships that a child develops with the staff are regarded as a significant and an integral part of the treatment. In addition, inpatient care allows for a more intensive coordination of medical, social and psychological approaches in the treatment of the child and his or her family.

In 1984, in the USA, E.R. Roth and L. Roth published the first systematic survey of children's concepts of their own psychiatric hospitalization. By using an interview conducted

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around the children's drawings at different stages of the hospitalization process, relevant staff made an attempt to elicit both cognitive and affective responses. Results indicated that initially children between the ages of 6 and 12 years did not have very specific concepts of their problems or the roles of therapeutic staff. Instead children's understanding was often stereotyped and general and related to their preconceived understanding of the roles of doctors, nurses and others in the medical field, in contrast to the psychiatric or psychological field. However, over time as psychiatric hospitalization progressed, children's understanding of their problems and the role of staff improved. Children's drawings indicated that although behavioural and cognitive gains were made while in hospital, poor self-image and feelings of anxiety remained unchanged following discharge. Additional information from drawings revealed that several children believed that they had been hospitalized because of their bad behaviour. Also issues of separation from the family and resultant sadness were apparent for most children (E.R. Roth & L. Roth, 1984).

It is widely recognized that children who have chronic physical diseases need explanations of their illness in order to allay fears and anxieties and increase cooperation with treatment (C. Eiser & J. Eiser, 1987). Awareness of developmental changes in cognition about illness is necessary, moreover, so that education is appropriate (Nagera, 1978; Pidgeon, 1985) and may lead to compliance (C. Eiser & J. Eiser, 1987).

Parents' perceptions

Previous studies have shown that parental understanding of child psychiatric services is limited (Burck, 1978; Garralda & Bailey, 1989). Poor communication has been highlighted, both at the level of outpatient referral, as well as following inpatient assessment. Garralda and Bailey's study looked at general practitioners' reasons for referral and concluded that explicit enquiry of parental expectations of the service provided (in terms of form, process and outcome) was associated with acceptance and use of services. Plunkett (1984) stressed that incongruent expectations of services must be adequately understood and responded to, if services were to be provided to children in real need. Indeed, the more short-term treatments and child-centred services provided over the last decade in the USA may be in part a response to parental expectations (Leventhal and Weinberger, cited by Plunkett, 1984; Labarbera, Martin & Dozier, 1982). Being aware of and addressing these factors may improve a child's progress while she or he is an inpatient.

In an editorial in the *British Journal of Psychiatry*, Williams and Wilkinson (1995) discussed methods of evaluating patient satisfaction in mental health care and stressed the importance of an in-depth understanding of the patient's perspective. Hence interview surveys may be preferable to questionnaires and may achieve a better response, for example, in a recent audit of parents' views regarding expectations of an outpatient child/adolescent referral service a response rate below 45 percent to a questionnaire was obtained (Mason, Watts, & Hewison, 1995). Despite being widely accepted that a better knowledge of families' views on illness promotes better communication and helps create empathy, as well as decreasing parental anxiety and improving the efficiency of treatment (C. Eiser & J. Eiser, 1987), we find that there has been relatively little effort expended in developing appropriate methods of information giving or identifying obstacles to communication.

Given the dearth of research to date, it is to be expected that no attempt has been made to establish how both child and parent from the same family view psychiatric input, its functioning and consequences and whether they share similar perceptions. This study seeks to redress the balance. In determining children's and parents' views prior to, during and after hospital admission, our aim was to study perceptions, and establish the degree of congruence over time with regard to three major areas: first, the reason for admission to the unit; second, the aim and objectives of treatment and the role of unit staff; and third, anticipated outcome. A further objective was to supplement an earlier study that focused on unit staff, particularly regarding how staff attitudes, education, training, values and philosophy might affect therapeutic relationships (Chesson, 1996).

Method

Subjects

The Lowit Unit is the only child psychiatric ward in the north of Scotland and accepts referrals from a large geographical area including Grampian, the Orkneys and the Shetlands. Since its opening in 1965, the unit has offered both inpatient and day-patient psychiatric facilities for children (Gray, Chisholm, Smith, Brown, & McKay, 1992). The unit is housed in a purpose-built wing of the Royal Aberdeen Children's Hospital, and at the time of the study there were 10 beds and up to eight day places. The unit school is staffed by three full-time teachers.

A retrospective examination of the units admissions recorded between 1970 and 1991 revealed that during this period the median annual number of admissions was 19 (range 14–35) and of all first-time admission approximately 75 percent were inpatient. Length of stay, however, was variable and found to be associated with diagnosis. For example, the modal length of stay for encopresis was 0–2 months, whereas for conduct disorders it was 6–12 months (Gray et al., 1992).

Referrals are made by a psychiatrist, clinical psychologist or other professional involved in outpatient work for the departments of Child and Family Psychiatry and Clinical Psychology within the children's hospital. There is a detailed referral form which gives information on the child's problems, previous assessments and treatments as well as parents' and children's attitudes to admission. Each case is discussed at a monthly admission/discharge meeting and suitable cases added to the waiting list. When a suitable place occurs (according to age, type of problem, time on list and degree of urgency) admission is arranged, with a preadmission meeting occurring about two weeks previously. At the preadmission meeting to which all professionals, ward staff and parents are invited, the case is reviewed and aims of admission clarified.

The unit nursing protocol regarding the involvement of the child and family/carers states that

> the proposal to admit the child is discussed with the child and their parents/carers, by the referring professional. Except in cases of emergency the child and their parents/carers visit the unit prior to admission. They are shown around the unit and necessary explanations given, together with an opportunity to ask questions. They also receive an information leaflet. A home visit by staff, and the pre-admission meeting are then arranged. . . . Throughout assessment and treatment the child and their parents/carers are being seen and during (this period) information about the childs assessment and progress is exchanged. This information is formalised and reviewed at the six weekly review meeting. (Paice, 1996)

The referrer is invited to attend all meetings regarding the case and may carry out some of the work while the child is in the unit. The referrer is expected to take up the case again if necessary at discharge from the unit.

Procedures and measures

An interview survey of all inpatients admitted to the Lowit Unit between June 1993 and December 1994 was carried out together with a concurrent series of interviews with their parents. Children were excluded if they had previous admissions to the unit or if they lived more than 35 miles from Aberdeen.

Parental consent was sought always prior to interviews and initial contact with the family made after nursing staff had spoken to them after the preadmission visit to the unit. Children and parents were interviewed separately and members of the same family were not interviewed by the same interviewer. Interviewing was carried out by three of the authors (RC, CH, & VL) who had no clinical involvement with the children. Interviews took place on a minimum of three occasions whenever possible:

1. prior to admission
2. six weeks after admission
3. two to four weeks following discharge

The main topics covered in both parent and child semistructured interviews were: reasons for admission; knowledge of treatment and unit staff; and perceived effects of hospitalization. The interviews with the children were not to exceed 30 minutes and parental interviews were scheduled for approximately 45 minutes. At least one of the interviews was in the child's home where possible (for further details regarding interviewing, see Chesson, Harding, Hart, & O'Loughlin, 1995). Parents were asked also to complete a Child Behavioural Questionnaire (Rutter, 1967) both prior to admission and following discharge.

Basic biographical and social data was collected from each case coordinator (e.g. psychiatrist or psychologist) as well as full details of the main treatment aims of admission and proposed interventions.

During the inpatient stay, a record was kept of professional assessments (such as for neurological examinations and occupational therapy). Child management interventions were recorded and these were categorized as follows: work with family/parents; school liaison; behavioural plan; peer relationships work; involvement with occupational therapy; speech and language therapy; pharmacology; play therapy; and specific psychology programme.

During admission, the child's level of intelligence was measured for most children by the Wechsler Intelligence Scale for Children III UK (Wechsler, 1992). The Raven's Progressive Matrices (Raven, 1981) was used in one case, when a child had not had a recent assessment and it was not thought to be an important issue or deemed necessary and, in a further instance, the Stanford–Binet Intelligence Scale (Thorndike, 1972) when this had resulted from use by an educational psychologist.

As part of the final interview, the parents were asked to rate their child's improvement on a simple visual analogue scale where 0 = no change and 5 = major improvement.

Data analysis

The children's and parents' answers to questions relating specifically to treatment aims prior to admission, six weeks following admission, and two to four weeks following discharge, were coded using a coding frame. This was constructed post hoc on the basis of respondents' answers. Codes were entered onto SPSS which were used to cross-tabulate information from children's and parents' interview data.

Children's answers to the question Why do you think you should have come into the unit? before, during and after admission were classified by two raters categorizing perceptions as accurate, related and not related according to specified criteria relating to diagnosis and main aim of admission. Kappa statistics were used to test interrater reliability (preadmission .92; during admission .74; and discharge .90).

Table 1. Number of interventions associated with child by initial diagnosis

Intervention	*Conduct/ emotional* (n = 7)	*Hyperactive* (n = 5)	*Conduct* (n = 2)	*Neurotic* (n = 2)	*Obsessive/ compulsive*[a] (n = 1)	*Depression* (n = 1)	*No diagnosis* (n = 2)	*Total* (n = 20)
Work with parents/family	7	4	2	2	1	1	2	19
School liaison	6	4	2	2	1	1	2	18
Behaviour plan	4	4	1	1	0	0	0	10
Peer-relationship work	4	1	2	1	1	0	1	10
Occupational therapy	2	1	1	0	0	0	2	6
Speech & language therapy	3	2	0	0	0	0	0	5
Medication	1	4	0	0	1	1	0	7
Specific psychology programme	4	0	0	1	0	0	0	5
Play therapy	0	1	1	0	0	0	0	2
Other	1	2	0	1	0	0	0	4
Total	32	23	9	8	4	3	7	86
Mean for type	4.8	4.6	4.3	4.0	4.0	3.0	3.5	4.3

[a] Later diagnosed as schizophrenia

Results

Children's characteristics

1. BIOGRAPHICAL AND SOCIAL

   The main characteristics of the 20 study children were: boys outnumbered girls (4:1); ages ranged from 5.6–13.5 years (mean 9.3 years); two children (both girls) had physical disorders (phenylketonuria and sight impairment).

Eleven children lived in two-parent families and eight were from single-parent families, and in one case the child was in local authority care. In the early stages of the study it was considered feasible to interview at least one of his parents, however, ultimately this did not prove possible.

2. INTELLIGENCE AND BEHAVIOURAL ASSESSMENT

   IQ scores ranged from 56 to 115–130 (mean range 80–89). Ten children had IQs 90 or below and in five cases it was less than 80. IQ scores could not be obtained for two children; child 8 was thought to be psychotic and couldn't be tested, and child 17 was very depressed and true assessment seemed unlikely. When prior to admission scores in the Rutter Child Behavioural Questionnaire (BSQ) (Rutter, 1965) were analysed: 16 children had scores above 13, likely to indicate psychiatric disorder, and in 4 of these cases, significantly high scores (>30) suggested severe disorder.

3. INPATIENT ASSESSMENT AND TREATMENT

   The majority of children was diagnosed as having either conduct disorders or mixed disorders of conduct and emotions (nine children). Five children had hyperkinetic disorders, one child had a depressive illness and one child presented with obsessive compulsive behaviour and was later diagnosed as having schizophrenia. Two children were not regarded as having a psychiatric disorder.

The children's length of stay in the unit ranged from 6–67 weeks (mean 27.8 weeks). The children had a range of assessments and interventions involving up to 10 different professionals (psychiatrist, nurse, teacher, occupational therapist, speech and language therapist, social worker, nurse therapist, clinical psychologist, educational psychologist, paediatrician). While not all children saw all professionals, the mean number of professional contacts was 7.3 (range 5–10). There was a total of 86 types of intervention for the children which varied according to the diagnosis, as can be seen from Table 1, with children receiving an average of 4.3 types of intervention. Three of the children with hyperkinetic disorders had been prescribed methylphenidate. Two children had anti-depressant medication.

Views on admission

Children In response to children being asked who had suggested admission: seven indicated that this had been a doctor; two named a clinical psychologist; and seven their mothers (four children were uncertain). Notably one child reported that 'his mother had been trying to get him in for years'. In fact three children said that they were looking forward to admission, and a further five made specific reference to being 'happy' at the prospect. Only three children stated explicitly that they were worried about coming to the unit, although the replies of 11 children suggested some apprehension, six reported no anxiety. Merely three thought that they would miss their families. While 12 children had been informed by their parents regarding admission, six said this was not the case (in the remaining instance the child didn't know). Mostly it was mothers, rather than fathers, who had spoken to the child although this often reflected family composition and living arrangements. For two children, fathers were thought not to know that they were in the unit. Fifteen of the children reported visiting the unit prior to admission, and a further three were emergency admissions.

When asked what kind of place the unit was merely two said it was a hospital, although in one case this was 'a sort of school near a hospital'. However a child commented 'it was a special place with beds' and another that it was 'quiet, friendly, it's home – if you sprain your ankle it would be fine'. Overall children's views of the unit tended to be vague but often reference was made to the unit's school. Indeed, as regards to whom would look after them, teachers (15) were more frequently identified than nurses (11); four children said that there would not be any nurses at all! Three children alluded also to doctors being present while three (one quite definitely) thought that doctors would not be involved. In addition several of the children answered the question in evaluative terms: 'good – get food there and juice – orange and apple juice'; 'Ace for playing games'; 'pretty nice place'. Replying to the question What will you do all day in the unit? 11 children referred to going to school and a further three to 'playing'. Six children were not able to suggest any likely activity. Children's response to a general question relating to how they felt about admission indicated that of those expressing a view, nine were positive ('it's bonnie'; 'brilliant'), eight were negative ('don't want to stay').

At the preadmission interview children did not have a clear idea of the reason(s) for their admission. In answer to the question Why do you think you should come into the unit/hospital? eight did not know. Some identified behavioural problems viz: 'have been bad'; 'help me to be good'; 'improve my behaviour'; 'because I'm fighting all the time' but only six gave a reason which was in accordance with their diagnosis or main aim for admission as supplied by the case coordinator. Five emphasized their need for help, although they were not able always to explain why this was required: 'for help'; 'to help me get on with others and my work'; 'to help me get back to school'; 'mum and dad said it would make me better'; 'to take the pressure off me'.

Parents Over half those interviewed described worries they had in relation to admission: some associated with the child's ability to cope (settle down); others with the child's likely resentment of the parent; and a number were concerned lest it was unsuccessful since it was the 'last resort' or 'last stop'. In addition others expressed their own feelings of loss.

Parents' reports of discussions of their own feelings revealed that family, rather than professional advice, had been sought. Approximately half the parents said that they had spoken to the child about admission to the unit but six responded negatively – in one case saying that 'the child didn't ask' and in another that this had been avoided in case 'the child feels pushed out of home'.

By far the majority of parents remembered visiting the unit prior to their child's admission and commented favourably on it. Several referred to the friendly atmosphere and expressed surprise that there were no uniforms.

Parents' descriptions of the unit and admission frequently included mention of the opportunity for assessment and 'tests' and there were few unsolicited references to the unit school. Accounts were at considerable variance with those of the children and demonstrated differences in perception. This clearly was one of the key areas where parents' and children's views were incongruent (see Table 2). Parents indicated that psychiatrists more than any other professionals had spoken to them about admission. In only three cases were GPs reported as involved in discussion prior to admission.

Table 2. Congruence of parents' and children's views on admission and treatment

Aspect of unit	*Children*	*Parents*	*Congruent/ incongruent*
Recall on visiting unit	Recalled	Recalled	Congruent
Initiator of admission	One-third identified parents as main initiator	Majority identified professionals, little mention of own role	Incongruent
Reason for admission	Difficulty understanding reason for admission	Difficulty understanding reason for admission	Congruent
Parental discussion on admission	Majority said parents discussed this; 6 said not	Majority said discussed; 6 said not	Congruent
Nature of unit	Frequently school seen a central feature of unit	Often seen as assessment unit	Incongruent
Professionals' roles	Although not precise, a number of professions identified; part played by nurses stressed	Narrow range of professionals identified; nurses role as information givers to parents stressed	Incongruent
Interventions	Not able to describe	Majority not able to describe	Congruent

Parents too had difficulties in identifying reasons for admission; seven were not able to say with any certainty why the child was admitted. Of those able to do so, generally behavioural problems, such as hyperactivity and relationships with peers, were cited. Two parents, however, referred to depression and emotional problems. Not all parents and children shared a common perception of the specific treatment aim (see Table 3) although analysis is confounded by a general lack of clarity among children and parents.

Understanding of treatment during admission

At the six-week interview children had a clearer view of why they had been admitted. Of the three children who had no idea as to why they had come into the unit, two were now able to give some reason for it. Thirteen children now thought that they had problems on entry, and 10 believed that their problems were now 'not so much'. One child poignantly expressed his difficulties thus: 'am trying to stop being silly. Not getting better cos every weekend I return home and then I'm silly'.

Few children were able to identify interventions, and the majority was unable to say if they were having any special programmes or medicines. Regarding the inputs of the multidisciplinary team, eight children reported seeing a doctor, although few were able to describe what he or she did. Three-quarters of the children (15) were able to identify at least one key worker. Two, however, thought that they didn't have one. Although not able to describe the role of a key worker with any precision, when children were asked what nurses did, seven said that they were key workers. Although teachers were made reference to, only six children (3, 17, 13, 14, 18 and 20) gave any indication of other professionals involved and mentioned either the speech and language therapist, clinical psychologists, occupational therapists, social worker or nurse therapist.

Parents had difficulty in outlining the treatment their child was receiving and very seldom did they suggest that they personally were in receipt of any professional help, for example, family therapy or counselling. An exception was one mother who referred to the clinical psychologist as being there 'to help me'.

Parents' accounts of their child's difficulties bore close resemblance at six weeks to those provided in the preadmission interviews. Six continued to have little idea as to why their child was attending the unit.

Table 3. Children's and parents' perceptions of main aim of treatment at initial interview ($n = 19$)

Child no.	*Diagnosis*	*Main aim*[a]	*Child's perceived aim of admission*	*Parents' perception of aim of admission*
1	Conduct/emotional	Peer relationships	Not sure, lazy eye	Stop child doing bad things
2	Conduct	Assessment/modification of difficulties	To improve my behaviour	Control behaviour
3	Nil-psychiatric	Specific O.T.	To learn to swim and run fast	Brain scan, disruptive behaviour
4	Conduct/emotional	Peer relationships	To be good	Find out what's causing aggressiveness
5	Conduct/emotional	Assess learning difficulties	To help me be good	Learn to become socially integrated
6	Conduct/emotional	Assess learning difficulties	Don't know	See how hyperactive the child is
7	Neurotic (school phobia)	Reintegration into school	To help me get back to school	Help child with school find out underlying problems
9	Hyperactive	Hyperactivity assessment/ management	Because I'm fighting all the time	Settle child at school
10	Hyperactive	Hyperactive assessment/ management	To improve behaviour	Don't know
11	Hyperactive	Hyperactivity assessment/ management	Don't know	Child can't settle, improve concentration
12	Conduct	Peer relationships	Don't know	Help child have more control
13	Psychotic	Diagnosis	To take the pressure off me	Don't know
14	Hyperactive	Behavioural assessment/ management	Problems	Find out why the child behaves the way he/she does
15	Hyperactive	Hyperactivity assessment/ management	No idea	Learning difficulties
16	Nil-psychiatric	Behaviour assessment/ management	Don't know	Change of behaviour
17	Depression	Treatment of depression	To stop me feeling sick and faint	X seriously depressed
18	Conduct/emotional	Behavioural assessment/ management	For helping but I don't know how	Not sure
19	Conduct/emotional	Assess learning difficulties	To get me to work	Find some way of motivating child
20	Neurotic (school phobia)	Assess anxiety	To going to school, going to the toilet a lot; relaxation and talk	Get child involved with other children

[a] As provided by case coordinator

Note: Child no. 8 excluded here as parent not interviewed

The majority of parents identified a narrow range of professionals involved with their children. Nurses were most frequently mentioned (11 references), although teachers and psychiatrists were referred to by 10 and nine parents respectively. In addition while there were seven and five references to psychologists and social workers only two mothers indicated the remaining members of the multidisciplinary team. Parents stated that information on their child's progress was provided most frequently by nursing staff, when they 'popped in' to collect their child. When asked directly their view of the six-week multiprofessional review meeting, mothers commonly described it as inhibiting and daunting because so many people were present. Parents could seldom provide even broad definitions of the roles of many of the professional staff and descriptions seldom discriminated between different team members.

Perception of outcome

Overall children's identification of their problems and concomitantly the aims of admission appeared to become more focused and more accurate over time (see Table 4). Children also appeared to have a more positive view of the unit and reflect on the social aspects of unit attendance, as illustrated in the following comments.

> It is helping – difficult to say how. Stop me swearing and spitting. I get grounded if I do. You have to sit in the play room and I'd rather be outside.
>
> I'm not being let fight, have to behave in class. Don't have bullies from old school.
>
> 1. Medication 2. Talking – the best thing. 3. Cuddles – help – not much at home.
>
> Don't know – can't really explain. Tell you why behaviour is wrong and discuss situation, what to do if similar situation crops up – helps some of the time. Don't do this at home or school.

When the children were all asked at the final-stage interview whether their problems were the same or better or worse since going into the Lowit Unit, of the 19 (one could not be interviewed) nine perceived their stay in the unit as helping (see Table 5). Although some of these perceptions were not linked to the main aim of admission or diagnosis in general terms they were linked to the child's problem, for example, child 13 was psychotic and was getting support from staff to help her adjust to these difficulties; child 12 was perceived as having attachment problems and there had been specific input to help with this both in terms of the Parent–Child Game (Jenner, 1992) and general advice; child 5 was found to have specific learning difficulties as well as emotional and behavioural problems and was making a fresh start in a new school.

A second group of four children thought the unit had helped a little or were not sure, and they also had an accurate perception of their problems.

A total of six children thought that nothing helped much, did not know if the unit had helped or gave no discernible response. Some of these children did not have a completed parental final interview, and in other cases parents had a negative view of outcome, 'has the same problems as when we started'.

Perceptions, age, diagnosis and IQ

Six children had an accurate perception of the aim of admission/diagnosis. All but one of these were above 10 years of age, and the younger child (aged 7 years) had been brought to the unit for a specific short spell of intensive occupational therapy or as the

Table 4. Child's perception of aim of admission at pre, post and final interview by age, IQ and BSQ and diagnosis (n = 20)

Child no.	*Age*	*IQ*	*BSQ score*	*Diagnosis*	*Child's perceived aim of admission at preadmission interview*[b]		*Child's perception of aim of admission at final interview*[b]	
1[a]	5.6	77	21	Conduct/emotional	Not sure, lazy eye	(NR)	Eye is broken	(NR)
2	10.9	88	23	Conduct	To improve my behaviour	(A)	To improve behaviour and all that	(A)
3	7.0	90	11	Nil-psy. specific problems	To learn to swim and run fast	(A)	Because I didn't hop and skip well; muscles wobbly	(A)
4	8.0	86	17	Conduct/emotional	To be good	(R)	Because I was bad at school; helped me to behave	(A)
5	10.6	90	34	Conduct/emotional	To help me be good	(A)	Because of trouble at school	(A)
6	11.2	<65	33	Conduct/emotional	Don't know	(NR)	Give Ma some peace	(NR)
7	13.5	115–130	15	Neurotic (school phobia)	To help me get back to school	(A)	To help me get back to school	(A)
8	10.6	—	—	Conduct/emotional	Don't know	(NR)	(not able to interview)	
9	9.2	93	17	Hyperactive	Because I'm fighting all the time	(R)	In trouble at school; can't sit still	(A)
10	12.8	78	21	Hyperactive	To improve behaviour	(R)	Don't know, school trouble	(R)
11	6.8	100	29	Hyperactive	Don't know	(NR)	Because getting a bit hyper	(A)
12	7.2	101	29	Conduct	Don't know	(NR)	Cos hyperactive	(R)
13	13.5	85	20	Psychotic	To take the pressure off me	(R)	Couldn't cope with school; took knives, hearing voices	(A)
14	6.8	56	34	Hyperactive	Problems	(NR)	Because I've got problems	(NR)
15[a]	6.10	71	30	Hyperactive	No idea	(NR)	(no verbal response – shrugs shoulders)	(NR)
16[a]	7.6	87	30	Nil psychiatric	Don't know	(NR)	Don't know; couldn't read books at school	(NR)
17	11.10	—	4	Depression	To stop me feeling sick and fainting	(R)	For depressive illness	(A)
18	11.5	100	22	Conduct/emotional	For helping but I don't know how	(R)	For my behaviour	(A)
19	11.3	118	32	Conduct/emotional	To get me to work	(A)	Not doing work and fidgeting	(A)
20	12.7	85	11	Neurotic (school phobia)	Not going school, going toilet a lot; relaxation and talk	(A)	Problems going to school	(A)

[a] Shy at interview

[b] Aim rated as accurate (A); related (R); not related (NR)

child saw it, 'to learn to swim and run fast'. These children had higher IQ scores (IQs 80 or above) and the two with lowest IQ were not extremely disturbed (BSQ scores 11 and 23), as shown in Table 4. A further six children had a perception which was related to the aim for admission or diagnosis. These children were also reasonably bright (only one having an IQ less than 80 and he was an older child); all the children were 8 years or older.

Eight children had really no idea as to why they had been admitted. Of these children, three were either extremely shy or distracted by toys and not wanting to speak and another child was very disturbed on admission. Six of the children were below 8 years of age and the two slightly older ones included the disturbed child and a child who was very limited intellectually (IQ below 69). This last group included, the youngest, the least intelligent and the most disturbed of the children – all had BSQ scores of over 20 (see Table 4).

By the time the children were interviewed later at six weeks and discharge, many of the children had a more accurate perception of the reasons they were in the Lowit. Twelve children now could be said to have a reasonably accurate perception, and two children had a perception which was vaguely related to their problems. These children all had higher IQs (IQs over 80) and were mainly older children. Of the three younger children who had a reasonably accurate perception, two were of average intelligence. Five children remained with little idea as to why they were in the unit, and one was not able to be interviewed. The children had lower IQs and/or were younger.

It is noticeable that, with one exception, the children who thought admission had helped had an accurate or related perception of the aims of admission and only included one child with a low IQ as shown in Table 5. The children's comments when given were mainly of a positive nature for the improved group, although responses could not be obtained from all the children. The four who thought that their problem had been helped a little, were all of lower IQ (below IQ 80), and three were 'younger' children (below 8 years).

Of the six children who thought that nothing helped much, didn't know whether the unit helped or gave no discernible response, most were younger (4/6), had a perception of the aims of admission which was unrelated to the given aims or diagnosis (4/6) or were of lower IQ (5/6).

Children's favourable view of outcome appeared related to parents' perception of outcome, but not to change in scores on the BSQ, as is shown in Table 5. Although some parents expressed very positive views on outcome, for example, parents of children 5 and 17, this did not inevitably result in a 5 rating (major improvement).

Discussion

Children's perceptions and developmental theory

Our analysis suggests a gradation from younger/less intelligent children having a less accurate perception of the reasons for being in the unit towards older/more intelligent children having a more accurate perception. This links with an extensive literature of children's beliefs about illness, medical procedures and hospitalization, the results of which are usually interpreted with reference to Piaget's developmental theory. Bibace and Walsh (1981) describe three types of thinking about illness: very young children (aged 2 to 6 years) see illness as occurring by contagion, as if by magic and they are strongly influenced by perceptions, since their knowledge is limited and they are egocentric and may be regarded as at the Preoperational Stage; children at the Concrete Operational Stage (aged 7 to 11 years) have a better understanding and knowledge, but

Table 5. Parents' and children's perceptions of outcome ($n = 19$)

Child no.	*Age*	*IQ*	*Child's perceptions of aim at discharge*	*Comments on child's view of outcome*	*Parent rating*[a]	*Parents comments*	*Change in BSQ score*
1	5.6	77	Not related	Get eye better	—	It's helping her to settle down	—
2	10.9	88	Accurate	Helped with changing my behaviour	5.0	Now manageable can take into company; has more control	–2
3	7.0	90	Accurate	Helped muscles; better now	5.0	Much more confident; self-esteem improved; marked imp. school work Ward can do no wrong	+7
4	8.0	86	Accurate	Helped me to behave	2.0	At least it keeps them out of trouble	+4
5	10.6	90	Accurate	Better now; New school	3.5	LU was a catalyst in changing X; got 80% more than expected; can't rate them highly enough	–15
6	11.2	below 65	Not related	Helped me behave	—	X safe getting help	—
7	10.6	115–130	Accurate	Some bits easier, some harder	3.0	X himself overall more relaxed; we can handle things better; stress reduced	–3
9		93	Accurate	Not sure; tablets might help	0	It has made no difference at all	+6
10	12.8	78	Related	Don't know	—		0
11	6.8	100	Accurate	Don't get so hyper	3.5	My mum will now look after him; people think he's subdued	+2
12	7.2	101	Related	I get more attention from Mum and Dad now	3.0		–7
13	13.5	85	Accurate	Medicines, talking, cuddles help	3.0	Given us a bit of respite at home; X looks much better	–1
14	6.8	56	Not related	Don't know, don't care	—		—
15	6.10	71	Not related	Nods head	—	LU a really good caring place X lived it there; asked to go back	–6
16	7.6	87	Not related	Nothing	0	None; has the same problems as when started	—
17	11.10	—	Accurate	Not sure; tablets make me feel ill	4.5	Vast improvement (90%) but still has some anxieties; lot of support from staff	+4
18	11.5	100	Accurate	Helps a little	—	We coped better before he came in	–6
19	11.3	118	Accurate	Nothing much helps	—	Have been told he's learning social skills; joining with peers, yet there's little communication	–7
20	12.7	85	Accurate	Helping step-by-step	—	Lot better behaved at home; X started doing the dishes	+7

[a] One child (no. 8) not able to be interviewed at final interview; 0 = no improvement; 5 = considerable improvement

their understanding is limited by reference to a cause, rather than causes; older children (aged from 11 years) at the Formal Operational Stage, have a more detailed understanding and perceive multiple causes.

Although there was only one child in this study below the age of 6 years, and she could be said to be very egocentric and lacking in understanding (she thought she was in the unit because of a lazy eye), most of the younger children (up to the age of 7.5 years) or those of lower IQ (and hence of lower mental age) had little idea of why they were in hospital. Answers, if given, were vague or egocentric. However, by the end of their stay some of these children had a more accurate perception of the reasons for being in the unit. It may be that these children were initially at a transitional stage in Piagetian terminology in development, and their stay in the Lowit Unit had facilitated their progress to the next stage – Cichetti and Toth's (1992) conceptualization of a crucial experience at a critical time facilitating growth – also may be helpful here. As described in studies of the child's understanding of illness, children at the Preoperational Stage are passive recipients of treatment, and may even experience hospitalization as punishment for wrong-doing and the nurses and doctors as hostile (Perrin & Gerrity, 1981). Although we had no evidence for such thinking in this study, this was not deliberately sought and alternative methods would be needed for testing this premise.

Of the middle-aged children (aged 7 to 11 years) who would be expected to be at the Concrete Operational Stage, some of them gave quite concrete replies, 'to learn to swim and run fast'. These children (and older children of lower IQ) mainly had a related if not entirely accurate perception of the reasons for being in the unit and they gave simple answers, often suggestive of single causality. At the time of the final interview many of this middle band of children had a more accurate perception also, suggesting their growth whilst on the unit.

Of the children who had an entirely accurate perception of the reasons for admission, all with the exception of one were older, and they could give a more detailed explanation of their problems 'because I'm not going to school, I'm going to the toilet a lot and I need relaxation and talk', 'to take the pressure off me, I couldn't cope with school, I took knives in and I was hearing voices'. These children could be said to be at the level of Formal Operational Thinking and answers suggest an understanding of multiple causes.

This development in thinking from Preoperational to Formal Operational stage has been indicated in many other studies on a variety of subjects including: perception of illness (Bibace & Walsh, 1980; Perrin & Gerrity, 1981; Brewster, 1982; E.R. Roth & L. Roth, 1984); health (Natapoff, 1978; Perrin & Shapiro, 1985); medical procedures (Ferrand & Regallulo, 1975); hospital (Eiser & Patterson, 1984); and death (Koocher, 1973). Others, for example, Berlin (1978) have emphasized the importance of understanding developmental issues in the psychiatric treatment of young children. As E. Roth (1984) has pointed out 'Children's understanding of the problem is important because it may affect the degree to which they are willing and able to co-operate in treatment.'

Lack of understanding and misperceptions: Causes and consequences

Significant implications for outcome are indicated in that one-third of the children interviewed saw their parents as the main initiators of admission, and some parents did not discuss reasons for admission. Children seeing their parents as initiating admission may well see themselves as bad and hospitalization as a punishment and rejection. In 1959, Marlens (cited in Peters, 1978) described how physically ill children who were hospitalized had a much greater sense that their illness was a punishment and that they were rejected because of it. Also this area of difficulty for parents may in turn reflect the difficulty society has in defining mental health problems in children (Chesson & Chisholm, 1996), and it was of interest that the children generally saw the unit as a school, rather than a hospital ward, and initially identified teachers as caretakers. It was only during later interviews that key workers were defined as nurses. Parents may be colluding in failure not only to adjust children's perceptions of the unit but also to foster it, being more comfortable themselves with an educational rather that medical descriptor, especially that of mental illness. The possibility may exist also that doctors and nurses may fail, at the very least, to challenge early perceptions. Such collusion, however, may seldom if ever be acknowledged and, therefore, be addressed. Similarly psychiatrists and others working with the family may avoid, by focusing on the child's problem, making it too apparent that family treatment is occurring. Certainly few parents stated at interview that they too were in receipt of therapy.

Not only has Plunkett (1984) argued that failure to deal with parents' initial expectations may create obstacles reaching children in need but Subotsky (1992) contends, regarding child psychiatry services, that outcome may be better if expectations of family and clinics are congruent. As seven of the 20 parents were unable to say why their child was admitted, questions must inevitably arise about parental understanding, level of commitment and cooperation as well as professional information-giving and communication. Given the low number of GPs said to be involved at preadmission, it may well be that a more proactive involvement by those in primary care may help to clarify the aims of admission and lessen parental confusion. To achieve this GPs may have to be made more aware of the services as recommended by Markantonakis and Mathai (1990). Difficulties and anxieties may arise for individual parents and children as a consequence of the multidisciplinary approach and the problem in knowing the nature of assessments and management strategies as well as the role of different professions. However, in an earlier study of the unit, team members reported difficulty in knowing others' roles and the nature of their input (Chesson, 1996). Thus as a means of enhancing parental understanding, staff may need to ensure that their own knowledge of professionals' function is accurate and up-to-date. Goal Attainment Scaling may offer a means whereby not only treatment outcomes may be measured but multidisciplinary contributions are clarified (Chesson & Young, in press). At the very least professionals may need to seek evidence actively that parents' understand key aspects of hospitalization, including reasons for admissions, aims of treatment and methods of treatment. Large review meetings may not be helpful in this respect and one-to-one contact with parents may be most appropriate and may also help to ensure that parents are supported and feel that their own needs are being met (Stephenson, McKay, & Chesson, 1991).

Psychiatric treatment, especially 'therapy' may be difficult to define and distinguish from everyday social interactive processes. This study also may have highlighted the difficulty lay members have in grasping essential elements incorporated in psychiatric hospitalization, a difficulty often shared by medical colleagues in other specialties. This may be relevant as well to parents' own perceptions of the therapy input they were receiving. Although psychiatrists and psychologists well-recognize the responsibility of making known aims and objectives of treatment when working with families, further research may be needed to identify obstacles to understanding and communication. Specific training may be required to ensure clear and explicit communication at all stages of admission through to discharge. Given the key role of nursing staff regarding information-giving as identified here, attention may need to be focused on their needs. This may well be a priority especially in Scotland since historically there has been no national provision for the training of specialist child and adolescent mental health nurses.

A retrospective Canadian study (Bradley & Clark, 1993) which looked at consumer (family) satisfaction of an inpatient psychiatric unit found that most parents rated the service positively. Of those who voiced dissatisfaction, poor communication at all stages was a key element (no feedback or information while their child was in hospital), as well as poor ratings of respect shown by staff, and minimal help and follow-up after discharge. Components of the inpatient experience which families found most helpful were direct behaviour-management strategies, support and consistency of the ward staff and other professionals, educational advice and family therapy. Similar results have been replicated in a retrospective Canadian postal survey assessing parental views (Loff, Trigg, & Cassels, 1987).

It is important therefore that parents seeming lack of knowledge and understanding be addressed. While the problem may not simply be that of providing adequate information, nevertheless this should be appropriately supplied, reflecting the growing literature on communication styles with parents (Perkins, 1986). Perkins and Spencer (1980), for example, have demonstrated that patient-education leaflets often lack any recognition of the problems of single parents, families on low incomes and those living with other family members.

In this study satisfaction did appear related to outcome, as reflected in parents' comments but not scores on the BSQ. However, in a recent review of the Rutter scales (Elander & Rutter, 1996) it was suggested that although they were useful in establishing prevalence rates of psychiatric disorder they were less satisfactory in detecting change, as reflected in the studies of Brown, Chadwick, Shaffer, Rutter and Trant (1984) and Trembley and colleagues (1991). Rutter himself believes that some behavioural changes may be 'too subtle or specific' for the scales to detect and advocates rating by behaviour type.

The lack of congruence found between parents' and children's views, especially at the final interview may have arisen because the children have a more intimate knowledge of the unit through experience. This would be particularly the case for interventions where children compared with parents had a much greater knowledge of their treatment and the professionals involved, especially the nurses. Parents' knowledge from first to last interview remained unchanged to a large extent. Parents may need therefore to have a greater involvement in the care of their children, and, although they attend meetings, are seen for family interviews and have the explanation of treatment from professionals, this may not be enough. If we are to involve parents in the treatment of their own children they may need more concrete experience of the work in the unit. This could take the form of:

1. attendance at times when their child's treatment could be observed
2. a parenting programme where the parents are empowered, for example, along the lines suggested by Webster-Stratton and Herbert (1994)
3. participation in the parent–child game (Jenner, 1992)
4. greater (or more explicit) involvement in treatment goal-setting or even incorporating parents views into Goal Attainment Scaling, where this is used

It is not surprising that methods for obtaining children's perceptions of health services are in their infancy, since only recently have consumerist approaches established a place within the NHS (NHS Executive, 1992). This pilot study suggests that it is not only feasible but valuable to know children's thoughts and opinions, even though there may be difficulty in establishing who is the consumer in child psychiatry (Subotsky, 1992). Our experience would reinforce the view that direct interviewing is both a simple and effective way of auditing and evaluating child mental health services (Pound & Cotterell, 1989). At the same time we acknowledge that it is difficult to find effective ways of communication which address both the affective as well as the cognitive domain. There could be considerable merit in extending the work of E. R. Roth and L. Roth who advocated that the use of children's drawings could be explored further. Talking Pictures (King,

1989) or the use of analogy scenarios (C. Eiser, J.R. Eiser, & Hubt, 1986) could be worth considering also as an aid to communication.

While currently there is a great deal of uncertainty about the future of child psychiatric units (Chisholm, 1996) it is essential to establish parents' and children's perceptions, especially regarding outcomes. This is vital given increasing recognition of the importance of patient defined outcomes (Ross Davies, 1994) and nowhere is this more crucial than in child and family psychiatry. Health gains were described by many of the parents and children, but it is important to acknowledge that some parents felt no discernible improvement had been made. Such information may be valuable in the long run if it enables the identification of families who may or may not benefit from hospitalization. We did not collect information of professionals' views of outcome; future studies should, especially to establish the degree of congruence between them and children's and parents' views, even though it may raise questions regarding whose views should be paramount. Indeed over 20 years ago patient and staff perspectives were studied in adult psychiatry (Mayer & Rosenbatt, 1974). The number of questions raised by this pilot study would indicate that it is desirable, if not essential, to establish perceptions of admission, treatment and outcome since meanings, especially shared meanings, are likely to influence outcomes.

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Children as consumers

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Children are important users of health services, accounting for up to a quarter of general practitioner consultations[1] and 30% of the workload in accident and emergency departments.[2] However, their needs are given insufficient priority by policy makers and health service professionals. Last year a report of the British government's health committee stressed that a change in attitude was needed and that it was important to listen to children and to take their views into account.[3]

Although consumers have an important role in reforming health care,[4] the paternalistic attitude still prevailing among health professionals when it comes to consumer involvement in health care and research can make this difficult.[5] Patient passivity begins early in life[6] so we should not be surprised that adult users acquiesce. In this article we discuss why children should be consulted directly, how this is to be achieved, and finally what may be required to bring about change.

Current situation

Parent as proxy

In Britain, although there has been an increasing emphasis on obtaining the views of health service users, children are rarely included. This probably reflects social attitudes and confusion about an appro-

Summary points

Children are major users of health services but are rarely consulted as healthcare consumers

Although parents are extensively used as proxies for children, their accounts may not always accurately reflect children's perceptions

Large numbers of children are cared for and treated by staff who have no paediatric training and abilities to communicate cannot be assumed

Children's concepts of hospital care and illness differ greatly from those of adults

Children may be able to express their opinions if they are sought using appropriate methods

Staff need to be trained to enable the child's voice to be heard and may need to consult colleagues in departments of child and family psychiatry and clinical psychology and develop closer contacts with teachers and social workers priate approach for children. Some adults may have little interest in what children think, while others regard the need to protect them as paramount. The children's charter on health was essentially a parents' charter and reflects a common belief that children's views may be represented by their parents.[7]

It cannot be assumed, however, that parents' perception of their child's response will accurately reflect the child's feelings and needs, especially as the child becomes more independent. A study of quality of life in young children with asthma argued that reporting by proxy may lead to measurement of the impact of the child's illness on the proxy rather than on the child, as shown in the the case of quality of life in young children with asthma.[8] Jessop et al found a relation between the mother's mental health and her ratings of the degree of disability of the child.[9] Furthermore, mothers and staff have been found to have divergent opinions on a child's likely perceptions. For example, in a recent study only 24% of mothers thought that their young children worried about being in hospital whereas 91% of staff believed this to be the case.[10]

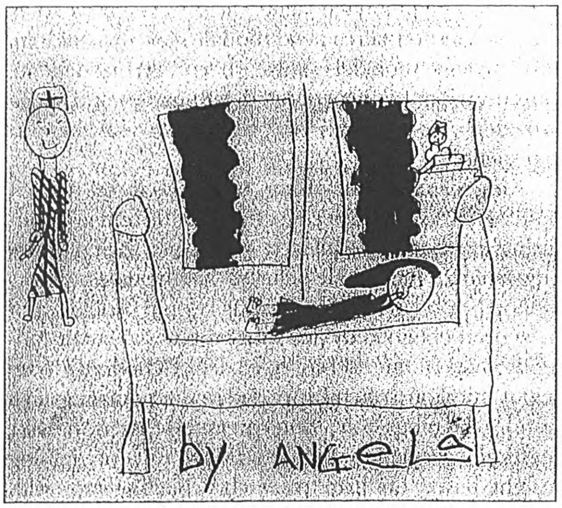
Staff know best

Healthcare staff are often assumed to be able to communicate effectively with children, but it may not be easy for those without paediatric training, even though many will be parents. This is important since large numbers of children are seen outside paediatric settings. Sixteen per cent of children aged 5-15 years are admitted to hospital each year.[11] In 1994 half the children admitted to English hospitals were not cared for by nurses qualified in nursing children. In Wales one quarter were admitted to adult wards.[12]

Staff training in communication lags behind good intentions, and the General Medical Council's report on reforming medical education makes no specific reference to communicating with children.[13] It is also assumed that staff know how children think and feel about treatment and care. A recent study, however, found that most children (75%) could understand the concept of localising their pain yet less than half the staff (41%) thought that young children could do this.[10]

Children's concepts of hospitals and illness

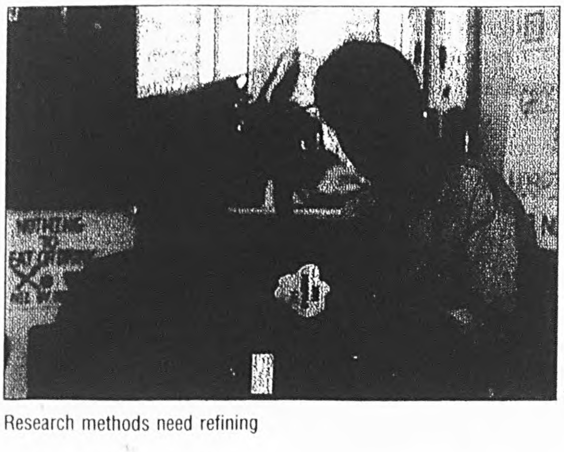
Children differ greatly from adults in their understanding about the cause of illness and its treatment and prevention as well as in their perceptions of hospitals. Preschool children may believe that doctors or nurses deliberately set out to hurt them.[14] Although it is difficult to generalise, children below the age of 7 years often see illness as occurring by contagion as if by magic or as a punishment for bad behaviour.[15] From the ages of 7 to 11 children have a better knowledge and understanding, though their views are not those of an adult. They often see illness as caused by a single factor—often a "germ"—and therefore contagious. They do not correctly infer the reasons for treatment. From 11 years children have a more detailed understanding and become aware that illness can become aggravated by psychological factors. They understand the notion of drug related side effects and the possibility of delay before responding to treatment.[16] Children with chronic illness, contrary to expectation, may not have a more mature understanding of their illness than those with little experience of hospitals. Especially little is known about children's understanding of mental health.[17] Medical terms may also be misinterpreted by children—for instance, a diagnosis of diabetes may be understood by a child in terms that they will "die of betes" or mention of oedema as a sign equated to a "demon in my belly."[15]



Although research on children's views on hospital care and treatment is sparse, American studies have yielded some unexpected findings. Schoffstall discovered that children in hospital perceived the greatest stressors to be missing their families, being afraid of surgery, pain from their illness, infection, and being touched by people they did not know. They rated "sleeping with someone they didn't know in their room" the eighth most stressful variable.[18] Unless children's perceptions are known, services cannot respond to their needs and improvements to achieve high quality care cannot be instigated.

Methods of consultation

Research methods for use with children are still unrefined. Although it has been suggested that children may need to be over the age of 8 to provide their views, children as young as 5 with emotional and behavioural problems were able to express their opinions on being in hospital.[17] Alderson contends that rigidly controlled methods are seldom helpful.[19] Thus validated measures, such as the metro assessment of child satisfaction (MACS), which can be used with children from the age


JOHN COLE/IMPACT

Research methods need refining

of 6,[20] may be of limited value. Clearly even basic tools such as questionnaires need modification for children, and activity booklets have been recommended. Questions can be incorporated with games and space provided for pictures to be drawn relating to experience.[2]

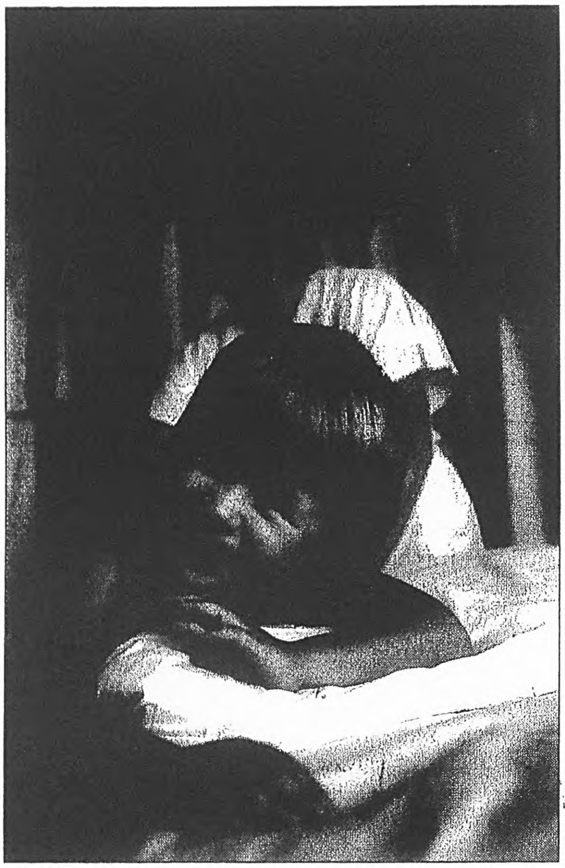
King maintains that using "talking pictures" to elicit opinions is a safer, easier, less threatening and less confusing method for children while also being more enjoyable for them.[21] He believes that the type of information he obtained from drawings would probably not have been obtained by any other method. Martin contends that emotions repressed from children's conscious minds are often expressed in their drawings in a non-threatening way; interpretation is not wild, mystical speculation but a rational way of gaining insight based on firm research.[22] Bach's work with spontaneous drawings by severely ill children often informed her of the somatic as well as the psychological condition of the patient.[23] Where children may have difficulties drawing or communicating their views directly—for example, those with learning disabilities—photographs may be helpful.[24] Account has to be taken of the child's understanding together with his or her age and stage of emotional and cognitive development.[17] A major difficulty with direct interviews, however, is that children's responses to healthcare staff may reflect what the child thinks the professional wants to hear rather than the child's true feelings.[25] The gratitude barrier may be as prevalent in children as adults.

In recent years several indirect methods of consulting children have developed, particularly in the context of trauma. Dent-Read communicated with children in hospital by eliciting metaphors for body functioning and symptoms.[26] Many of the methods used to help children describe distressing events and express their feelings, such as puppet play in the case of abused children,[27] may also be appropriate and valuable means of learning what children are thinking.

How is change to be brought about?

In 1959 a government report recommended that children should be treated as children and not "mini adults" in hospital and emphasised the need for staff training in paediatrics. Thirty years later the Department of Health advocated that health needs must be met by those specifically qualified in child health and that staff training in the developmental and emotional needs of children is essential to a high quality service.[28] These recommendations have yet to be implemented. Targets need to be set with timescales for meeting them if progress is to be made.

Communication skills with children need to be specifically included in the undergraduate curriculums of doctors and nurses. Health professionals could also benefit from closer liaison with those who possess expertise in child development and communication. For instance, greater use could be made of colleagues in departments of child and family psychiatry and clinical psychology. Specialist knowledge and experience could be exploited. Contact also needs to be extended with other non-health professionals such as teachers and social workers, who also work closely with children, as recommended by the report of the National Commission of Inquiry into the Prevention of Child Abuse.[29] The report highlights the general practitioner's role in identifying children at risk from abuse,[30] for which doctors must be able to help children to express themselves.



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Children's views matter, too

To suggest that service providers should consult children does not mean that parents' views should be ignored. Parents need to have the opportunity to express their expectations, which are likely to differ from children and will be based on many years' experience of health services. Parents' knowledge may be vital to understanding how best their child may be approached to avoid causing unnecessary distress. But parents have to recognise that children need to develop responsibility for their own health and health care. Children are not possessions but individuals with rights and developing responsibilities.[29] Parents may need to be encouraged to stand back and enable children's voices to be heard.

Conclusions

Healthcare professionals will not be able to allay children's fears and respond to their needs unless they are prepared to develop effective means by which children can communicate with them. Seeking children's views appropriately is important not only for the individual child and his or her family but also for the future of the NHS. Consumer participation is a prerequisite in bargaining assertively for quality health care.

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The Use of Photographs as a Means of obtaining Views of Occupational Therapy held by Children with Learning Disabilities: a Pilot Study

Debbie Joy, Anita Young, Val Harvais and Rosemary Chesson

As an adjunct to a pilot project on the use of Goal Attainment Scaling in occupational therapy for children with learning disabilities, children's views of therapeutic intervention were explored. These were investigated by means of interviews held at the residential special school that the children attended and were carried out by a therapist who was unknown to them.

During the interview, six photographs (three therapy and three non-therapy related) were presented. Each child's response was recorded by the interviewer. Despite the seven children having emotional and behavioural difficulties, all cooperated during the interviews, looking at the photographs and not displaying any challenging behaviour. When the children's responses were categorised in terms of their unique styles of communication, more positive reactions to the photographs relating to occupational therapy than to the others were noted. It is acknowledged, however, that further development work is required in order to establish the reliability and validity of the method.

Introduction

A pilot study was initiated to investigate Goal Attainment Scaling (GAS) as a means to determine the impact of occupational therapy on children (aged 5 to 18 years) with learning disabilities, attending a residential special school (Linn Moor) near Aberdeen. Pupils are usually referred to the school, which has a national catchment area, as a result of 'emotional and behavioural problems presented by the child at home' (Linn Moor Residential School 1993). As well as seeking to measure outcome (Young et al 1997), it was considered important to attempt to establish children's own views of their therapeutic experience. However, there has been little systematic investigation of such clients' satisfaction with treatment, particularly regarding therapy. Thompson and Martin (1993) attempted to examine the effects of sensory stimuli for people with a range of learning disabilities by the recording of non-verbal responses, and Dagnan et al (1994) used happy and sad faces to help clients with severe learning disabilities to express their feelings about a community psychology service.

Researchers in the USA and the UK have demonstrated that valid views and meaningful responses can be obtained from children and adults with learning disabilities (Sigelman et al 1981, Atkinson 1988, Booth et al 1989). While a number of approaches have been used, one that seemed particularly appropriate was the use of photographs. Photographs of familiar people have been used successfully by Oliver (1986) to investigate self-concept ranking in a 14-year-old girl, and more extensively by Fox and Norwich (1992) with adults with severe learning disabilities. The present study had two main objectives:

1. To explore ways of assisting children with learning disabilities to express their views of therapy
2. To determine if photographs might offer a means of children communicating their views.

It was intended that once the feasibility of the method had been established, it would be refined further and used with a greater number of children.

Method

The study participants

All seven children who were part of the GAS investigation at Linn Moor school were included in this consumer study. These were pupils who had been identified by school staff as having the highest need for occupational therapy. Therapy was provided to help with significant difficulties experienced in the following areas: personal activities of daily living (ADL), domestic ADL, fine motor skills, gross motor skills, purposeful activities, cooperation with people and the use of community resources.

Three of the children could speak but one was reluctant to do so, especially with unfamiliar people. The rest could not converse or answer questions, although one child (Helen) used some Makaton signs in a limited way. The remainder used neither speech nor a formalised alternative. Two children

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communicated at a pre-intentional stage in that their non-verbal responses to the environment had to be interpreted by those around them (Coupe and Joliffe 1986). The children's non-verbal communications were heterogeneous, as described by Burford (undated) and exemplified in Table 1. None had significant visual impairments. The children were aged from 7 years 7 months to 18 years (mean 12 years 3 months).

The methods chosen to identify the children's strengths and needs in the main study meant that only contraindications to and precautions for occupational therapy were noted from medical and educational records. The names of children used in describing the study are pseudonyms to protect confidentiality.

Table 1. Examples of indicators of child's response

Child	Positive	Neutral	Negative
Tim	Look at photo Smile at photo Want to sit next to interviewer Reach out for photo Put interviewer's hand in his	Spin photo Flick photo No smiles Obey request only	Turn whole body away Move away Push interviewer away Push media away Engage in self-stimulating activity including high-pitched noises
Helen	Look closely Tap photo with both index fingers Giggle Smile Clasp hands together Look at interviewer Make eye contact with interviewer	Glance at photo No smiles	Use Makaton signs for 'tired', 'home', 'boat' Not look or glance at photo Push interviewer away Nip, scratch, pull hair or bite interviewer

Therapy

All the children had received occupational therapy from the same experienced occupational therapist (VH), who provided individual treatment in blocks of sessions (minimum six, maximum 10). Treatment sessions were usually 30, 45 or 60 minutes in duration, depending on the nature of treatment. For example, a dressing programme may have been implemented within 30 minutes, but a complex sensory motor programme may have required a full 60 minutes.

The interview survey

The interviewer: An occupational therapist (DJ), previously unknown to the children, conducted the interviews in order to gain as objective a view of the children's responses as possible. It was acknowledged that the children might be less forthcoming and relaxed with an unfamiliar person. However, this was offset to some extent by familiar surroundings, an introduction and handover given by a familiar staff member, and the expertise of the interviewer in meeting and establishing communication with people with learning disabilities.

Interview preliminaries: The interviewer obtained child-related information relevant to the interviews from the therapist providing treatment (VH) via semi-structured interviews. The therapist was informed beforehand of the topics to be discussed. She was asked to contribute information based on her own knowledge, experience and consultation with members of the school multidisciplinary team, including each child's class teacher, residential keyworker and the school speech and language therapist. Her knowledge included information on precautions and contraindications from the children's medical and educational records held at the school, accessed as part of the assessment and treatment planning process. Her experience was gained in treatment sessions and informal observations of the child within the residential school setting.

The interviewer used the resultant data to plan the children's interviews regarding preferred interview setting, the children's communication styles, reactions to photographs, challenging behaviours, sensory impairments, type of support needed, likely attention span of the participant and the use of Makaton signs (where appropriate). In addition, the information gathered at this point also gave the interviewer a means of interpreting each child's reactions to being interviewed and to the photographs, as follows:

- *Positive responses:* the child likes what is happening or is being presented to him or her
- *Neutral responses:* the child neither likes nor dislikes the event
- *Negative responses:* the child dislikes the event.

Responses were only used as indicators if they were verified by the occupational therapist (VH) and other members of the school's multidisciplinary team. There were variations from child to child, as demonstrated in the two examples given in Table 1.

The interviews established that looking at photographs was a familiar, valued and understood leisure activity for the children. However, some staff expressed doubts to the therapist as to whether all the children would be able to tolerate such an interview with an unfamiliar person and judged that some curtailed interviews and displays of challenging behaviour were likely.

The interviews: Each child was interviewed individually. The interviews were conducted after at least one treatment block had been completed, in a small room annexed to one of the school classrooms and furnished with a table and two chairs. It was familiar to most of the children and relatively free of visual distraction. Auditory distraction and disruption to the routine of the school were minimised by interviewing during the school lunch break. A central feature of the interviews was the photographs.

The photographs: Photographs were taken at the school prior to the interviews by a professional photographer using a prepared schedule. This included three photographs connected to each child's occupational therapy and three non-therapy photographs of subjects which were judged by the research team to be of comparable familiarity, interest and relevance to the participants. The number of photographs was chosen with regard to the children's tolerance of structured activity. Non-therapy subjects expected to have positive or neutral values were selected in order to reduce the risk of causing distress to participants, jeopardising the completion of the interview or causing injury to the interviewer.

The therapy photographs showed the therapist (VH), the child with VH engaging in occupational therapy, and treatment media (Figs 4, 5 and 6). The media were objects used regularly in treatment, with a direct relationship to therapy goals (see Table 2). Some were used exclusively in sessions (such as a purpose-made goal-scoring game), while others were introduced in sessions and subsequently used more widely in the child's daily life, such as adapted tableware. Thus, objects that had strong links to therapy were depicted, but some of these objects would also be encountered outwith sessions.

The non-therapy photographs included the child, a lounge area and a corridor in the school (Figs 1, 2 and 3). Figs 1 – 6 show one child's set of photographs. The photographs of the therapist (Fig. 4), lounge (Fig. 2) and corridor (Fig. 3) were common to all sets, while the remainder were different for each child. Table 3 describes the content of the active therapy photographs.

Fig. 1. Non-therapy: child self-portrait.

Fig. 2. Non-therapy: lounge area.

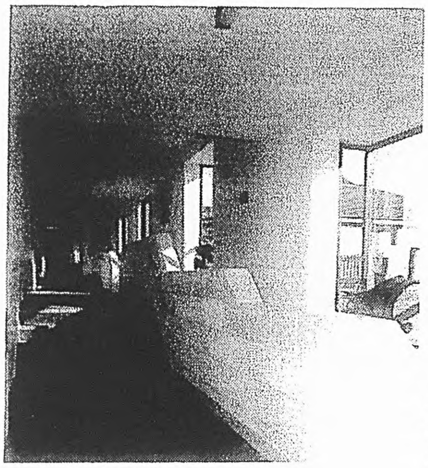

Fig. 3. Non-therapy: corridor in school.

Fig. 4. Therapy: occupational therapist.

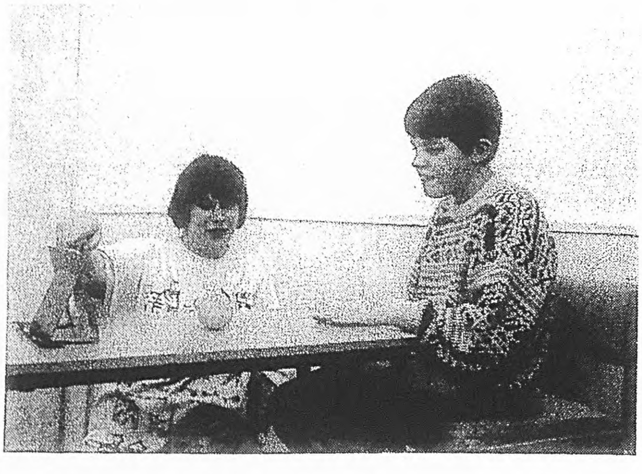

Fig. 5. Therapy: child with therapist engaging in therapy.

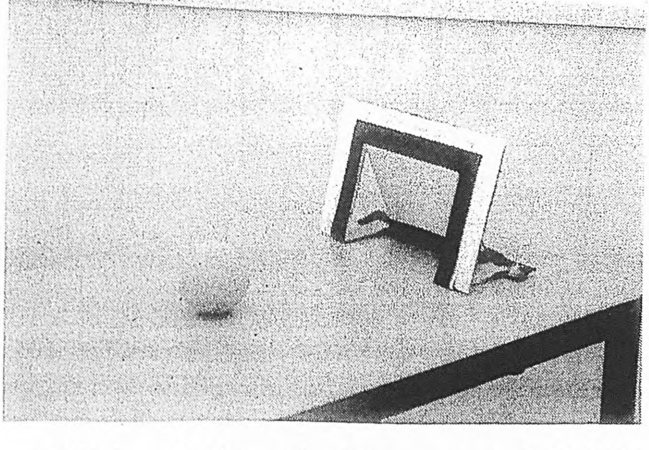

Fig. 6. Therapy: treatment media.

Table 2. Treatment media shown in photographs and therapy goals

Name	Media	Therapy goals
Mark	Purpose-made goal and tennis ball on table	Develop hand-eye coordination and fine motor control
Neil	Suspended platform and shorts	Vestibular stimulation and practise dressing skills
Tim	Bubble wrap, net, talc, brushes, fake fur, shaving foam, sponges	Sensory integration
Helen	Adjustable cut-out table, bean-bag, balls, skittle, hoop, shorts	Develop grasp and release, trunk control, shoulder movement and dressing skills
James	Knives and chopping boards with purpose-made pictorial prompt cards	Teach the difference between slicing and chopping in food preparation
Angus	Adapted cutlery with plate	Develop independent eating skills
Paul	Plate guard and adapted cutlery with plate	Develop independent eating skills

NB. Some children had more than one set of goals. In the tables, only examples for one set are given.

Table 3. Therapy activities shown in photographs

Name	Activity in photograph
Mark	Mark seated at table playing the goal-scoring game with VH observing
Neil	Neil kneeling on suspended platform, interacting with VH sitting on floor beside platform
Tim	Tim brushing own foot with a soft paintbrush, with VH observing, on soft play mats
Helen	VH kneeling behind a seated Helen, passing a skittle. Helen reaching back over her own shoulder to take the skittle.
James	James chopping potatoes, with VH pointing to a pictorial prompt (line drawing of chopped potatoes, in kitchen)
Angus	Angus sitting at dining table with place setting, holding adapted knife, in dining room
Paul	Paul rolling along mats and wrapping self in length of bubble wrap. VH kneeling close by and encouraging him

Assessment of the children's response

During each interview, the interviewer (DJ) observed for the positive, neutral and negative responses as described above. Responses were recorded on a checklist, using a method which reflected that of Thompson and Martin (1993). Actual responses were scored as (+, 0, –). For example, if a child showed three positive responses to a photograph, he or she would score + + +.

As each photograph was presented, the interviewer observed the child's response whilst offering prompts ('Look at the photo' and 'Do you like it?'). Although the researchers were aware of the problem of acquiescence, or yea-saying (Sigelman et al 1981), when closed questions were used the children did need simple familiar prompts. Variations of response from photograph to photograph were therefore particularly important. The overall reaction to the interview, rather than to the photographs, was gauged in terms of toleration of, or cooperation with, the activity. For example, a willingness to stay seated and to look at each photograph were seen as signs of toleration, whilst showing a discernible response to photographs was seen as cooperation.

At the end of the interview, all six photographs were displayed on the table and the child was offered the choice of one photograph to keep as a gift. This, it was envisaged, would indicate the favourite. Although it was acknowledged that some children would not be able to select one photograph from so many, this approach was considered preferable to presenting photographs two or three at a time and gradually eliminating them. The latter was regarded as likely to cause confusion and exceed the children's ability to concentrate and attend to an activity. Each interview was timed by the interviewer, who recorded observations during and immediately after the interview. The results were not analysed statistically because the number of participants was too small for this process to be meaningful.

Results

Timing and recording

The interviews took from 3 to 10 minutes to conduct. The total process for each child included: preparing the interview; collecting and returning the child; and recording times and observations. This took from 25 to 32 minutes in total.

Response to the interview

None of the children confirmed fears expressed by school staff that they would not participate at all, would not look at the photographs or would damage or destroy them. None of them, moreover, displayed any other challenging behaviour (damage to self, others or property). Table 4 shows that the children took 42 of the 49 opportunities to tolerate or cooperate offered to them. One child (Tim) left the interview room on several occasions but returned on request, and another (Paul) left his seat once but sat down again when asked. Indicators suggestive of tolerance only, or lack of understanding, were lack of eye contact and/or smiling; invariable reaction from photograph to photograph; and attention to media irrelevant to the process.

Table 4. Children's response at interview

Sign of cooperation or tolerance response	Individual child						
	Mark	Neil	Tim	Helen	James	Angus	Paul
Stayed in room for whole interview (or returned when asked)	✓	✓	(✓)	✓	✓	✓	✓
Stayed in seat for whole interview (or sat back down when asked)	✓	✓	(✓)	✓	✓	✓	(✓)
Looked at each photograph	✓	✓	✓	✓	✓	✓	✓
Reaction varied discernibly from photograph to photograph	✓	✓	✗	✓	✓	✓	✓
Did not attend to irrelevant media (e.g. recording materials, toys)	✓	✓	✗	✗	✓	✓	✓
Smiled during introduction or closure	✓	✓	✗	✓	✗	✗	✓
Made eye-contact during introduction or closure	✓	✓	✓	✓	✗	✓	✓

✓ = Indicated cooperative or tolerant response, (✓) = Returned or sat down when asked, ✗ = Did not indicate cooperative or tolerant response.

Reactions to the photographs

A total of 58 reactions to 42 presentations of photographs was recorded (Table 5). It is evident that there were seven more positive reactions to the photographs relating to occupational therapy than to the other photographs.

Table 5. Nature of response to photographs (n = 7)

Response	Subject of photograph		
	Therapy	Non-therapy	Total
Positive	23	16	39
Neutral	6	9	15
Negative	2	2	4
Total	31	27	58

The participants' response to the inanimate objects which were used as media for occupational therapy was of interest (Table 6). Only photographs of themselves (9+) and of themselves taking part in therapy (9+) were preferred. Other photographs which did not include people (for example, a lounge) had lower scores (3+ and 4+). This result is supported by the choices made by the two children who were able to respond to the offer of a photograph to keep as a gift. Both of them chose their treatment medium: adapted tableware for Neil and an adapted table goal-scoring game for Mark. The children's recorded responses reflected the research therapist's own judgement that the children enjoyed therapy, demonstrated by, for example, their willingness to attend and participate in treatment sessions.

Table 6. Child's response to photographs

Photograph	Child						
	Mark	Neil	Tim	Helen	James	Angus	Paul
OT – VH	++	++	–	+	+	0	0+
OT – Therapy	++	+++	0	+	+	0	++
OT – Medium	++	++	–	0	++	0	+
Non-OT – Lounge	+	+	–	0	0	0	0+
Non-OT – Child	++	+++	0	+	++	0	+
Non-OT – Corridor	+	+	–	+	0	0	0+

\+ = positive response, 0 = neutral response, – = negative response.

Discussion

Reliability and validity

The reliability and validity of this method of eliciting children's views could not be tested within the confines of this small-scale study. Moreover, given that fundamentally it is an individualised approach (each set of photographs included different items and children's response profiles were unique), its validity *per se* may be challenged as has been that of GAS (Palisano 1993, Grenville and Lyne 1995, Young and Chesson 1997). Content validity is dependent on the reliability of the indicators and the judgement of the rater, who must determine the nature of the child's response. Further, a bias towards positive or neutral responses is likely to occur, since efforts have to be expended to minimise negative responses because these may lead to harm to the child, the environment or the interviewer. Also, it should be noted that responses may relate to the therapy process rather than to outcome.

Future development

To make the method more robust, it is recommended that:

1. Response profiles constructed after consultation with multidisciplinary team members be piloted for reliability prior to use in the photo-interview
2. The feasibility of videoing the photo-interviews be explored, in order that inter-rater reliability in relation to the categorisation of children's responses be established
3. Prompts to be used during the interview be developed, so as to avoid acquiescence while being appropriate to participants' needs
4. Children's response to a wider range of photographs be determined.

Conclusion

The study demonstrated that it was feasible to conduct interviews with the children, since they were willing to cooperate and did not damage or destroy the photographs. This was despite, firstly, the participants having significant emotional and behavioural problems as well as learning disabilities and, secondly, reported difficulties in interviewing children with emotional and behavioural problems (Chesson et al 1997). It is suggested also that response profiles developed on the basis of multidisciplinary consultation may be useful in predicting behaviour and may facilitate the use of independent interviewers to obtain views, an important consideration in service evaluation (Stallard 1995). Although in its infancy, this method clearly has the potential to provide a voice for these health service consumers whose opinions are largely unknown. The study suggests also that the children were positive about therapy, but further verification is needed.

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Chapter 5

Quality of life with Parkinson's disease: views of Scottish consumers and providers

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This chapter reports two studies funded by the Parkinson's Disease Society (PDS) which together help to provide a better understanding of the expectations of and satisfaction with health care of people with Parkinson's disease (PD), especially with regard to the provision of therapy and quality of life. Both investigations were undertaken within the context of major changes occurring in health and social care following the implementation of the NHS and Community Care Act (1990). Not only were changes in organizational structure required, but also health care providers had to develop new ways of thinking and new models of care. In particular, patients, as consumers, needed to be given a greater say in decision making, and partnerships had to be forged. Indeed, current government policy, as reflected in the White Papers *Designed to Care* and *The New NHS: Modern, Dependable* (Department of Health, 1997a,b), emphasizes patient involvement. Hence the studies described here, in which patients' as well as professionals' voices can be heard, have a significance for service planning for the twenty-first century.

The two studies

In 1993/4, a study on the availability of therapy services – occupational therapy, speech and language therapy, and physiotherapy – to people with PD living in Scotland began. This included Scotland-wide surveys of Scottish PDS members, their therapists, general practitioners and consultants. It emerged from this work that psychosocial factors and, specifically, quality-of-life issues associated with the disease were identified more frequently by patients than professionals, who tended to focus on physical dysfunction. This finding led to the second study, on health-related quality of life in 1996, which explored aspects important to people with PD and examined the relationship between patients' and their therapists' perceptions of quality of life. Whereas in our first survey a large number of people were contacted so that we might obtain as broad and as representative a picture as possible, in the second we restricted the numbers so that we could attempt to achieve an in-depth understanding. Thus the two projects should be regarded as complementary.

This chapter begins by describing briefly the wider context of the research, before outlining the aims and objectives of each study and describing the research methods employed. Subsequently the findings of each study are presented in turn. In the final section, the work overall is evaluated and its implications discussed.

The social and research context

The successful management of PD patients has been seen to depend on 'a network of medical and paramedical services working together to ensure the best possible quality of life for both the patient and family' (Whitehouse, 1994, p. 448). Speech therapy, physiotherapy and occupational therapy may help with the clinical features of the disease. Research over the years has investigated the timing and nature of such interventions, as well as their effectiveness. However, the evaluation of therapy is beset with difficulty and much of the evidence is inconclusive, although there are a few studies where patients' own assessment of benefit is included. Nevertheless, of all three therapies, speech and language therapy is most widely acknowledged to have demonstrable benefits, not only for those with communication difficulties, but also for those with swallowing disorders (Scott and Caird, 1983). Physiotherapy has for many years been advocated for people with PD, as it is primarily concerned with disorders of movement, whether musculoskeletal or neurological in origin, although a substantial body of supportive research is lacking. Nevertheless, the nature of physiotherapy provision is changing, with fewer people being treated in hospitals and more in community settings (health centres and general practice surgeries, for example). Home visits are being increasingly recommended, since they provide therapists with the opportunity to assess the patient in a real life environment and may enable closer cooperation with partners and relatives. Occupational therapists, on the other hand, have a long established tradition of home visiting, where clients and carers are advised on the best methods of coping with PD, and appliances and equipment may be provided to help achieve maximum independence (Beattie, 1991).

There appear to have been low levels of service usage among those with PD living in the community. In 1982, Oxtoby reported that of the 261 respondents in a survey of people with PD, 13% had received occupational therapy, 17% physiotherapy and only 3% speech and language therapy. As a result of these findings, therapy working groups were set up by the PDS to provide an information resource for the therapy professions and to publicize the value of their expertise in helping people with PD (Baker and McCall, 1991). Yet in their community study of the prevalence of PD in Aberdeen, Mutch *et al.* (1986) found that 25% of the 227 patients assessed had seen an occupational therapist, 7% a physiotherapist and 4% a speech and language therapist. Since referrals to the paramedical professions are made largely by medical practitioners (hospital consultants and general practitioners), their views regarding accessibility, efficacy and priorities are of crucial importance.

Before the 1990s, clinical investigation and quality-of-life research tended to remain apart. But with an increased emphasis on cost-effectiveness and the development of the QALY (quality-adjusted life year), health care professionals have had a growing interest in the concept. However, quality of life is an elusive concept; it has been likened to happiness, in that it is a term we all understand but it defies definition (Slevin, 1992). Indeed, a good quality of life may be expressed in terms of happiness as well as satisfaction, contentment, fulfilment and the ability to cope (Calman, 1984). Specifically in the clinical context, it has been proposed that the more focused term ‘health-related quality of life’ (HRQL) be used, defined as ‘the individual’s ability to function in a variety of social roles and to derive satisfaction from them’ (Jette, 1993).

Healthy psychological functioning and the ability to adjust and adapt to different illness states may be crucial to a good quality of life (Fallowfield, 1990). As might be expected, researchers have reported that quality of life is of primary concern to people with PD and their families. Yet there has been very little research on therapy and quality of life. In fact, most therapy research has focused on functional outcome, and has been concerned with therapist-defined rather than patient-defined aspects of treatment.

It is hoped, therefore, that the two studies presented here start to fill some of the gaps in our knowledge and understanding, as well as stimulating debate on key issues relating to therapy and quality of life.

Research objectives of the study ‘Availability of therapy services’

The main objectives were to:

1 establish how those with PD gain access to therapy services;

2 delineate patterns of service use (e.g. level of input, timing, frequency) with particular reference to disease course;
3 investigate the role of general practitioners and voluntary agencies, such as the PDS, in the provision of services;
4 identify users' perceptions of the benefits of therapeutic intervention in relation to improved quality of life;
5 determine perceived future needs for this client group and the potential demand for services.

Research objectives of the study 'Health-related quality of life'

The main objectives were to:

1 describe the perceptions of people with PD of their current quality of life and priorities for improved quality of life;
2 assess the congruence between health professionals' and patients' perceptions and expectations regarding quality of life;
3 establish the congruence between therapists' and patients' priorities with regard to quality of life.

Research design and methods of the study 'Availability of therapy services'

The study had five main elements:

1 questionnaire survey of Scottish PDS members;
2 survey of therapists;
3 questionnaire survey of general practitioners and consultants;
4 telephone survey of local voluntary agencies;
5 face-to-face interviews with 'experts'.

This chapter is concerned with the results of the first three elements. The results of the voluntary agency survey and expert interviews are given in the full report (Chesson *et al.*, 1996).

1. Questionnaire survey of members

During spring 1993, a questionnaire was developed for members and was piloted in Sussex. Following minor modifications in June, the PDS mailed 2,496 questionnaires directly to all Scottish members included on its membership list. This was undertaken by the Society in order to ensure confidentiality. A major concern related to the quality of the list, in particular regarding its inclusion criteria and the extent to which it was up to date.

The main topics covered in the questionnaire were:

i respondents' age and gender; date of membership and diagnosis; extent of disability; home circumstances and informal care networks;
ii past and current contact with services; frequency and duration of therapy input (if any); contact with general practitioner and voluntary agencies;
iii perceived need for services; perceptions of value and limitations of services; and prediction of future needs.

2. Survey of therapists

First, a questionnaire was sent to therapy managers and then telephone interviews were conducted with therapists employed by the National Health Service (NHS) or local authority social work departments (hereafter referred to as practitioners).

The questionnaire survey was intended primarily to investigate 'managerial' issues – for example, patient numbers, policy, procedures and priorities relevant to patients with PD – as well as to facilitate the identification of the therapists most involved in the treatment of people with PD. All managers (89 were contacted) were employed in the same geographical areas as the questionnaire member respondents. Managers were requested to provide the names of therapists who could be telephoned to discuss issues relating to 'hands on' work. A high response rate (79 managers, 89%) facilitated the compilation of a list of therapists to be interviewed by telephone.

All 79 therapists 'volunteered' by their managers agreed to participate. There were 29 occupational therapists, 33 physiotherapists and 17 speech and language therapists. The interviews took place between November 1993 and February 1994 and were mainly concerned with the referral of and current treatment methods for patients with PD. All interviews were carried out by the same interviewer (DC).

3. Questionnaire survey of general practitioners and consultants

Questionnaires were sent to 44 general practitioners and 25 consultants (neurologists, geriatricians and physicians) during February 1994. The former were randomly selected, while the latter were a purposive sample; both were selected from lists of practitioners from the geographical areas from which PDS members had responded. The questionnaires were short and limited in scope in order to encourage their return. They were concerned specifically with reasons for referral of patients with PD to therapy services and perceptions of the role of the therapies. Before reminders were sent, over half of all those contacted had responded.

Research design and method of the study 'Health-related quality of life'

Qualitative design

A qualitative approach was regarded as appropriate given the major objectives of this study and it was believed that in-depth interviewing offered the greatest opportunity for people with PD to voice their views, expectations and priorities. Through interviews, it was hoped that the concept of quality of life might be explored, enabling the patient to focus on self-determined, rather than researcher-determined, issues.

Also, it was envisaged that interviews with therapists would be more useful than questionnaires, since the interviewer could ensure that the therapist had accurately recalled a patient. In addition, they would enable issues to be examined in more depth.

The study group

Volunteers with PD were recruited via the local PDS branch in Aberdeen and through specialist outpatient clinics in Glasgow and Dundee (where there are no PDS branches) as well as therapy departments within Tayside, Aberdeenshire and Strathclyde. These three areas were chosen for their differing socio-economic characteristics, varying PDS activity and diversity of therapy available. By studying these three district locations, it was hoped that a picture of the quality of life of people with PD across central and north-east Scotland might emerge. The three regions each has a large city (Dundee, Aberdeen and Glasgow) and includes a large teaching hospital. However, despite their urban centres, each region also has many rural parts, with small local hospitals providing local care and therapy to the elderly and people with chronic illness.

Volunteers were recruited via local branches of the PDS and non-members from clinical settings. Volunteers were selected for participation if they had been in receipt of therapy (occupational therapy, physiotherapy or speech and language therapy) in the preceding nine months.

This was both so that a long time period had not elapsed between therapy and study participation, thus facilitating patient and therapist recall, and so that the volunteer's illness or social situation was unlikely to have altered significantly since therapy. Permission to recruit volunteers was sought and obtained from relevant regional ethical committees.

People with PD who took part in the study came from a diversity of locations, ranging from council-owned high-rise flats in the inner city, to quiet residential areas on the outskirts of town, as well as from isolated rural cottages. The therapists were based at large teaching hospitals, day hospitals, local community hospitals and in the community.

The pilot study

Before any of the research instruments were used in the study, they were tested for effectiveness and acceptability on a small number of patients and therapists in South Wales (six in total). Participants for the pilot study were recruited from a Welsh branch of the PDS, and each had to meet the same selection criterion used in the main study.

The interviews

The volunteers were visited once in their own home by the same researcher (DRA). After participants had completed the Nottingham Health Profile (the results of which are not reported here), the researcher proceeded to interview them to discover what was important to them regarding their quality of life, how this has changed since developing PD and what their views were on the therapy received. Interview questions were open ended. The questions used by Farquhar (1991) in her study on the measurement of quality of life were used as a guide, but were adapted and implemented to meet the specific needs of this study. Unlike in Farquhar's study, they were not coded on a Likert scale. Direct quotations from patient interviews are presented below to let the participants speak for themselves, and to avoid some of the distortion which occurs when responses are 'forced' into a limited number of categories.

Therapists were interviewed, again by the same researcher, after the client interviews. Before interview, therapists were asked about their experience of quality-of-life measures and were requested to grade each patient's level of disability using the Hoehn and Yahr scale of physical disability (Hoehn and Yahr, 1967) (see Chapter 1), as used by Clarke *et al.* (1995) and Lee *et al.* (1994) in their study of the medical, social and functional profile of patients with PD. The therapists were asked similar questions to their patients, to enable comparisons to be made between the two sets of responses. Patient and therapist interviews began in January 1996 and were completed in August 1996.

All interviews were tape recorded, to allow for a detailed content analysis. Permission was sought from each participant to use a tape recorder. The researcher also took notes to act as a 'back-up' in case the tape playback proved to be of poor quality. This was the case in a small number of interviews where the person's speech had been adversely affected by PD, or where there was a high level of background noise.

Some observations on our research methods

A major problem regarding our first questionnaire to members was that we could not have access to the membership list. This had major implications for the study, since we were not able to scrutinize the list and exclude carers and benefactors, for example, even though our questionnaire was designed solely for people with PD. As is evident from Table 5.1, only approximately half the respondents fulfilled this criterion. Fundamentally, it meant that as researchers we lost control of the research process, as we had to depend on the Society with respect to all contact with members.

Regarding our second study, we had difficulties in recruiting participants as so few people had had therapy in recent months. It is significant that our contact with the many people who expressed a wish to help revealed that a large proportion had had therapy in the past (including many years previously) and the fact that there was considerable discrepancy between the numbers who had been seen by a therapist and who had actually received a course of therapy. This, in fact, reinforced the findings from our first study.

In both studies, a considerable volume of data was generated. Moreover, the analysis of end-opened questions was very time consuming. However, we are convinced that our findings should facilitate a greater understanding of people with PD and their problems and expectations, and doubt that a similar level of understanding would have been possible from a pre-coded questionnaire. Moreover, the interviews enabled people to set the agenda and express their opinions in their own words, which we do not believe often occurs in health settings. However, this does not lend itself to the 'executive summary' type of reporting which is often required by the health care manager bombarded by information. This is indeed a challenge for the future, since without doubt there is a need to develop methods of reporting qualitative data which make it accessible to health care managers making major decisions regarding service delivery.

Main findings of the study 'Availability of therapy services'

PDS members

Following reminders to non-respondents, 1,388 questionnaires were returned, representing a 62% response rate. Although people with PD were the single largest group to reply, representing 47.9% of respondents, significant numbers of questionnaires had been completed by a wide range of individuals, including carers and health care professionals (Table 5.1). There were also some questionnaires which were partially completed. Here we consider solely the 665 completed questionnaires returned by people with PD.

Health care professionals: therapists and general practitioners

Levels of response varied between professions, from 81% (13/16) for occupational therapists in social work departments to 94% (18/19) for speech and language therapists. Of the 79 named therapists, all of whom participated, 29 were occupational therapists, 33 physiotherapists and 17 speech and language therapists. Questionnaires were returned by 29 general practitioners, representing a 65.9% response rate, and by 15 of the 25 consultants.

Characteristics of respondents

Questionnaires were returned from people with PD living throughout Scotland. Approximately half (53.6%) were men and the overwhelming majority (86.8%) were over 60 years of age. The age distribution of men and women was broadly similar. Nearly two-thirds of respondents owned their own homes. Approximately one-quarter lived alone but most people (471) lived in two-person (or more) households (most commonly

Table 5.1. *Respondents to the 'Availability of therapy services' questionnaire*

Respondents	*No.*	*%*
People with PD	665	47.9
Carers	298	21.5
'Professional' members	52	3.7
Questionnaires incomplete (or unusable)	308	22.2
Other	65	4.7
Total	1,388	100

with spouses). However, 62.2% of those living with a partner or relative considered that they would not be 'able to manage' living alone. Less than a tenth of respondents reported living in sheltered housing, even though approximately 80% indicated that they were either moderately or severely affected by PD. Indeed, when asked if they were 'able to turn over in bed', only 34% indicated that this could be achieved.

The therapy manager respondents comprised 40.5% physiotherapists, 36.7% occupational therapists, and 22.8% speech and language therapists; 76% described themselves as managers, while 24% were senior therapists.

The therapists were distributed throughout Scotland and over a quarter (26.6%) reported working in the community – these were largely occupational therapists within social work departments or health service speech and language therapists. Most commonly, NHS therapy managers were located within departments of neurology or care of the elderly. A small number of respondents reported working within rehabilitation. As expected, given the method of recruitment, the practitioner therapists reflected the profile of the managers regarding, for example, geographical location, speciality and work setting.

General practitioners who responded were working throughout Scotland, from Thurso to Dumfries and Oban to Aberdeen. Both fundholding (7) and non-fundholding (22) practices were represented. Of the 15 consultant respondents, 13 were geriatricians and two neurologists.

Access to therapy services

Nearly half the members with PD who completed the questionnaire (47.5%) had received therapy. Approximately one in ten of all respondents, and one in five of all who had had therapy, had received all three therapies (Table 5.2). Of the 104 respondents who had had two therapies, the most common combination was occupational therapy and physiotherapy, and more people received physiotherapy (80.1%) than any other therapy (Table 5.3). Across all three therapies, 8.5% of respondents (27) in receipt of therapy had seen a therapist, usually a physiotherapist, in private practice. A quarter of respondents indicated that their local branch was able to arrange therapy, but nearly 75% of these people lived either in Edinburgh or Glasgow, where multidisciplinary clinics were run by the PDS.

Patterns of referral were broadly similar in all therapies, although more of the physiotherapy referrals were from general practitioners and greater numbers of self-referrals were reported in occupational therapy and speech and language therapy (Table 5.4). Eighty-two per cent of

Table 5.2. *Number of therapies received by respondents*

No. of therapies	*No.*	*% of all who received therapy*	*% of all respondents*
Three	58	18.4	8.7
Two	104	32.9	15.6
One	316	100.0	47.5

Table 5.3. *Type of therapy received*

Therapy	*No.*	*% of all who received therapy*	*% of all respondents*
Physiotherapy	253	80.1	38.0
Occupational therapy	161	50.9	24.2
Speech and language therapy	122	38.6	18.3

Table 5.4. *Source of referral, by therapy*

Source	*Occupational therapy (n = 111)*		*Physiotherapy (n = 201)*		*Speech and language therapy (n = 97)*	
	No.	*%*	*No.*	*%*	*No.*	*%*
Consultant	41	36.9	74	36.8	41	42.3
General practitioner	30	27.0	71	35.3	28	28.9
Self	20	18.0	22	10.9	17	17.5
Health visitors/ district nurses	20	13.5	34	16.9	11	11.3

respondents said that if they felt they needed therapy services, these would be requested, and nearly two-thirds indicated they would ask their general practitioner.

Approximately two-thirds of respondents were able to state the number of visits during their most recent course of therapy – nearly one in five of those who reported receiving therapy had had one session, but 7.5% had over 15 sessions. Those who had occupational therapy were more likely to have received it in their own homes but had had fewer sessions compared with the other two therapies. Sixty-two per cent of those who replied thought that they might need therapy services in the future and nearly one-third considered that they might require all three therapies. Nearly half stated a preference for any future therapy to be at home.

Therapists' accounts of service provision

Both therapy managers and practitioners indicated more than one main source of referral. However, 67 NHS therapy practitioners cited geriatricians (44.8%), GPs (29.2%) and neurologists (11.9%).

'Assessment' was given as the single most common reason for referral. Surprisingly, only eight of the 158 respondents (six were social work department occupational therapists) reported referral for activities of daily living or aids and adaptations.

When managers were asked at what stage in the disease course they were most like to see a person with PD referred, approximately half (49.9%) thought that this should occur either at diagnosis or within a year of it. The majority of managers (70.9%) thought that once people with PD were referred, they should be assessed on a regular basis, such as every six months.

Although treatment was provided in a range of different settings (Table 5.5), which reflected the distinctive working patterns of the different therapists, it occurred most frequently in hospitals rather than people's homes.

Managers were asked specifically if they felt voluntary agencies should provide services such as information, the provision of transport, equipment and therapy for people with PD. Above all else 'information

Table 5.5. *Location of treatment, by therapy*

Location	*Occupational therapy*		*Physiotherapy*		*Speech therapy*	
	No.	*%*	*No.*	*%*	*No.*	*%*
Outpatient/hospital departments	40	28.6	111	46.8	61	54.5
Home	44	31.4	29	12.2	18	16.1
Hospital	20	14.3	42	17.7	15	13.4
Outpatients, hospital and home	16	11.4	15	6.3	6	4.1
Hospital and outpatients	6	4.3	18	7.6	7	6.3
Hospital and home	12	8.6	14	5.9	2	1.8
Other	2	1.4	8	3.4	4	3.6
Total	140	100	237	100	113	100

about access to services' received the highest support (91.1% of managers), and nearly a quarter (24.1%) thought that voluntary agencies should provide therapy services.

General practitioners' referral and access to therapy

All respondents were able to refer patients directly to physiotherapy. Referral to either occupational therapy or speech and language therapy, however, was not possible for three general practitioners.

Main findings of the study 'Health-related quality of life'

Patient interviews

Twenty men and ten women participated in the study, the number reflecting the availability of patients who met our criteria. Twelve, eleven and seven respondents were recruited from Aberdeen, Tayside and Glasgow, respectively. All interviews were held in participants' homes and interview duration ranged from 30 minutes and two hours. Variation often reflected the severity of PD, as well as differing personalities. Eleven patients (36%) had their speech affected in some way. Speech problems ranged from mild, where the voice was quiet, to severe, where the speech was extremely difficult to understand. Generally, those with less severe symptoms had less to say, as they perceived that their lives were not greatly affected by the disorder. Some patients with more severe symptoms, whose social life was restricted, said that they were glad to have somebody to talk to about the disease, and to have a chat with a visitor. Carers were present at 14 interviews and occasionally contributed. Carers' responses have been included in the findings where relevant.

Patient characteristics

Ten patients had less severe PD as indicated by a Hoehn and Yahr score below 2, although there were eight people with scores of 4 and one of 5 (for full details of the study participants, see Table 5.6). Seven of the eight people who lived alone had a Hoehn andYahr score of 3 or more, six of whom were women. Eighteen of the participants lived with their wives, two with husbands and three with either a son, daughter or brother. None of the interviewees were currently employed. When the women who were described as housewives were excluded, the participants were

Table 5.6. *Characteristics of interviewees with PD*

Patient	*Gender*	*Age*	*Length of PD (years)*	*Hoehn and Yahr score*	*Former occupation*	*Lives with*	*Home status*
A	M	63	42	3	Cook	Wife	Tenant
B	M	65	14	1	Steward	Wife	Tenant
C	F	59	10	3	Machinist	Alone	Tenant
D	F	81	2	2	Teacher	Alone	Owner
E	M	60	17	3	Lecturer	Wife	Owner
F	M	70	13	4	Joiner	Wife	Tenant
G	M	63	5	1	Gardener	Wife	Owner
H	M	77	9	3	Rail guard	Wife	Tenant
I	F	74	14	4	Mill worker	Alone	Tenant
J	M	78	5	1	Clerk	Wife	Tenant
K	M	74	3	3	Teacher	Wife	Owner
L	M	88	5	4	Veterinary surgeon	Wife	Owner
M	F	61	1	2	Shop assistant	Son	Owner
N	M	57	7	3	Lecturer	Wife	Owner
O	M	71	1	3	Shop owner	Alone	Tenant
P	M	80	8	5	Farm manager	Wife	Tenant
Q	M	61	16	2	Teacher	Wife	Owner
R	M	82	12	4	Clock maker	Wife	Tenant
S	F	73	1	3	Housewife	Alone	Owner
T	F	66	1	3	Canteen worker	Alone	Tenant
U	M	69	1	2	Bricklayer	Wife	Tenant
V	M	85	2	3	Office foreman	Wife/ daughter	Owner
W	F	69	2	2	Clerk	Brother	Owner
X	M	77	2	4	Self-employed	Wife	Owner
Y	M	71	2	1	Housewife	Husband	Owner
Z	F	71	7	4	Policeman	Wife	Owner
AA	M	67	2	2	Labourer	Wife	Tenant
BB	F	79	10	4	Clerk	Husband	Owner
CC	M	76	6	3	Farm manager	Alone	Tenant
DD	F	71	34	4	Shop assistant	Alone	Tenant

equally divided between manual and non-manual occupations on the basis of their previous employment. Manual occupations included a cook, gardener, rail guard and a bricklayer. Nearly half of the former white-collar workers had been teachers or lecturers but there were also two farm managers, three clerks and a veterinary surgeon. The majority of interviewees who had professional and managerial backgrounds were home owners, and these comprised half of the study group. Membership of the PDS, however, appeared to be associated with geographical location rather than socio-economic status.

What is quality of life?

When asked what quality of life meant to people with PD, patients equated the concept with a number of aspects of living: 'It's how you get about, how you enjoy life, being able to do what I did before, being independent' (Patient B). These aspects were mentioned frequently by other interviewees, although all four were not necessarily mentioned in combination. However, these factors were the most widely regarded as the key aspects of quality of life.

Patients often referred to enjoyment: 'Having interests which allow you to enjoy your days without being bored or miserable' (Patient D). Patient L, who was very elderly and fairly disabled (Hoehn and Yahr score of 4) said that quality of life was 'The joy of living. If there is joy in it', while Patient Y, one of the least disabled participants, thought that it was 'Being able to enjoy life the way you did before'. Apart from enjoying life, Patient Y also said that being able to do what she did before was part of quality of life, a view expressed by many of those interviewed. In order to maintain former activities, reference was often made to mobility. 'To be able to move around and do the things that you like to do' (Patient H). Others highlighted the relationship between mobility and social contact. Quality of life is 'How you are able to get out and about and meet other people and enjoy yourself' (Patient W) and for Patient I essentially it meant 'Getting out and about and socialising', as it was also the case for Patient G: 'to be able to get out and about. It's pointless dwelling on Parkinson's. You have to accept it and get on with it. You can't make everyone else's life hell.'

Many people felt that attitude of mind was related to quality of life. For instance, Patient G believed that having a good attitude was important and said 'Nothing gets me down', a view reinforced by Patient V: 'You've got to accept what you get'.

Only one patient (Patient O) equated material possessions with quality of life and said 'Standard of living, I suppose'.

Evaluating quality of life

Patients usually were able to evaluate their quality of life and a third of people (11/30) taking part in the study described it as good. A further 11 patients did not evaluate their quality of life as either being particularly good or bad, or did not evaluate it at all. 'I would say I suppose it's all right. I don't do an awful lot. I take care of the house and do the shopping.... I don't have a great lifestyle or anything. I never did go mad of course.'

Patients with greater disability were more likely to describe their quality of life as poor: 'Well, when you ask that, I'm comparing with what it was like before. Now I can't walk.... Now I'm confined to a chair, it's poor, my quality of life is poor' (Patient P). Patient Z likened it to being a 'Prisoner Cell Block H'. As he came to have tears in his eyes, his wife added 'This is something we don't talk about usually. We try to pretend our life is normal. Probably the fact that you are talking about it brings it to the surface.... We try to keep in touch with people, but we're in a different world to everyone else.'

Medication

The majority of people interviewed believed that without their drug regimen, their quality of life would be reduced, even though difficulties regarding dose and side-effects were reported.

Patient M explained that the drugs initially made a big difference to her life, but when the dose was increased by half a tablet four times a day to help improve her walking, she experienced side-effects, particularly of confusion: 'I was away with the fairies.... I didn't know how to cook or what to buy or what to eat.' Now on a lower dose, she said: 'I'm perfect'.

Many interviewees highly valued their drugs and saw them as central to their quality of life, which would be threatened should they become ineffective. 'You can say you get no quality of life until you get that tablet. I don't know where I'd be without my tablet. I swear by it. The only way to describe it is like a car without petrol until, I get my tablet,' said Patient C. Her greatest fear was: 'My tablet just stopping. Just not working on me. What would I do? I often worry about that. I live in horror about that. It's a real dread I have.'

A number of patients mentioned that their tremor was significantly helped by medication, and some thought that it improved general mobility. 'I had trouble turning in bed at night, but I'm much better since my new medication' (Patient Y). Patient Z, despite having ten injections for his freezing said, 'I've been taking these frozen periods where I feel as if I've been nailed to the ground.... I can be frozen for anything up to five hours.... Once I take the injection, the frozen period disappears.'

Factors related to quality of life

During the course of an interview, a participant was likely to refer to a wide range of factors in the context of quality of life. Combinations, however, were unique to particular individuals. Nevertheless, particular activities or considerations were mentioned repeatedly and these have been subsumed within broad categories, under the headings below.

Mobility, movement and tremor

Nearly two-thirds of people interviewed referred to difficulties with mobility, although different aspects were highlighted.

Ability or inability to walk was mentioned by 13 interviewees: 'Sometimes I can walk all right and other times I can't walk at all. Sometimes it just stops, like your battery running out and you just stop' (Patient F).

Transfers also were problematic for some people. Patient X described major difficulties in 'Getting in and out of bed', whereas Patient Y regarded her problems as: 'Getting up off a low chair. I'm a bit embarrassed if I'm visiting anywhere. I wonder if I'm going to be able to get up okay without help.' Several people raised problems regarding comfort and turning in bed. One patient said: 'At night it affects my sleeping and is in itself quite alarming.... When you're lying in bed at night, the weight of the covers and the inability to get comfortable means one spends a lot of the time being awake. It's a constant battle to try and be at ease to fall asleep. The simple operation of trying to turn over with covers on is a bit frightening. You feel as if you're going to die. As a consequence I frequently get up at night and come downstairs to try and experience freedom of movement.' Patient AA also had problems getting comfortable in bed and had problems turning over, as did Patients A, F, I, J and Y. Patient R had a different source of distress: 'I have to sleep in the bed like a little child in a cot, railings on both sides in case I fall out.'

'Off' periods were described as difficult to live with: 'I was in hospital for three weeks to try to sort out my medication. One afternoon, I was I bed and I couldn't move the whole afternoon.... When I explained I was frozen, they asked me if I wanted another blanket' (Patient Z); 'The mind doesn't tell the body or the legs to move and if you force it you fall. I find it hard to answer the door, to get started. If the postman knocks, he is gone before I can reach the door' (Patient H).

Tremor was mentioned by half the interviewees as being a significant problem: 'My hand shakes like anything.... I'm not able to do things properly, like model making' (Patient G). For Patient I, her tremor was regarded as a real nuisance, as were her involuntary movements. Patient T's main concern regarding her tremor related to going shopping: 'It's just the shaking. Once I get to the shop, the nerves take over. The shopkeeper had to take the purse off me because my hands were shaking so much.' Other patients with tremor also said that it was worse in situations of stress, or if they were in a hurry. Patient J also believed his tremor was worse when he was aware of people watching him: 'If I'm somewhere where there's people it's [the tremor] worse. Going to the bank for instance or booking a holiday I find that when it comes to writing [in public] it's a problem.'

Communication and speech

Patient M concluded that 'Being able to speak to people' was one of the most important things to her quality of life: 'Until I was on that drug I had no interest in anybody. I wasn't able to speak, I couldn't speak and I felt I was in the room with people but I felt far away.' Patient A discussed how he was frustrated by his speech problems, especially when people did not take the time to listen to him, or spoke for him. Patient J found it embarrassing because he spoke so quietly: 'People lean forward to hear you.' Patient N, who previously was a lecturer and did much public speaking, now feels inadequate when addressing a group: 'Unless I concentrate now, my sentences run out of power.... I can't think on my feet and change track any more. If I get a phrase in my head I have to come out with it regardless, whereas before, I used to be able to improvise and be spontaneous and enthusiastic.... I very rarely feel in charge in a group. I perceive to myself that I have lost that capability.'

Activities of daily living

Problems with things such as dressing and undressing, bathing and eating were mentioned by nearly all those interviewed (28/30), with 17 stating that they experienced major problems of living.

Psychological impact

Loss of confidence, worry and anxiety, loneliness, embarrassment and depression were all raised by interviewees.

Attitude towards the disease was mentioned specifically by over a third of patients (12/30) as important in maintaining quality of life. Patient N, who regarded himself as preoccupied with his condition said: 'As time goes by and the disease gets a stronger hold, actually gaining some relief from the disease seems to be one of the main points of living. It's not a very inspiring spectre.... As you approach each stage of decline with the Parkinson's you're concerned about what the next stage will bring.... I'm concerned about what the future holds. Sometimes, from a personal point of view, I think it would be rather nice just to slip away. Though, of course, one doesn't say that sort of thing to one's family.... Before my horizons were always dotted with ambition, whereas now there's the realization of receding opportunities, which is a gross restriction on my hopes. I'm more conscious of my physical state, my health, than ever I was before. It's also frustrating to see one's powers of communication and mobility so sadly declining. It seems a one-way journey, which is depressing.'

Patient Z's wife also thought that PD could take over: 'I try to keep our life normal ... we just don 't talk about it.... The only way you can survive is by playing a game, and you hope you don't draw on all the pretence you have, because what would happen then?... Sometimes I feel I'm going to explode with it. Instead of crying, it just takes you over. I can't explain: it's just so sad and all consuming.'

Six participants, however, appeared to accept their situation and were 'making the best of it'.

In terms of the psychological aspects of living with PD, six people spoke of the emptiness, loneliness or sense of isolation they felt as a result of the disease: 'I used to be a right gad-about.... I don't mix with people so much. I've a different nature entirely. It was as if I went away and somebody else came in my place' (Patient AA).

Some patients mentioned anxieties at the time of the diagnosis: 'The name frightens me. I didn't know what Parkinson's disease was' (Patient U). Patient D, too, was alarmed when she was told she had the disease: 'I think the thought of having Parkinson's bothered me for a while. I thought "what's this going to come to?" But I've lived with it for two years. I think the thought of being told I had it did upset me at first.' Patient D did not tell her family she had PD for about one and a half years after her diagnosis, and revealed: 'Very few people know. Not that I'm ashamed to admit it, but I don't want their pity because people will feel the way I felt about Parkinson's.'

A few participants appeared poorly informed. For example, one interviewee enquired, 'It doesn't actually kill you does it?' (Patient O). Similarly, Patient F said, 'I'm not aware what's going to happen, you don't know what's coming next. Does it kill you in time? I don't know much about Parkinson's except that it causes people to shake' (Patient AA).

Family, friends and neighbours

Patient A stated that: 'I live for my family.' He resides with his wife, and his children and his 12 grandchildren live nearby and visit almost daily. Patient AA, married for 42 years, said in response to being asked what would make his life worse, 'If I lost my wife'. Patient D, who lives alone, but has children close by, said her family were the most important aspect of her quality of life: 'The feeling that there is somebody looking after you, which is important at my age.... It gives you a feeling of safety, knowing you can just pick up the 'phone and they will do what they can.'

Family relationships frequently were mentioned in relation to quality of life and those with less disability generally referred to their family less often than those with greater disability. Those who were more disabled often saw fewer friends and found their social interaction reduced, leaving the family often as the main source of social contact: 'The only thing now is my family, being there for them. I haven't anything else that's important. I don't want to be a burden too' (Patient S).

Many people mentioned the importance of friends, neighbours and the company of others: 'The neighbours round here are really marvellous. Upstairs they are really good to me, even cook me a meal sometimes' (Patient O). Patient U said that being able to get out and chat to people was one of the factors most important to his quality of life: 'I meet plenty of people in the street. I talk to everybody who comes up and down the road. I'm not lonely or isolated.' Diminished social contact was seen by others as a consequence of their disability.

Patient V, who was unable to meet people when he would like to, missed being up to date with the news in his local community: 'I used to go down the road every morning to the shopping centre for half an hour which I can't do now.... I miss all the banter and the scandal.' Patient X was very aware of his own and his wife's diminished social life and, being a very jolly person who was always telling jokes, he regretted the loss of this part of his life: 'We used to go out more, we used to go to shows every week, used to go to restaurants every week. All that's gone now. We don't entertain friends any more.... The biggest help to Parkinson's is the television.'

Apart from the effects on their own lives, some people worried about how their symptoms might spoil occasions for others: 'It's the shaky hand at bingo and the like, it's getting in the way and I feel it's annoying others, not so much myself' (Patient B). Lack of understanding by others was sometimes seen as adding to people's problems: 'I think one of the problems is that certain people treat me as if I was an imbecile' (Patient P); 'I would like to be able to walk into a room without people staring and folks looking at you queer' (Patient A).

The PDS was praised as a valuable support system for people with PD and their carers: 'I expected to find it [the PDS meeting] depressing, but I didn't. Your carer is there too, so you're not sitting with a load of invalids.... I've found them quite jolly honestly, I enjoy the meetings.... I think it helps. You see people who are bad, but you see that they are coping. Most people are really jolly. I would recommend anyone who has it to go' (Patient D).

Leisure and interests

Every participant mentioned some aspect of how their interests and social life had been affected by the disease. When asked about ways in which their quality of life had changed since developing PD, three-quarters (22) referred to changes in these areas. However, a few people (largely those with lower Hoehn and Yahr scores) thought that their quality of life had not been significantly affected in this respect: 'No, I don't think so.... The only thing I've given up really is the golf. Everything else is as it was' (Patient J).

Many men missed being able to participate in sports: 'Now I can't walk.... In 1989 I climbed three mountains in a week. I wouldn't be able to do that now. These are some of the things about my quality of life which I miss' (Patient P). Dancing was particularly missed by women: 'I haven't got the energy to dance any more, which I miss, but at least I can go out and watch others enjoying themselves' (Patient C). Dancing was mentioned by one man too: 'I wish I could go dancing. Even at 87 I would like to go dancing' (Patient X).

Several patients said they missed playing a useful role in society and felt a loss of status as a result of having PD. Patient P was formerly an elder in his church, and was no longer a member of his club because there is no wheelchair access to the meeting room. Patient N, too, was a fairly prominent member of his local community but now felt restricted as he was no longer not able to play a full part.

Independence

Being able to do things for oneself and not having to rely on others was often mentioned as being a significant element of quality of life. Patient BB regarded it as 'the most important thing' to her quality of life, and she wanted 'To be able to get up and clean the house and clean the windows and not have to watch somebody else doing it for you.' Loss of independence was mourned by the people interviewed and many dreaded having to be dependent on others. Loss of freedom was mentioned even by those with positive attitudes.

Therapy, therapists and day hospitals

The majority of patients (18) thought their therapists did have an understanding of their PD problems: 'Definitely. The people here are very good and patient' (Patient X). Some patients (five), on the other hand, felt their therapists lacked understanding of their specific problems. The remaining seven people were either not sure if their therapist understood them or did not express a definite opinion.

Several patients highlighted a lack of continuity in the therapist treating them and how this affected understanding of their problems: 'I wouldn't think so, maybe perhaps. It was a different one each time I'd gone. I only got about quarter of an hour and it wasn't always the same exercises' (Patient J).

Patients hoped for some improvement in their condition, or maintenance of their abilities, although some felt there was little that therapy could realistically do for them.

A further five people hoped for equipment to help them: 'I got a seat for in the shower and a few other things' (Patient I). Patient CC valued the equipment her occupational therapist provided, but she appreciated 'Company most of all'.

Seventeen participants thought that therapy was beneficial: 'Yes. It hasn't helped my balance, but it keeps me going and it keeps me moving. I do enjoy going to therapy' (Patient BB). One patient (X) appreciated therapy because he felt 'something was being done. I enjoy her company [the physiotherapist]. She's a most interesting person.... I quite enjoyed going and it definitely helped me to relax' (Patient D). Patient X, while believing that therapy was beneficial, found it tiring: 'When I finish I have the self-satisfaction that I've done something to help myself. It's tiring. It's not enjoyable but it's bearable.'

Overview of patient interviews

1 Patients had few difficulties in attempting to define quality of life.
2 Descriptions of quality of life related closely to physical disability and severity of PD (as indicated by Hoehn and Yahr scores).
3 One patient's global description of quality of life well summarized many interviewees' viewpoint: 'It's how you get about; how you enjoy life, being able to do what I did before, being independent.'
4 The four most consistently mentioned aspects of quality of life by all patients were: family; social life; getting out and about; not being a burden. Important to note is that the less disabled did not want to become a burden and valued their independence, while the more severally disabled regretted being dependent and more than anything wished for independence.
5 Effective medication was seen as contributing to people's quality of life. Many participants were anxious therefore that it might cease to be effective or that they would have to take increasingly stronger doses.

6 In terms of evaluating quality of life, 27 patients were able to judge the worth of their quality of life: 13 said that they had a good quality of life; five regarded it was moderate; and nine rated it as poor.
7 The main problem of PD mentioned in the context of quality of life was tremor, which often caused much embarrassment, as well as frustration.
8 Difficulties with activities of daily living most commonly centred around dressing, but slowness was repeatedly mentioned in interviews. Problems with personal care and tasks requiring precision were often described.
9 The impact of the disease on the carer's quality of life emerged during interviews.
10 Patients without family or relatives living nearby appeared to be the most distressed and lonely and often reported that they received little by way of care from social agencies.
11 The social aspect of therapy and the supportive role of the therapist was important to patients, who often said they enjoyed therapy.
12 Seventeen patients considered that they benefited from therapy and seven thought that they did not. Very few interviewed made reference to quality-of-life issues when discussing the benefits of therapy.

Therapist characteristics

All 22 therapists approached were willing to be interviewed and expressed interest in the project. Ten were occupational therapists, nine physiotherapists and three speech and language therapists. They worked in a range of settings, including private practice (one physiotherapist), hospital (day and general) and the community (see Table 5.7). Therapists' experience covered a broad spectrum, and they had qualified between 1960 and 1993 (mean 13.7 years). When asked to self-rate the extent of their experience with patients with PD, six felt they had extensive experience, with the remainder equally divided between moderate or limited experience. Twenty-one were women.

All of the 22 therapists interviewed had treated at least one of the patients included in our study. However, two therapists had seen two patients each, three others had seen three patients and one had seen four patients. A physiotherapist had treated one patient who was also receiving occupational therapy (see Table 5.7). Only a few therapists had difficulty recalling a patient. Interviews were held in the work setting and lasted approximately 45 minutes, but where a therapist had treated more than one patient they lasted longer.

Table 5.7. Therapist characteristics

Therapist	*Patients treated*	*Therapy*	*Designation*	*Year of qualification*	*Experience*
1	Patient D	Physiotherapy	Private practice	1984	Limited
2	Patient C	Physiotherapy	General hospital	1977	Extensive
3	Patients A, N	Speech	General hospital	1981	Extensive
4	Patient B	Speech	Community	1963	Limited
5	Patient G	Occupational	Community	1978	Limited
6	Patient I	Occupational	Community	1973	Moderate
7	Patients K, R, S	Physiotherapy	Day hospital	1990	Extensive
8	Patient F	Physiotherapy	Community	1982	Moderate
9	Patient L	Physiotherapy	Day hospital	1987	Limited
10	Patient E	Occupational	Community	1971	Moderate
11	Patient P	Physiotherapy	Day hospital	1983	Limited
12	Patient M	Physiotherapy	General hospital	1990	Limited
13	Patient Q	Speech	Community	1970	Limited
14	Patients O, CC	Occupational	Community	1989	Limited
15	Patient T	Occupational	Day hospital	1989	Moderate
16	Patient R	Occupational (and physiotherapy)	Day hospital	1990	Moderate
17	Patients X, Y, Z, AA	Physiotherapy	Day hospital	1960	Extensive
18	Patients U, V, W	Occupational	Day hospital	1979	Extensive
19	Patient DD	Occupational	Community	1986	Moderate
20	Patient H	Occupational	Day hospital	1993	Moderate
21	Patient J	Occupational	Day hospital	1991	Moderate
22	Patient BB	Physiotherapy	Day hospital	1989	Extensive

Use of quality-of-life measures

Despite the fact that only two therapists had used quality-of-life measures, all were familiar with, had used, or were using functional measures of some kind, ranging from simple in-house checklists of activities of daily living to standardized measures such as the Functional Independence Measure and the Barthel index.

Therapists' views of patients' quality of life

When asked if they consider quality-of-life issues when assessing or treating patients, ten therapists indicated that they were: 'I think we try and look at the effect on a person's life not just what the problem is. We look at their lifestyle and try to see how things (therapy wise) will fit in. I do anyway and I'm sure others do too' (No. 2); 'For some, improved quality of life is the ultimate goal; for others, improvement in physical outcome is more important' (No. 9).

Other therapists drew attention to the approach of their profession: 'The OT assessment is a holistic approach. We look at all aspects of a person's life.'

The remaining 12 therapists were less definite regarding consideration of quality-of-life issues. All said it probably was taken into account, but not formally: 'I don't know if we consider it under that title, if you see what I mean, and yet any sort of assessment of people's communication with their fellow man is bound to touch on quality of life isn't it? ... I think when you're dealing with communication, you do have to be knowing about what makes a person tick, and how he ticks. I often say to people, it's not like I can just sit here and peel the corn off your toe and say goodbye without knowing what's inside you. When I'm working on how you're communicating, there's got to be a bit of you in it' (No. 4).

Four therapists felt unable to describe their patients' quality of life because they felt it was a concept which was difficult to define. Therapists who offered an opinion did so by evaluating their patients' quality of life, while others listed activities patients could achieve and referred to dependency levels. In terms of evaluating patients' quality of life, therapists identified nine patients who had a good quality of life and six who had a poor quality of life. Therapist 7 thought Patient R's quality of life was 'Quite poor. He's having problems at home with his marriage. He feels very trapped in his own body and feels he's a huge burden on his wife.... He's had it [PD] for so long. Thirteen years progressively getting worse, so I would say in the last two or three years, he would say his quality of life has gone down.'

Many therapists identified aspects of activities of daily living as being patients' main problems in the context of quality of life: 'The main areas are functional problems he's having in the house. In the kitchen, opening tins, preparing vegetables, that sort of thing. He was having problems with transfers, on and off the toilet. He was given a toilet seat ... and something to help him get in and out of the bath, a high chair and dressing aids' (No. 14).

Therapists' awareness of psychological aspects

Many therapists were well aware that PD has psychological as well as physical dimensions, and that these affect quality of life. Therapist 1 felt it important to know about a person's emotional reaction to the disease in order for therapy to be more effective. Some therapists thought that embarrassment could be a major feature of the disease.

Therapist 5, an occupational therapist, believed that a significant part of her role was responding to psychological aspects of the disease and helping people to feel confident in themselves: 'I always feel with people, even if you can't help them physically, if you can help them come to terms with it, that often in a way is an improvement in itself and you can't only work on the physical side. One has to work on the mental aspect.... Counselling is a very important aspect and I think OTs can handle that more than physios actually.'

Therapist 18 thought that sometimes having a family who were willing to do too much could have a detrimental effect on a person. Therapist 7 said how important it was to Patient R's quality of life to be as independent as possible.

A few therapists thought that help from health professionals could sometimes make a patient *more* dependent. Therapists 5 and 18, both occupational therapists, thought this could sometimes happen: 'OT isn't about organising everything for a person, it is about encouraging them to organise things for themselves. And I think this is so important. Particularly with the home helps. There's plenty of people who I think could manage with such a small amount of home help but once, you've put in that home help, the person really quickly becomes reliant on them.'

Therapist 3 felt that speech difficulties hindered Patient A's social interactions: 'If his communication was more consistent, I have no doubt that would make him feel more happy and confident about himself in social situations.' Similarly, another speech and language therapist (No. 4) was concerned that if Patient B experienced a 'deterioration of his condition and probably, particularly, his speech, [then this would detract from his quality of life] if it were to become worse; because as I say, he's very sociable. He needs that.... He also worries about other people's reaction to his speech.' Indeed, several therapists said that a patient's social life had been affected by PD.

Therapist 19 pointed out the Patient DD's social life was of prime concern: 'He doesn't have much in the way of family so his social life is very important to him.... He is determined to get out and about despite his arthritis.... Getting out and about and seeing people, his networking and keeping up with the local gossip.'

Therapists' understanding of problems associated with PD

When asked if they understood their patients' problems, therapists gave a number of responses. Some said that all patients were different and that they should be treated as individuals. Others said that while they could never fully understand another person's problems, they could perhaps empathize or sympathize. Therapist 18 did not think PD was any more difficult to understand than other conditions.

Therapists 22 and 12 thought it may be easier to understand patients' problems through seeing them in their own environment: 'I think it's difficult to understand totally. I think we see patients through a medical model rather than a social model and therefore don't see the whole picture.... I'd like to think I have an idea of the problems, but I doubt if I understand the true complexity of them. It's difficult when you see someone in a ward setting or day hospital. It would be different if we saw people in their own environment. I think that's where an OT has a slight advantage, in that they see people in their own homes' (No. 22).

Some therapists thought that experience of working with people with PD helped in understanding their problems: 'I think over the years you learn to understand. You can't put yourself in their place, but I think you have to understand their problems if you're going to help them. I think that one of the biggest problems with PD is the lack of understanding of the disease, although I do think this is improving, especially when clinics like our own are set up. I do think it's a problem for GPs who may only see one or two cases a year. They don't have the experience and they're maybe not referred to the neurologist as soon as they should be, as many of the earlier symptoms are similar to these of old age. So they are not diagnosed as quick as they might be' (No. 17).

Therapist 4 thought that being ill herself perhaps gave her a better insight than somebody who had not experienced ill health: 'I have a chronic illness myself. I feel that I'm a little better at understanding chronic illness having it myself. But I think it's terrible if a therapist has to be old and ill before they can understand.'

Therapists' understanding of patients' expectations of therapy

Several therapists thought that the social element of seeing a therapist or attending therapy was some patients' objective. Therapist 17 also said one of the most important aspects of therapy for many is 'The fact that someone is taking an interest in them and you have a link'. The chance of maintaining independence was also regarded as a common objective of patients.

Most therapists thought that patients were expecting some improvement. A few occupational therapists thought that some patients did not know what to expect of therapy: Therapist 19 remarked, 'I find most people don't know what we do, what's available, and how we can help them.' Therapist 7, a physiotherapist, said: 'I always ask what the patient wants to achieve and I try and make my goals what they want to achieve if they are realistic. If they're not realistic, we try and modify what they would like. One of my questions is always, what do you want me to do for you, what would you like physiotherapy to offer?'

Medication

Medication for PD, and medical care generally, was mentioned by therapists during the interviews. Some expressed frustration at the limitations of medication, and the fact that much of what they did was dependent on the patient's drug regimen. Therapist 2 referred to this: 'As a lot of PD symptoms are controlled by drugs, I find it frustrating, in that most changes in the patient are the result of the drug regimen and very little is the result of physio input. As therapists see the problems, they may outline these to the prescriber, but it can be as much as three months before any changes to medication are made. It can take many months sometimes before the drug regimen is adequate.'

Outcomes of therapy

When asked if they saw any benefit in their patients after therapy, therapists thought this to be the case with 14 patients, thought it not to be so with eight, and were non-committal with regard to the remaining eight patients. Many therapists believed that therapy helped patients to gain more independence. However, therapy was not always seen as beneficial: 'I think in a way she probably thought she knew better than I did and she was just going to do what she wanted to do. I don't think she feels she gained much from coming to see me' (No. 2).

Some therapists saw benefits as more related to the provision of information on the service and future use, rather than 'hands on' work. Therapist 19, referring to Patient DD, remarked: 'I think in his case, because he was managing quite well and did not need much OT intervention, my visits served more as a foot in the door and an introduction for him as to ways in which we could help him in the future if the need arises. It was also a way of discussing any other problems. He knows now what we can offer him and that he only needs to telephone if he wants further help.'

Many therapists emphasized the importance of patients having access to information on PD, and some saw it an important aspect of their role. The PDS was mentioned specifically as a useful source of information for patients.

Many therapists spoke of the fact that patients enjoyed therapy and that the opportunity for social interaction and enjoyment was of major benefit.

Day hospitals

Several therapists regarded attendance at a day hospital as a vital social link for many patients. On the other hand, day hospitals were not seen as appropriate for all patients. Therapist 17 thought that although Patient AA was not benefiting from attending day hospital in a physical sense, he was gaining psychologically.

Overview of therapist interviews

1. While some therapists were concerned about quality-of-life issues, most appeared to consider the physical aspects of a patient's disease as their priority.
2. Many therapists thought there should be someone to take responsibility for quality-of-life concerns (emotional, psychological and social) but the majority did not consider that it was their responsibility.
3. Most therapists (15/22) were unfamiliar with specific quality-of-life measures. Very few had used them previously (2/22) and none were currently in use.
4. Despite lack of familiarity with quality-of-life measures, most therapists (14/22) thought that it would be useful to have access to this type of information on patients.
5. Therapists with longer experience of treating PD (or exceptionally a special interest in the condition) appeared better informed and more interested in all aspects of a patient's life than those with little experience or interest.
6. Tremor as the main problem for patients was mentioned during only eight therapist interviews (four with occupational therapists, two with physiotherapists, and two with speech and language therapists).
7. Therapists thought that improved function and independence or practical considerations such as rehousing or equipment would improve quality of life for patients.
8. It appeared that the quality of the relationship with a patient and duration of the therapeutic relationship affected therapists' awareness of quality-of-life issues for a patient (greater awareness was associated with more positive feelings and a prolonged period of contact).
9. While therapists said that they considered quality of life on an informal basis, nine seemed unaware of some aspects of patients' lives which crucially affected their quality of life. Twenty-one, however, were aware of a patient's home circumstances. In general, occupational therapists seemed more aware of quality-of-life issues than physiotherapists.

Overview: congruence between patients and therapists

1. Overall, there was agreement between patients and therapists regarding how patients evaluated their quality of life.

2 In half of all cases, therapists identified accurately key aspects of the patient's quality of life. Of the 14 therapist interviews where there was incongruence regarding essentials of quality of life, nine were with occupational therapists, and five with physiotherapists.
3 More therapists disagreed with patients with regard to what would improve their quality of life than agreed. Therapists generally referred to functional factors and improving independence on a practical level. Patients, while citing these aspects, either more often emphasized social aspects of their lives, or else were content with their situation and did not identify anything which would improve their quality of life.
4 In general, therapists suggested improvements to their patients' quality of life which were achievable, whereas some patients had unrealistic expectations, such as wanting a cure for PD.
5 Patients and therapists agreed that any deterioration in physical condition would be the main factor adversely affecting quality of life.
6 Most patients felt their therapists understood their problems, whereas most therapists felt they could never fully understand, although they could empathize. The majority of therapists agreed on the main problems associated with PD for the patient. Lack of concordance was evident in six cases, in five of which patients referred to tremor as a major problem, whereas this was not mentioned by therapists. Indeed, tremor was referred to by half of all the study participants, but by only a quarter of the therapists. Pain was frequently referred to by therapists as detracting from patients' quality of life but was mentioned by only three patients during interviews (in two instances seen as unrelated to PD).
7 Most patients believed therapy was beneficial in treating PD, compared with approximately half the therapists. Therapists, however, thought their patients gained in some way from therapy, although much of this was of a psychological or social nature, and was not related to physical outcome. Psychological benefits did not appear to be rated as highly as functional outcome.
8 Regarding all aspects covered during the interviews, there was evidence of more congruence between patients and therapists than incongruence.

Discussion

The findings presented well demonstrate a close relationship between the two studies; our second investigation often amplifies issues raised the first. Six main themes emerged from our work:

1. participation and involvement in PD research;
2. professional and patient perspectives on PD;
3. the local and national picture regarding therapy provision;
4. the role of therapy and potential benefits;
5. educational needs (patients, general public and health care professionals);
6. the role of the PDS.

1. Participation and involvement in PD research

Throughout both studies we experienced widespread support, despite the apparently low proportion of replies to our membership questionnaire (62%). As noted earlier, however, the response rate we regard as an underestimation because of difficulties regarding the membership list. Nevertheless, people with PD who did respond often provided much additional comment and some spontaneously volunteered to help us further. Moreover, all the people with PD approached in our second study agreed to participate in the interviews and they were unstinting in the time they made available to us. It should also be noted that, especially in our quality-of-life project (as reflected in the quotations given), people with PD were willing to discuss with us not only their physical problems but also details of emotional difficulties and intimate relationships.

Similarly, we were impressed by the considerable commitment shown by health professionals in completing questionnaires and participating in interviews. In particular, the high rate of participation of therapists is perhaps indicative of their interest in the treatment of patients with PD.

2. Perspectives on PD

There were no major differences in perceptions either between health professionals or between therapists and people with PD regarding a number of disease-related factors. Patients and those treating them identified similar physical difficulties as well as functional problems. However, generally, those with PD approached the concept of quality of life in a different manner to their therapists. Clearly, the concept was meaningful to people with PD, and very few interviewees had difficulty with definition. In fact, those who found quality of life easiest to describe were the most disabled, perhaps reflecting that awareness is heightened with loss.

Patients were able to bring together disparate elements of their lives – the physical, psychological and social – for the purpose of the definition. Their answers reflected their lives in their own homes, in which diverse elements are present and interact. This may be seen to contrast with the hospital, or therapeutic setting, where aspects of individuals' lives often are isolated before treatment begins. For example, therapists in this study tended to focus on the physical problems of patients and, indeed, often seemed to be uneasy regarding the concept of quality of life. Frequently they had greater difficulty than their patients in seeing its meaning and applying it to the clinical situation. Whereas patients' evaluation of their quality of life was reflective and sometimes profound, many therapists' responses were perfunctory. Therapists' definitions often included a reference to holistic care and seldom were they as comprehensive as those given by patients.

It is important to note that a crucial aspect of quality of life for patients was 'being able to do what I did before'. The use of standardized measures, therefore, may not be appropriate, as baseline data for each individual will be different. It is of interest to note that this crucial element, that is loss of former activities, in quality of life was highlighted by Calman over a decade ago (Calman, 1984).

Vogel has contended that PD is not socially acceptable, and the concomitant uncertainty causes problems, such as isolation (Vogel, 1992). Vogel concluded that the psychological aspects of the disease are worse than the physical and that patients feel alienated by society's lack of understanding of the condition. We found numerous instances in both studies where patients reported that they turned inward and avoided situations expected to be stressful. This avoidance of social situations was particularly poignant since patients wanted to be able to get out and about, and a change of scene was all important. This gradual withdrawal must be seen also within the context of people wanting to be part of the outside world and not wishing to wait for the world to come to them.

The studies highlight the importance of social interaction to the participants. Shindler *et al.* (1993), in their study of PD, found 40% of respondents felt lonely and experienced mobility problems outside the home, and that these represented areas where help was most needed. Lee *et al.* (1994), following the identification of the main social problems of PD as loss of social contact, recommended that advice be given to patients on lifestyle management as well as aids to help overcome disability and improve quality of life. Our study supports the need for such help, and indicates that patients could be encouraged to overcome fears and anxieties and need to be discouraged from retreating to their homes. Counselling may be needed to help manage feelings of embarrassment.

The vital contribution of family to interviewees' quality of life emerged from our second study and, in general, the greater the disability the more significant were family members. They were a source of psychological support, as well as providing practical help with everyday activities.

Those patients without family contact emerged as having the highest levels of distress. Indeed, the need for social support was revealed in both studies.

3. The local and national picture

In this chapter two Scottish studies have been reported but is it possible to generalize to other parts of the UK? First, it must be acknowledged that the response rate to our membership survey was lower than might have been hoped (38% of the questionnaires sent were not returned), and our second study was qualitative and involved a relatively small numbers of patients and therapists, although the people with PD were of different ages and social backgrounds. Secondly, from both projects a picture of variable service provision emerged. For example, specialist clinics were available in Dundee and Glasgow but not Aberdeen, and it was apparent from our questionnaire survey that individual experience varied considerably with, for example, variables such as the general practitioner's interest in PD and the length of waiting lists for occupational therapy. We have no reason to believe that this would not also be true of other parts of the UK and pre-existing research would support this.

Nearly half of the members with PD who completed the questionnaire had received therapy, which suggests that a higher proportion of people with the disease are receiving therapy than in previous decades. Nevertheless, caution is necessary in interpreting our findings since Oxtoby's study (Oxtoby, 1982) was carried out 15 years before our own, and Mutch's figures were based on presenting cases and not PDS members (Mutch *et al.*, 1986). It seems likely also that, as 63% of our respondents were home owners, they were more likely to be better informed and more confident in requesting services than other socio-economic groups.

Furthermore, our findings consistently demonstrate different rates of referral between medical practitioners, as have previous studies. Only 6.3% of therapists indicated neurologists as the main source of referral and, of our 15 consultant respondents, 13 were geriatricians and two neurologists. Notably, one consultant reported that patients were rarely referred for therapy.

Although the majority of general practitioner respondents were able to refer directly to all three therapies, few therapists identified general practitioners as a main source of referral and, in fact, they were described as 'poor referrers'. Yet 61.9% of member respondents stated that they would approach their general practitioner if therapy were required. Clearly, we need to understand better why consultants and general practitioners refer patients for therapy.

4. The role of therapy: what are the benefits?

The fact that approximately half of our survey respondents had not had therapy, and that we had difficulty recruiting to the second survey, needs to be considered in the light of respondents' reports of their difficulties. Therapists' and practitioners' replies indicate that referral to therapy is not automatic or standardized throughout Scotland, even when functional problems are apparent.

Differential patterns of referral to physiotherapy, occupational therapy and speech and language therapy were also evident, which, given the nature of problems described, might suggest under-referral, especially to occupational therapy and speech and language therapy.

Respondents in both studies voiced fears about medication dosage and its likely future effectiveness. Since worries detract from quality of life, it would seem important to consider likely strategies. Patients may need to be better informed regarding drug regimens and discussion is needed on who should assume this role – nurse, doctor or community pharmacist?

Both therapists and patients in the quality-of-life study commonly saw a major benefit of therapy in the social aspects of treatment. The role of therapy for people with PD needs to be further examined. Since social aspects are to the fore, and the effectiveness of treatment may be open to doubt, is referral to an occupational therapist, physiotherapist or speech and language therapist appropriate? Fundamentally, is there a need for a new role to emerge – part therapist, part counsellor, part psychologist – or does therapy education and training need to place greater emphasis on the psychological aspects of disability, advice and information giving, and patients' self-management strategies? At the same time, it needs to be established whether social needs currently met by attendance at day hospitals could be equally well fulfilled by attendance at day or social centres, or community leisure facilities. A crucial question is the extent to which specialized health-related education and training are essential, if patients' needs are primarily social. Volunteers may be able to fulfil a social support role, given that health professionals are likely to become an increasingly scarce resource.

Although therapists often referred to a holistic approach when interviewed, the main emphasis was placed on physical problems and how these could be overcome from a functional point of view. Nevertheless, solutions were not always found. For instance, difficulties regarding sleep remained and would highlight the need for further research in this area. Many therapists did, indeed, acknowledge the psychosocial aspects of PD, but often expressed the opinion that either this was not their responsibility, or there was insufficient time to address such issues. Some mentioned that perhaps a nurse could help, but there was little overall agreement as to who should focus on such problems. Some therapists expressed a degree of helplessness, and felt unable to tackle the loneliness and isolation of many severely disabled people. For instance, one therapist said the extent of patients' problems 'make you feel inadequate. There's a huge feeling of inadequacy as to how you deal with these things.' Moreover, there was seen to be limited clinical psychology and social services provision. Therapists tended, therefore, to refer back to the general practitioner the problems which they felt they could not address. However, research to date on general practice and chronic illness, and specifically PD, indicates that general practitioners themselves often lack specialist knowledge and have insufficient time to discuss psychosocial problems.

The therapy profession may need to review their own roles regarding the management of psychosocial problems and may conclude that their part should be to screen and make onward referral, for example to clinical psychology. On the other hand, if it is regarded as undesirable and difficult in practice to separate the emotional from the physical, then both undergraduate and continuing professional education may need to be reviewed so that skills are extended.

In broad terms, it may be valuable to consider, given smaller families, the increasing numbers of composite families and the current rates of geographical mobility, whether social support for people with chronic disability should be provided by health and social care organizations. The precedent has already been established through, for example, support provided for mothers of low-birthweight babies. A volunteer network, organized by the PDS and extending the support already given, could make a valuable contribution.

For some people, e-mail may be an acceptable substitute for face-to-face meetings, especially since increasing numbers of households have access to the World Wide Web. This would be an option for relatively few people, but it is of interest to note that the PDS is currently investigating how televisions may be used in this context.

5. Educational needs
(patients, general public and health care professionals)

A need continues to exist for information for patients. Surprisingly, in the quality-of-life interviews at least two people appeared to lack basic information regarding the disease. Our interviews also revealed that when placed in the 'patient' role, people are often reluctant to express opinions or preferences. People may therefore not only require help and advice, but also advocates if they are to be empowered. Our work indicates that patients should be more involved in decisions regarding therapy, and be better informed regarding the purpose of treatment regimens.

At the same time, the general public needs to be better educated and have a better understanding of PD. A particular objective should be to remove fears which the lay person may have, and increase awareness of the social consequences of their response. The general public may need guidance so that, for example, they are able to cope with a person's tremor. Health professionals need both to contribute to this and to be more aware of patients' concerns in this respect and explore coping strategies. But to do this they may need further education themselves, including regarding appropriate referral. In our first survey, for example, it appeared that early referral to therapy was rare.

6. The role of the PDS

Throughout our projects, the work of the PDS was highlighted by members, therapists and doctors alike, and a wide-ranging role for the Society was described. Many respondents highly commended the Society, although none of our questions invited them to comment specifically. It was evident from accounts provided that pioneering work had been carried out by the Society regarding therapy, for instance the setting up of specialist clinics. Our survey revealed that therapists had diverse formal and informal links with the Society. Talks were given at local branch meetings and PDS-sponsored study days were attended. Over a third (37.5%) of practitioners said that they received training for treating patients through courses organized by the PDS. In addition, both members and therapists highly valued information provided by the Society. However, only a minority of members and therapists thought that the PDS should be a provider of therapy services. Ninety-one per cent of therapy managers, nevertheless, believed that the PDS should provide information about access to services.

The possibility would appear to exist, therefore, for the Society to extend its role, for example in the ways indicated in the quality-of-life study. Local branches already provide regular outings for members, but it may be that people would appreciate also one-to-one regular trips and visits, to shopping centres for example, to maintain social contact. More generally, the Society could investigate how social support might best be provided, especially for people with few friends and family. Further research may be needed to investigate alternative ways in which this provision might be made. Indeed, a significant role of the Society to date has been to fund non-medical research, and our research would not have been possible without its support.

Conclusions

During our research over recent years, we have asked a wide range of questions regarding therapy and quality of life. Unfortunately, several remain unanswered and our work has highlighted the complexity of several issues. For example, what are the functions of therapy for people with PD? Our studies would suggest that they are more diverse than previously thought. In order to meet people's needs, a first objective must remain to obtain as clear a picture of them as possible, and then to examine a range of alternative means by which their needs may be met. We conclude that, above all else, people with PD have psychosocial needs that are currently insufficiently met, and this may be the major challenge for the next millennium.

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More than a sympathetic ear? A report on the first year of a writer in residence in a unit for young, physically disabled people

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Objective: To describe a writer in residence scheme and report the views of patients and staff.
Design: Qualitative study including interviews with patients, a questionnaire survey of staff, and dialogue with the writer.
Setting: A unit for young people with physical disability.
Subjects: A convenience sample of patients admitted to the unit and members of the multidisciplinary rehabilitation team.
Intervention: A writer in residence working 15 hours per week in the unit.
Results: A small number of patients worked regularly with the writer and this led to the publication of a play, short stories and poems. Patients described wide ranging benefits including improvements in mood state. Staff regarded the writer in residence scheme as enhancing their treatment and care and thought it helpful in addressing their own psychological needs. The writer saw herself as a catalyst 'for the creativity of others'.
Conclusion: Such schemes have an important role to play in rehabilitation settings.

Introduction

Social and psychological factors such as psychosocial readiness are known to influence the outcome of rehabilitation.[1,2] Creative writing, however, has not been extensively explored as a therapeutic tool in rehabilitation. In this article we describe the work of a writer in residence in a unit for young physically disabled people.

Narration and storytelling are well-established and universal means of acknowledging the commonality of experience and reducing distress.[3] Writing as a therapeutic tool has been used traditionally in psychiatry and psychotherapy to help foster insight and produce solutions to life problems,[4] and has been reported as reducing hallucinatory experiences and encouraging a more mature way of expressing primitive aggressive feelings in the treatment of schizophrenia.[5] During the 1980s in the USA writing was advocated by healthcare professionals, reflecting the significance which medical anthropologists and sociologists placed on the subjective experience of illness.[6,7] Kleinman saw the illness narrative (patients' ordered account of their illness and its

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meaning) as giving 'coherence to the distinctive events and long term course of suffering'.[8]

More recently, journal writing has been recommended in rehabilitation nursing to help patients and their families face challenges. In particular, it may help people with brain injuries to focus on their emotions related to personal changes.[9] Journals serving as a written account of feelings, thoughts, actions and abilities throughout the rehabilitation process may be valuable as an indicator of progress. Poetry, too, may reflect this as illustrated by the recent publication of a patient's poems describing her pain and its progression.[10]

In health care in Britain more attention, however, has been given to the visual arts rather than creative writing. The largest growth area has been art commissions, through for example the partnership of the Scottish Arts Council and British Health Care Arts Centre.[11] Artists in residency exist in a variety of healthcare settings and offer 'a potent example of the power of the arts to give expression, to provide identity and to assist healing'.[12]

Writers in residence, on the other hand, have worked in British universities, schools and libraries since the 1980s, and latterly in prisons. Few have been established in health settings, but a notable exception is the writer of residence appointed by the Isle of Wight Health Authority, who has worked with a range of patient groups including people with mental health problems and learning disabilities.[13] Age Concern has funded a writer in residence in Newcastle, and the Westminster Health Care has set up writing projects in six of its nursing homes.[14]

The social contribution of people with disability, moreover, has been emphasized in recent years. Members of the United Nations have been instructed to ensure that: 'persons with disabilities have the opportunity to utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of their community .... Examples of such activities are dance, music, literature, theatre, plastic arts, painting and sculpture.'[15]

Thus a significant development was the introduction of a writer to a unit for young physically disabled people, since to the best of our knowledge this was the first appointment of its kind.

The unit

The unit – the first purpose-built facility in Scotland – has 24 beds and rehabilitation is provided by a multidisciplinary team. At the time of the writer's appointment, medical staffing was represented by one part-time medical officer and three consultant sessions and nursing levels were maintained at 24 (WTE). A full-time social worker was based in the unit and therapy provided by specific departments (physiotherapy, 2.5 WTE; occupational therapy, 2.5 WTE and speech therapy, 0.6 WTE). An occupational therapy helper offered diversional activities. In addition, music therapy was available, and an art tutor was employed for one session a week.

During the 12 months prior to the study period, 94 patients were admitted to the unit on at least one occasion. Total length of stay was seldom less than two weeks, and for approximately a quarter of patients it was over two months. Patients' ages ranged from 21 to 64 years (mean age 47.5 years). Approximately half of all women admitted (22/41) were diagnosed as having multiple sclerosis and 13 of the 53 male patients had brain injury. Eighty-six patients were wheelchair users.

Writer in residence

The principles of the residency were described in the job description as 'enhancing the environment in which care is provided . . . by stimulating in an imaginative way the awareness and perceptions of staff, patients and visitors'. The writer was to work a 20-hour week (project-related work was to occupy approximately three-quarters of the time available but the writer would be free to pursue her own work in the remaining hours).

The writer, who was to be self-employed, was a prize-winning poet with several volumes of published poetry. As a trained social worker she had worked previously in a hospice for six years, as well as acting in a voluntary capacity as a writer in residence for four years at a high-security prison.

Method

Pilot evaluation

It is recommended that residency schemes should be evaluated by incorporating the viewpoints of the host organization, patients/residents and the artist.[16] We set out to achieve this by including patients, staff and the writer herself even though previous evaluations of artists in residence have excluded patients,[17] and the objectivity of the writer's account might be questioned.

Data collection

Patient interviews

The severe physical disabilities of some patients precluded the use of questionnaires, for example some patients could only express themselves with the help of either specialist electronic aids or a carer. Therefore we decided to interview patients, especially since they could be encouraged by the interviewer to be candid about the scheme.

All interviews were carried out by a nurse with extensive interviewing experience. Clinical knowledge of this patient group was regarded as essential since many of the patients had wide-ranging complex problems. Although the interviewer had previously held senior managerial responsibility for the unit she had not been based in it, nor had contact with the majority of the patients. Thus the possibility of bias was minimized.

The interview was based on 13 questions and was intended to be a maximum of 45 minutes long. As a memory prompt the writer's photograph was shown to patients with difficulties in recall. Because patients had been uncomfortable with audiotaping during a pilot study, the interview was recorded in written form. The slow pace of the interview enabled detailed notes to be taken, and indeed, often permitted comments to be reported verbatim. Following the interview notes were written up in full.

Only the 30 patients who had worked with the writer were considered for inclusion in the study, and all those who continued to attend the unit (18/30) were invited to participate.

Staff survey

The multidisciplinary team members' views were obtained via questionnaires. Thirty-two staff, including doctors, therapists (current and previous rotation) and nurses (day and night staff and nursing auxiliaries) were identified for inclusion. Only general questions on the questionnaire could be piloted since the writer in residence scheme was unique.

Writer's account

An interactive method of data collection developed between the writer (AT), RC and EM. Initially AT provided a written account of the background to the project, description of her work on the unit, and her journal. Specific questions were subsequently identified and formed the basis of discussion with the writer. Summaries of these meetings then were written up by AT and agreed between AT, RC and EM. As further issues emerged these were examined and the process repeated.

Data analysis

Patient interviews

Categories were derived for the more quantitative data, such as amount of contact with the writer, and themes developed for narrative comment. Categories and themes were then agreed by RC, EM and AT and a coding frame developed. All data were subsequently coded.

Questionnaires

Responses to all open-ended questions were read and the main themes identified. A coding frame was developed and data was coded prior to entry into SPSS-PC.

Writer's account

All factual information provided by the writer was validated where possible through a content analysis of relevant documents, such as from minutes of meetings, and patient records. Personal reflections of the writer were compared with the responses given by patients and staff and attempts at triangulation were made as appropriate.

Reporting

Data are presented with regard to the main issues identified regarding the residency, wherever possible including the views of patients, staff and the writer. However, concordance does not imply accuracy.

Findings

The respondents

Eleven of the 18 identified outpatients were interviewed as one patient had died, another declined to be interviewed, and four patients no longer attended the unit. In one further case deteriorating health precluded interviewing.

Patient characteristics reflected the overall pattern of admission to the unit (Table 1). The majority of patients had degenerative conditions which severely restricted their abilities to eat, talk and walk. Of the 11 patients interviewed (six men and five women), all had mobility problems, eight were wheelchair bound and three used a wheelchair occasionally. One patient had a sight impairment. Nine patients had received a basic general education (patients A, B, C, E, F, H, I, J and K) and two had proceeded to further and higher education.

Staff

Twenty-six of the 32 questionnaires distributed were returned, representing a 81.3% response rate. All professions who formed the multidisciplinary team for the unit were represented. Nonrespondents included night nurses and nursing auxiliaries.

Views of the residency

Above all else, four main issues emerged regarding the residency: (1) expectations of the scheme; (2) contact between the writer, staff and patients; (3) role and function of the writer; and (4) outcomes of the residency. These are considered below from the point of view of patients, staff and the writer.

Expectations of the scheme

When patients were asked if they knew who the writer in residence had been, eight were able to refer to her by name, and three had recognition on sight of the photograph. Interviewees then were asked their expectations of the scheme. Responses varied; four patients had not known what to expect, one hoped to gain 'just a friend' and four aspired to 'get things written' or 'published' (patients A and G).

Staff first heard of the project from a variety of sources including from colleagues, team brief, ward meetings and the writer herself. None of the respondents had previous knowledge of a writer in residence scheme. A team member informed us that staff 'were initially sceptical possibly slightly threatened – as to how and where she would fit into the proceedings'.

The writer reported that on her first day on the unit following a basic introduction she was taken to meet one patient 'and was then on her own'. Her journal entry for the day reads 'Arrived at [the unit] amidst gale force winds and rain to be met with . . . what? An absence of expectations.' An early difficulty encountered was making initial contact with patients as only one knew who she was, or anything about her role. She dis-

Table 1 Characteristics of interviewees

Patient	Age	Gender	Marital status	Diagnosis	Date of first contact with unit
A	54	M	M	Muscular dystrophy	1990
B	54	M	M	Brain injury	1983
C	28	M	S	Post-traumatic	1992
D	41	F	M	Paraplegia	1991
E	36	F	M	Multiple sclerosis	1983
F	49	F	M	Multiple sclerosis	1988
G	56	M	S	Cysts on spinal cord	1984
H	50	M	S	Multiple sclerosis	1991
I	35	F	S	Brain injury	1986
J	50	M	M	Multiple sclerosis	1984
K	45	F	M	Multiple sclerosis	1985

covered that careful planning was required to build relationships and that establishing trust and rapport took time.

Some weeks after the writer's arrival her journal reads 'There is now a feeling of being tolerated, everybody talking to me, and no more hurdles to jump. H shared his "ordinary life" with me, E. told me stories about his fish, and T. spoke of his dying.'

Contact between the writer, staff and patients

Four patients (A, B, C and K) reported little contact with the writer ('met her briefly but she was very busy and didn't get back to me' patient A) and five regular contact (patients C, E, F and G) ranging from 'half on hour per week' to more 'daily contact on a one-to-one basis'. Two patients indicated that they had had intensive contact 'we were very close – we worked a lot together' (patient I) and 'she spent a lot of time taking my notes then would type them up at home in her own time' (patient J). Similarly, the writer reported little contact with three patients (D, F and K), more contact with patients A, B, C and E and significant contact with patients G, H, I and J. Approximately half the patients thought that they had sufficient time with the writer whereas three (patients A, B and H) would like to have seen her more often or for longer periods of time.

Seven staff questionnaires were returned uncompleted, in six cases we were informed that this was because of lack of contact with the writer. Specifically one therapist wrote that she 'did not feel qualified to comment'.

Fifteen of the staff indicated that the writer spent 'about the right amount of time with patients' but three thought it to be 'too short' and no information was provided by one respondent. However, one staff member wrote '[she] was somewhat elusive and I was never sure when she was going to be around'. The social worker observed also that it is 'questionable whether it is money well spent employing somebody in this capacity when only a few patients are likely to be involved'. This was a view shared by two further team members who believed that only a minority of patients were likely to benefit.

The writer reported working with 30 patients (approximately one-third of all admissions) and felt that this was the maximum number given the allocated 15 hours per week. In the writer's opinion, moreover, it would never be possible to work with all patients in the unit. Some were unconscious on admission, others required intensive care, and for others their emotional state rendered writing unsuitable, although this might change over time. A further consideration was that contact could be difficult with day patients because of demands on their time. Indeed, two therapists cited a disadvantage of the residency to be that it could interfere with a patient's therapy. The slow pace of writing also limited the number of patients seen. The writer highlighted how at the start of a session preparatory activities, such as patient toileting and positioning were required, and that often it was necessary to 'pick up the threads' from the previous meeting. Indeed, the patients' disabilities often resulted in 'laborious progress' since thoughts had to be dictated to the writer for recording, and once read back they would often require further reworking.

Role and function of the writer

Only two of the patients interviewed had written previously – one had two unpublished novels and published research papers while the other had written poetry at school. Three patients, in fact, indicated a dislike for writing altogether, one said 'I'm not really into that sort of thing – I hate writing. Even when my friend died, I tried to write to his sister but I couldn't – it just sounded like rubbish'.

In order to learn patients' perceptions of the writer's role, comparison was made with team members such as physiotherapists, occupational therapists, nurses and doctors. Five patients thought that the writer's role was comparable but six identified differences, four for example highlighted the writer's personal approach: '[she] would always come and find me but the others were always involved and busy'; and another said 'her work was very caring, it amazed me that anyone wanted to spend so much time with me'. Two further patients saw differences because of the uniqueness of the role and one said 'The occupational therapist, physiotherapist and the nurses were the essentials, they really got my life back on track. [The writer] was part of the nonessentials – the icing on the cake!'

Although staff described the purpose of the residency in varying terms, over half described it as encouraging patients to be more creative and to express their feelings (Table 2). Other responses included: 'to encourage patients to think about their disabilities'; 'to provide an additional focus'; and 'to build up self-esteem'.

When staff were asked to delineate the writer's role from a list of 14 possible descriptors (friend, letter writer, resource person, poet, reader, author, counsellor, confidante, team member, teacher, advocate, therapist, journalist and carer), she was most commonly seen as a friend; letter writer; resource person; and poet. Indeed, all 19 respondents identified the writer as 'a friend' but less than one-third (6/19) saw her as a carer. Several team members saw the writer as helping patients to re-establish their self-worth and be a person rather than a patient. A therapist described the writer's role as 'allowing patients to express themselves as an individual. Discovering hidden abilities, creativities. Some individual time to discuss/express themselves, not necessarily concentrating on their illness.'

Several staff intimated throughout the questionnaire that the writer's work with staff needed to be acknowledged, together with her efforts on behalf of patients. 'Although not contributing on a formal basis at ward meetings etc. she assisted by acting as an advocate on the patient's behalf.' 'The writer became a valued and respected member of the team with her particular and distinctive role for patients and staff recognized and appreciated.'

An initial priority for the writer was to establish the role in the unit, although this was seen as more about 'clarifying what it was not (chaplain, student, social worker) than what it was, namely writer'. For all patients the process of writing was described as being 'self-determining and catalytic'. Depending on the patient's wishes, work could be on something for the patient, for the family, or for wider publication representing anything which might be written or spoken, ranging from a few words to a book. Strategies were developed for patients who were reluctant to start writing and this often involved 'just talking, and sharing anecdotes'. For some these gradually became 'stories' which could be written down. The writer regarded no two situations as being the same. A few patients, for example, were able to use the voice-activated tape recorders gifted by Craiginches Prison, but the majority preferred to work with the writer. Poor concentration (caused in some cases by the disease process, in others by head injury or medication) created the need for the writer to pick up the threads of a story, or to sustain the focus.

While the writer anticipated difficulties with staff, in the event she discovered that most were unfounded, once communication and trust had been established. The writer over time regarded herself as a team member and attended team meetings and nursing 'hand overs'. At the instigation of staff she led a workshop on loss and change.

Previous work in a hospice in the writer's view was valuable in working with patients since 'dealing with unfinished business was a key area of work, as was the definition of self, which was to be left for the world'. Although the role required listening to patients, the writer saw herself as a facilitator rather than a sympathetic ear. In order to facilitate writing, she had first to assess the suitability of the activity for the patient, and then interact in a way which would 'move people on' to expressing their thoughts in 'an authentic way, avoiding trivialisation', and aiming for a 'quality product'. Throughout the writer attempted to focus patients' ideas, leading to the completion of a specific piece of work, which she might help to reach a wider audience through publication.

Table 2 Unit staff's view of the impact on patients (n = 18)[a]

Dimension	Had impact	Not had impact	Don't know
Psychological	18 (100%)	–	–
Social	18 (100%)	–	–
Emotional/spiritual	17 (94.4%)	–	1 (5.6%)
Physical	5 (27.8%)	10 (55.5%)	3 (16.7%)

[a] One case of no information.

Patient and writer were, therefore, likely to become close in producing something together.

While some patients never developed the confidence to see themselves as story tellers the writer believed others came to enjoy seeing their words take on an importance not previously experienced. For example, the writer reported that one patient spoke, with great difficulty, of her feelings about her home. When, with her permission, they were written down verbatim, and read back 'she declared with real joy', that this was the 'first poem she had ever written'. Another patient, who was dyslexic as well as physically disabled, was able to 'write' his life story and as he said, was able for the first time 'to put the record straight'.

Outcomes of the residency

All 11 patients felt that they had benefited from working with the writer, and nine referred to psychological outcomes. 'I take moods but I didn't have any when I was with (the writer) – she made me more placid' (patient B); 'I felt more confident and relaxed because she was so interested in what I was saying. You can tell when someone is really listening; she was like a tape recorder, (patient F). Two also referred to heightened self-esteem: 'She acted as if she thought I was interesting' (patient E).

A further seven stated tangible benefits (3) and feelings of achievement (4): 'She helped me join the library' (patient C) and 'She gave me a voice activated tape recorder' (patient G); 'I felt I was doing something important – MS sufferers don't often get the chance to write down what happened to them' (patient J); 'Books of my poetry were published' (patient I); and 'I was interviewed by Channel 4 and had my picture in the paper with A' (patient H).

Social benefits were identified explicitly by two interviewees and one said 'I got friendship and company'; 'She had quite an impact on me – I gained a friend' (patient B). Nine patients reported that they enjoyed the sessions.

The majority of patients (seven) identified long-term gains, for example patient H reported: 'I became computer literate' while another patient believed 'I learnt contentment and it stayed with me – I think other people noticed a difference too'.

All staff thought that the writer had had a psychological and social impact on patients and 17 saw her as influencing patients' spiritual well-being (Table 2) as reflected in the following comments from staff: 'Patients appeared happier, more integrated and relaxed'; 'Most of the patients need something or someone to help get rid of bad feelings and help to put things down on paper'. A member of the team who was not a health professional and therefore believed that she was 'Not informed enough to comment on (impact on physical well-being)', reported that she 'definitely noticed improvement in [the] psychological state, social interaction and emotional well-being of people working with the writer. Self-esteem and confidence as well as personal growth were clearly evident'. Several staff referred to the improvement in one particular patient's circumstances: 'In one instance it is fair to say that [the writer] brought this person back from the brink of a downward spiral and was instrumental in giving . . . a reason to live . . . through creative writing and poetry this patient was able to express [thoughts] and gleaned comfort and praise from having work published.'

The writer's work with patients led to a play, short stories, autobiographies and poems (see Appendices 1 and 3). However, it was considered that for some patients there was no need to write as the act of oral story telling was sufficient in itself, by virtue of the fact that through the process of articulation they were able to rediscover a sense of their own value.

The writer over the year had increased contact with the therapists and an Arts Group, including the ward sister, music therapist and art tutor was established. The writer also developed links with a local occupational therapy centre and an education college and was successful in kindling local interest in the project and a television company made a programme on the residency. Contrary to the writer's expectation patients were very willing to participate and enjoyed the attention and flurry of activity. In the long run the writer was able to maintain her creativity (Appendix 2).

All 11 patients thought that the project should continue. Indeed, one said 'these projects should be actively encouraged and made compulsory. The embarrassment of doing these things should be trained out of us' (patient H). Three, however, gave conditional answers, including one person who expressed a preference to have meetings at home.

Finally, patients were asked what they would tell other people about the scheme. Only one had difficulty in formulating a response; six referred to the writing aspect of the project, 'If you don't give it a try and forget about the stigma attached to this kind of arty thing then you'll never know, so try it' (patient H) and four emphasized the writer's own approach: 'It doesn't matter if you don't do any writing – go ahead' (patient B).

Over two-thirds of staff who completed questionnaires (13) considered that there were advantages in having a writer in residence in the unit. Twelve respondents felt positively about the writer, five of them, in fact, expressed very positive views and failed to identify any disadvantages. Several staff believed that their own therapeutic input was enhanced by the writer's work:

> Clients often spoke about what they were working on and this offered new areas to communicate with patients.
>
> Information gained was often a useful vehicle in order to form therapeutic relationships i.e. discuss the diary the patient is currently keeping about their life history etc. [It] enables us to get a full perspective of the individual rather than the patient.
>
> Extra therapy onto already existing therapies – to encourage patients to write/think about their lives and disabilities.

Nevertheless a common view was that staff, as well as patients, had gained from the residency: '[Staff benefited from] finding a place to express their own feelings about (the unit) and their work. Perhaps (a major gain was) in recognizing the importance of the psychological needs of staff and patients and how that may have been avoided in the past.'

One of they key elements of the residency for the writer was the evolution of patient empowerment. The writer thought patients' writing over time revealed a renewed interest in life. Concomitantly she saw them gaining in confidence and becoming more assertive. Through the process of writing patients were observed as redefining their identity and discovering a new sense of self-worth, which helped them to find their voice and begin to express themselves. Writing, the writer considered, became a focus around which other issues, like physical and emotional pain were easier to manage.

Discussion

Role of the writer

Our findings from patients, the multidisciplinary team and the writer herself indicate that the writing residency performed a unique function in the unit. As has been reported of artists in residence, the writer was not a supernumerary clinical staff member.[18] Indeed, the writer in being a catalyst for 'the creativity of others' performed a similar function to artists in residence. She enabled 'the release of long pent-up feelings' and thus on occasions was at 'the receiving end of a deluge of negative feelings'.[18] Above all else the writing residency offered the patient the opportunity to be an individual with his or her own distinctive experiences and emotions. It enabled anger to be expressed, often denied or discouraged within the discipline of a healthcare setting. It seemed also to help our study patients by making the person 'feel whole again, a human being with a story to tell'.[19] Interesting to note is that a writer within a hospice has described her job as 'to encourage people to write: to give sorrow words but also ordinary pain and pleasure – anything from grief to giggles. To give words to being ill or being well or just being'.[18]

Clinical application

Although the writer was not a clinician, writing may have a significant role within clinical practice, and this appears to be more widely rec-

Clinical messages

- Creative writing may help some patients to gain confidence, manage pain and redefine their identity.
- Staff can benefit from a writing residency since it may address psychological needs and offer alternative ways of working.

ognized within the USA than Britain. In America bibliotherapy has been used with adults and children,[20,21] and storytelling constitutes an extremely important but underrated mode of discourse in occupational therapy, which may facilitate collaborative goal setting.[22]

In recent years in the UK with an increasing emphasis on a patient/client-focused approach to health care, more attention has been paid to patients' views and accounts of treatment. It has been claimed in relation to the writing residency in the Isle of Wight that links were made between writing as an arts activity and healthcare aims.[19] In the context of writing within primary care it has been asserted that writing 'fuses value for money with values for living'.[23]

We found, nevertheless, that a relatively small numbers of patients may have benefited from the residency, albeit within the context of the writer's 15 hours per week. Can the cost therefore be justified? Outcome, however, needs to be considered also in terms of benefits to staff and rehabilitation services. Not only do such schemes offer potential opportunities for working with patients, they also may challenge prejudice and traditional approaches to care; the residency demonstrated alternative ways of working.

Literature and the education of healthcare professionals

British commentary on creative writing to date appears to have underestimated the significance for all staff, even though the relationship between literature and medicine has been recognized for some time. The role of the arts in health care in improving ethical awareness and communication has been highlighted and its relevance for medical education recognized over the years.[24–26] Coles argues that literature serves to remind 'how complex, ironic, ambiguous and fateful this life can be' and that the conceptual categories learned in psychiatry, in psychoanalysis, in social science seminars are not the only means by which one might view the world.[27] Recent research by the Nuffield Trust suggests that the arts may help medical students to develop a more compassionate understanding of individuals and medical schools have been urged to incorporate creative humanistic subjects, including literature, into the curriculum by the millennium. Other healthcare professionals are likely, therefore, as well to find merit in incorporating creative writing into undergraduate education and its role in continuing professional development has yet to be acknowledged.

Future developments

From the work reported here we believe that we have raised a number of issues which deserve future investigation. In particular, it would be valuable to know if writing is only appropriate for a small group of patients or if larger numbers could be involved given greater resources. We need also to have a better understanding of how a writer's presence may impact on patient care and clinical practice. If patients' emotions and psychological needs are more visible is it more likely that these will be acknowledged and care modified? Do the roles of staff need to be extended or should there be greater input by clinical psychologists? From this study alone it is not possible to assert that a writer in residence may have therapeutic benefit, although our work suggests that this was the case for a small number of patients. Thus we will await with interest the outcome of a current randomized controlled trial on the healing power of poetry in mental health.[28] However, our experience indicates that writer in residence schemes may offer a potentially valuable additional input for people with physical disabilities and may have an important place within NHS rehabilitation settings.

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Appendix 1

MOSHE RA'AMIME

My Jewish soldier,
about my age.

Walking along the beach,
me in the sea,
you in the sand,
I wonder how long
our footprints stayed on the beach?
Not too long, I think.
Yours would soon have been washed away.

Going to see 'Grease',
coming out
and making love on the beach,
then having a shower in my room
to wash the sand off ourselves.
I bet we ruined the towels!
The cleaner must have wondered
what we were up to,
but I guess she knew very well!

I'm sorry I never kept your address,
but I don't think you'd want to see me now,
in my position.

Keep your memories.
I miss you.

Karin

Appendix 2

WINGS

You sit,
folded in upon yourself
like an exotic butterfly
or a kimono-ed Empress,
holding your thoughts
like a secret treasure
to your breast.

Occasionally,
your eyes flash,
splashing the world
with blues and whites,
as if the silk of your wings
had momentarily
unfurled.

Then
I am reminded
of the Buddhists, who say
that the beat of a butterfly's wings
can be felt
around
the world.

And
I see the power
in your stillness,
as you hold
your secret knowledge,
until you need it
to fly free.

Alison

Appendix 3

THE SHARP END

Regaining consciousness, after a long period of giving a good impression of a 'Neighbours' character, does not happen as portrayed by Hollywood. You don't shake your head, rub your eyes and grab the nearest 40'' chest. It's a long process. Most people are so far gone that it is the loved ones who experience the most pain. It's an easy thing to say, having now survived, but their sympathy would have been better directed towards somebody who was aware of the sentiments. I had many dreams. Mainly they confused ambition with capability. One was that my children had been kidnapped and their legs transplanted onto horses. Another involved me joining a French steamer, as a volunteer, to have various afflictions given me by a strange doctor, who then cured me using previously untried surgical practices. My friend, Andy, joined me in another, repairing, using medical techniques, wet suits that had been damaged by the examiners.

There were many more, all fragmented, but they all seemed to revolve around the medical profession. As I have no recollection of that period, when those very people were my everyday contacts, it is either a massive coincidence or I remember more than I think I do. Remember or not, I have been told enough to know that I will never be able to repay the debt I owe.

I think I was transferred to Maidencraig when it was felt that they could repair me, if repairing was possible, and so it was there that the rest of my life began.

The person who I first remember is Judy, the Speech Therapist. She endured the time when I was at my most obnoxious and treated everyone to grunted Anglo Saxon phrases, as I had not regained the power of speech.

She provided me with a board, holding the letters of the alphabet, and I constructed sentences by selecting letters she systematically pointed out. I did this first by blinking, then by moving my head to the left or to the right. Judy was good, but others used to get brassed off after five or six letters and took to guessing what I proposed to spell. As a result, after spelling 'I want.....' the guesses resulted in my invading Poland, wanting bottles of whisky or involving the young, blue eyed, blonde nurse in some very deviant practices. I vehemently deny these charges (except perhaps the last one) but the people were kind and want to save me the effort involved but, after a while, I abandoned the board. Judy also has the dubious honour of being the only woman ever to give me flowers. In my previous macho life I would have regarded that as soppy, to use a word that can be used and understood, but now I am thrilled that a lady should go to the trouble.

Judy is unlikely to ask for my assistance but I will not refuse her anything.

All through the early months the nurses withstood my verbal onslaughts and gradually eased me back into the human race. They encouraged, cajoled and berated as was required, but we were winning.

Gareth

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Is this satisfaction survey satisfactory? Some points to consider in their planning and assessment

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Abstract

Measuring patient satisfaction is one of the commonest evaluation activities in the NHS. The main aim of the article is to highlight some of the most important aspects of planning, undertaking and critically appraising satisfaction surveys. Key areas considered include: survey aims; definition of concerns; nature of survey populations; methods; interpretation of results; and outcomes and implementation.

Is this satisfaction survey satisfactory? - Some points to consider in planning and assessment

Measuring 'patient satisfaction' is one of the commonest evaluation activities undertaken in the NHS. It is increasing in popularity,[1] especially in primary care, since *Working with Patients*[2] and the *Patients' Charter*[3] There have been 4,056 entries on Medline alone over the last five years, as well as many more local unpublished studies some of which have influenced the future purchasing of services.[4,5]

Satisfaction surveys are used for a number of very different purposes[6,7,8,9,10,11] and this creates confusion especially when attempts are made to compare surveys. There are no widely agreed protocols for good practice, or even common definitions of satisfaction. Satisfaction surveys are seen as an activity which everyone, from academic departments to voluntary organisations, can do without any special training.

There have been a number of useful review articles[5,8,12,13,14] and meetings discussing the problems of satisfaction surveys, but good practice is slow to be implemented. Once this is recognised, there is more chance of satisfaction surveys actually influencing good practice in commissioning and quality monitoring.

Key areas to consider

1. The aim and purpose of the survey.
2. A clear definition of what is being measured.
3. The population being studied (patients, potential users, staff, etc.).
4. Whether the method is suitable to meet the aim and whether patients are considered.
5. The presentation and interpretation of the results.
6. The outcomes from the survey and whether specific improvements are likely to follow.

Aims of the satisfaction study

The primary purpose of the study needs to be clear. This includes: the issues being studied; why these issues/questions have been chosen at this particular time; who chose them; and whether the cost of the study is justified. All of these aspects need to be addressed explicitly at the planning stages, and full details provided.

Common aims include:

Audit. When satisfaction surveys are part of an audit the source of the standards needs to be given and justified, if possible citing the literature. If the audit loop is to be closed there will need to be local ownership of standards and commitment to improving services. The information will therefore need to be sufficiently specific to encourage action.

Personal feedback and staff development. Researchers and managers need to be confident that staff are ready for negative feedback (which may be well outwith their comfort zones).[15] Providers therefore must be willing to discover 'bad news'. Thought needs to be given at the start of the study on how the information will be used and fed back to staff; and whether it will be confidential to individuals or staff groups. Its relation to 'Clinical Governance' may need to be clarified.[16]

Making external and internal comparisons. Increasingly surveys are being used to make comparisons between hospitals, trusts and GPs for benchmarking purposes. It is essential, therefore, that surveys are comparable in that populations share similar characteristics and service provision. The research instruments used also need to be comparable. Many providers will also wish to make comparisons over time. However, attention should be given to potential differences in patient populations over the years, as well as to changes in service organisation and delivery.

Improving services for patients. Patients or users should be involved in the identification of topics for surveys as well as determining priorities for investigation. Focus groups can be useful for promoting user involvement and ensuring surveys reflect patient concerns. The description of the study given to patients and carers should be honest and realistic. Expectations should not be raised if there is little chance of improvements being made.

Definitions of 'satisfaction'. "Satisfaction" is rarely defined in surveys, and there is evidence that patients do not judge health services in this way.[1] In a recent literature search of over 100 references to patient satisfaction,[17] only one author (in 1961) defined "satisfaction". The definition in that case was 'unqualified approval by the patient of the topic being scored'.[17] "For some, satisfaction means a minimum state of acceptability of services, for others near perfection".[18] Without a clear definition, patients are unlikely to make reliable distinctions between 'satisfied', 'very satisfied', and 'not satisfied' - let alone rate their 'satisfaction'[1] on a scale from one to ten! Checking at the piloting stage, and adding descriptions or information about what might be expected can increase the reliability of responses.[19] Staff may not always be aware of patients' understanding and criteria for satisfaction,[21,22] and focus groups at the piloting stage can help refine these.

The theoretical basis of satisfaction is so poorly developed[23] that content validity, specificity, sensitivity, criterion validity and a 'gold standard for satisfaction' often seem spurious.[8,12,24] 'The search for the holy grail of a standardised patient satisfaction questionnaire'[12] continues, and the feeling persists in some quarters that all problems will disappear when it is finally found. It should not be assumed that a validated questionnaire will be available or that it will be appropriate to local needs. Research has found that some aspects of satisfaction can be estimated more reliably than others e.g. items on respect for privacy, treatment with dignity and sensitivity to feelings are more reliable than questions concerning communication of information or involvement in care.[25]

Survey population. The population studied affects the survey design and results. A recent study found that satisfaction with the NHS had declined, but subsequent analysis found that 72% who had used hospital care were satisfied, compared with 56% who had not.[26] Current users may differ from previous patient populations as diagnostic techniques change and demographic trends emerge. Decisions need to be made regarding whether or not 'potential' patients or proxies be included. The characteristics of the survey population and any people excluded should be described in detail. The needs of children, or people with learning disability, for example, will differ and influence the methods of data collection. All too frequently in the past 'challenging populations' have been excluded, even though it is possible to learn their views, given sufficient effort.[27]

Methodology and/or appropriateness. The timing[12,28] and setting of surveys[4] need to be considered, as there is a trade off between immediate feedback, and the chance for patients to reflect on the whole course of an illness. The balance will vary between maternity patients, and frail elderly patients with poor life expectancy and memory. As a minimum, the setting and the interval between an intervention and a survey need to be clearly described.

Recruitment. Inclusion and exclusion criteria should be realistic, explicit and tested by piloting. Potential "effect modifiers",[29,30] such as age, should be identified at the study design stage by reviewing the literature.[29] Surveyors need to consider what effect the study may have on patients. Some patients are made anxious by the process of questionnaires and interviews, possibly fearing consequences for themselves or for staff; some find it difficult to understand what is required, even when the process is explained and demonstrated to them; and some view it as a test, asking whether they have given the right answer.[31,32] User fears should be acknowledged and sufficient information given to enable them to be clear regarding the purpose of the survey and their part therein.

Sampling. The use of samples needs to be justified and size determined as rigorously as in any other research. The numbers in the study require sufficient power to be able to distinguish between inter-patient variation in opinion and inter-staff variation in performance.[33] Especially when numbers are small and individuals are likely to be identified, staff need to be involved in the planning stages of the survey and informed early of the outcomes.

However, for some purposes it is not necessary to seek the views of all patients. It might be better to select a representative sample of those with a particular attribute, for example, concentrating on patients who have made complaints.[14]

Ideally, the protocol should list the criteria to be used for recruiting patients and should make a prior estimate of what sample size is required for detecting reliable differences in satisfaction, what satisfaction levels would be acceptable, how any deficiencies would be addressed,[8] and the threshold for taking remedial action. However literature on this is scarce.

Tailoring the survey. Precoded questionnaires are cheap and convenient for researchers, but present problems for those with severe difficulties with communication,[23] understanding and memory.[24] Piloting will confirm whether patients will be able to fill in questionnaires themselves. In one recent study, one third (50/150) of stroke patients were unable to complete questionnaires independently, and a further third preferred an assistant to help.[34] Carers are sometimes used as proxies, but this requires checking that their views reflect patients,[35] and that the costs to their time have been considered. The definition of who qualifies as a 'carer' should be agreed before the study starts. Questionnaires should include a section to indicate who has helped with completion.

Clear instructions need to be given on questionnaires about leaving answers blank if the respondent feels the choice of replies is unsuitable. Checking at the pilot stage can increase the reliability of responses.[19] Staff may not always be aware of patients understanding and criteria for satisfaction[20,21] and focus groups in the initial phase of the project can help refine these.[10,22]

Design affects results.[12,36] Bland questions tend to produce bland information:

- Difficulties with completing questions, or genuine ambivalence,[1] may be disguised if there are no precoded boxes for patients to state that they "did not know". Indeed some questionnaires have been deliberately designed to "force a response".[37]
- Basic questionnaire design should be checked thoroughly, avoiding statements/questions which are double barrelled,[38] for example, "I was treated with kindness and respect"[39] (patients may find the nurses very kind, but dislike being addressed by their first name).
- Positive (or negative) wording[24] can introduce bias.
- Some 'questionnaires' do not ask questions: patients are asked to agree or disagree with a number of statements.[40] More research is needed on whether statements produce different results from questions.
- Data entry and analysis should be as simple as possible, but over-simplification of questions may produce "lowest common denominator" data, and have little meaning, for example "I have had enough therapy".[37]

Non-questionnaire methods of determining satisfaction are often regarded as time-consuming, technically difficult and more expensive[7,17] because of the need for independent, well-trained interviewers. However, semi-structured interviewing, open-ended questions,[41] or space for written comments, come closer to most patients' everyday experience than ticking boxes. It has been found that patients are often more willing to give their opinions, if they are able to put this into context.[42] For example, describing a particular incident, rather than generalising about 'nurses' or other staff. It can be painful to hear what patients think of professional help, but it is important to hear what patients say on their own terms (before these views are homogenised into statistical correctness.)

Most of medical practice is based on the importance of the patient as an individual,[43,44] and satisfaction studies should reflect this, inviting patients to express their opinions in their own words. However, satisfaction surveys often encourage the patient to respond to his or her own health care on an individual basis without reference to the wider community of healthcare users, whereas patients are anxious to acknowledge the needs of others, or the effects of staff shortages, etc. Surveys may encourage patients to engage passively and superficially in their care, rather than to take a more participative approach to healthcare, which could genuinely challenge professional interests and priorities. Surveys do not usually acknowledge patients as partners and co-producers of their own health outcomes.[14]

Cost. Costs arise both in undertaking surveys, and in addressing any deficiencies which they uncover.[45] However, decisions between qualitative and quantitative methods should not be based on cost alone. Satisfaction questionnaires tend to be perceived as cheap, but may not represent value for money.

Costings of surveys should include:

- the costs of delivery (much cheaper if done while receiving care), travelling costs for interviews (more expensive than postal surveys, but response and completion rates often higher);
- time costs to carers if they have to help with completion;
- the overhead costs of setting up a study (including costs of accommodation, grant applications, backup services, and the salaries of senior researchers), piloting, developing and validating new questionnaires, recruiting patients, data entry and analysis;
- the time and travel costs of coordination if more than one centre is being studied.

Counting all costs can rapidly bring the bill for even small surveys up to five-figure sums,[46] plus the potential for much greater expense if areas of dis-satisfaction are to be addressed. This tends to increase the pressure to use off-the-shelf questionnaires, even if they do not fully meet the study's aims, and therefore are not good value for money.

Interpretation of findings

Findings should not be taken at face value and it is important to consider them in the light of the tools used. Problems may arise because 'a validated' questionnaire has been applied in a different situation. This may be important in national studies,[47,38] but less important in local studies. Local ownership of a less than perfect tool can be the key to achieving local commitment to change and improvement.

Confusion has arisen in the past between psychometric testing of biological attributes which remain relatively discrete and stable (for example IQ or Activity of Daily Living Indexes),[48] and the medley of different patient experiences during one visit to hospital. Patients' contact with health services has been compared to a 'story', during which patients experience moments of expectation, disappointment, frustration, hope, pessimism and relief.[14] Yet, patients are often asked to generalise about the whole of their experience of 'nurses' or 'doctors', across several wards and/or hospitals, and over weeks or even months. The difference between 'test-retest reliability' and 'sensitivity to change' in this situation is debatable! To establish validity, comparisons have been made with Barthel,[39] Nottingham Health Profile, Smiling Faces,[37,39] or other (unvalidated) tools, such as patients' casenotes! 'Validity and especially reliability are not intrinsic once and for all attributes',[49] and questionnaires should always be piloted before use in a new study.[36] Population norms are needed on pertinent domains[50] for satisfaction, as regional and cultural variations affect satisfaction.[24,51]

If the questionnaire results are summarised by a 'total satisfaction score', a score cannot be obtained if any items are incomplete.[37] Likert or numerical rating scores may produce different results,[52] and often five point scales are collapsed to three in the final analysis. Analysis and profiles for each of the questions or sections may be more informative:[23] for example, showing that patients were less satisfied with particular aspects of their hospital stay.

Response and attrition rates may provide some indication of the study's acceptability and should always be included in reports. Raw data should be given in tables rather than relying on percentages. As response rates to different questions may vary, denominators will not always be consistent. The source of information should be clear (patient or carer), with acknowledgement that this can be a major source of bias.

Statistical tests should be appropriate for the questions asked. Levels of significance should always be stated and 95% confidence intervals are particularly important when numbers are very small.

Findings should always be interpreted with caution. In a large American study, it was found that more than 90% of the variation in the number of problems patients experienced was accounted for by factors other than the measured patient and hospital characteristics.[53] Patients' opinions may reflect misconceptions about treatment[54] - simple completion of checklists may not reveal whether expectations are realistic, although expectations are integral to satisfaction. Patients' views also may not reflect changes which may have occurred in the organisation of care.[55]

Satisfaction surveys may sometimes be used for political purposes; for example, to justify changes in services. Baseline measurements of patients' satisfaction levels with existing services before changes might help ensure that patients are consulted before changing services, and might help to indicate areas of least satisfaction. For example meticulous methodology was used in recent studies about changes in delivery of primary care out of hours service. However, patients were asked mainly about their views on the re-organised service rather than how they would like out-of-hours services to be organised.[56]

Outcomes: impact and effectiveness. Measuring patient satisfaction can give us the comforting illusion that we are listening to patients.[14]

"There is no published evidence that the use of the results of satisfaction surveys has led to increased satisfaction",[37] and little research on how they have influenced service delivery. Surveys may provide little help in addressing policy questions, such as by how much waiting times should be reduced. All too often surveys ignore scarcity of resources. Satisfaction may be used as an outcome simply because other measures are difficulty to apply. Studies are needed to evaluate the effectiveness of satisfaction surveys, particularly on the quality and patient-focus of services; and also on the design of subsequent studies and services. There is a risk that high satisfaction levels may create complacency. To aid research on effectiveness, satisfaction studies should produce a prioritised, and costed, list of recommendations, which can be audited.[23]

Conclusion

Surveying patient satisfaction is a major creeping development which is proceeding with little critical evaluation . However, we are delighted to see that the Health Technology Assessment Bids in 1997 included 'measuring patient satisfaction' and we hope that this may lead to the setting up of guidelines on good practice, and a major database of satisfaction studies - similar to the Cochrane Collaboration. More could then be learned about satisfaction surveys, with rigorous scrutiny,[29] and perhaps even a grading system for quality, value for money, and effectiveness in achieving improved patient care, and greater satisfaction. The Cochrane Collaboration has had a major effect on randomised controlled trials. What we need now is a Satisfaction Collaboration! As far as we know, there has been no systematic attempt to discover how many providers respond to recommendations in satisfaction surveys.

We believe that consumers views *are* important, and that the main obstacle to obtaining them at present is that those who read, publish, fund and carry out satisfaction studies may not be consciously aware of many of the problems. It is only by carrying out some weak studies ourselves that we have come to recognise and reflect on how things could be done much better. Many of the problems discussed here have been highlighted repeatedly in books and journals on satisfaction surveys for the last twenty years.[5,8,12,13,14,18,57]

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87 Hird C. & Chesson R. (2000) *Evaluation of the GP Referral for Exercise Scheme at Moray Leisure Centre,* (Report to Moray Leisure Centre), pp 1-36.

88 Chesson R., Cobb G. & Finch L. (2000) *Student Health Needs Assessment.* (Report to Albyn Medical Practice), pp 1-36.

89 Chesson R., Maehle V. & Wardell F. (2000) *Helping to Manage Parkinson's Disease: the role of the carer.* (Executive Report), pp 1-12.

Conference Presentations 1996-2000

Oral

90 Kettle J.[*], Downie G., Chesson R., Palin A. *Pharmaceutical care activities within a multi-disciplinary mental health team.* Health Services Research and Pharmacy Practice Conference, Manchester. 1996.

91 Mathers S., McKenzie G.A., Graham D.T and Chesson R. *The role of radiographers performing barium enemas.* Radiology, International Convention Centre, Birmingham. 1996.

92 Mathers S., McKenzie G.A., Graham D.T. and Chesson R. *An investigation into the role of radiographer performing barium enemas.* Research symposium, Aberdeen Royal Hospitals NHS Trust. 1996.

93 Mathers S., McKenzie G.A., Graham D.T. and Chesson R. *Role development and the Radiographer.* Clinicians and Educators Research Forum, Aberdeen. 1996.

94 Chesson R. and Todd C. *Interdisciplinary working in a pre-school early development group for children with motor disorders.* 2nd World Congress on Allied Health, Telford. 1997.

95 Mathers S., Duncan K.A., McKenzie G.A., Graham D.T and Chesson R. *A method of establishing diagnostic accuracy of radiographer performed barium enemas,* Radiology, International Convention Centre, Birmingham. 1998.

96 Mathers S., McKenzie G. and Chesson R. *What do patients know about MRI?* European Congress on Radiology, Vienna. March 2000.

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[*] underlining denotes presenter

97 Wardell F. and Chesson R. *How can we help carers to care?* Partnership, participation and power, 2000 Annual Public Health Forum, Harrogate. March 2000.

98 Chesson R. *Avoiding the messy world of words : challenges in the use of drawings, pictures and photographs in qualitative research.* Sixth Annual Qualitative Health Research Conference, Banff, Alberta, Canada. April 2000.

99 Chesson R. *GP referral for exercise schemes at leisure centres and social exclusion.* Leisure Studies Association, Glasgow Caledonian University. July 2000.

100 Mathers S., McKenzie G.A., Chesson R. *What do first time attenders know about CT scanning on initial referral : a UK perspective.* Radiological Society of North America, 86th Scientific Meeting, Chicago, USA. November 2000.

Posters

101 McKenzie GA, Mathers S, Duncan K, Graham D T, Chesson R. *Radiographer performed barium enema examinations.* Aberdeen Royal Hospital Research, Medical School. 1997.

102 Mathers S, McKenzie G A, Graham D T, Chesson R. *Radiographer performed general diagnostic ultrasound.* British Medical Ultrasound Society, 29th Annual Scientific Meeting, Bournemouth International Centre, Bournemouth. 1997.

103 Chesson R, Romney-Alexander D, Maehle V. *Health related quality of life.* Parkinson's Disease Society Welfare Research Conference, London. 1997.

104 Mathers S, McKenzie G A, Graham D T and Chesson R. *Radiographer performed barium enemas : current UK practice - same or different to the US experience.* RSNA Conference, Chicago. 1998.

105 Chesson R, Wardell F. *Helping to manage Parkinson's disease : the role of the carer.* Parkinson Research conference, Coventry. 1998.

106 Chesson R and Wardell F. *Therapists' attitudes to carer participation in treatment.* Third European Parkinson's Disease Conference, Barcelona. 1998.

107 Chesson R, Chisholm D, Hart C, Jones J & Nicoll S. *Children's mental health needs.* NHS Science Day, Royal College of Physicians, Edinburgh. 1999.

108 Chesson R, Tavendale A. *Creative writing in a healthcare setting and relinquishing the patient role.* Culture, Health and the Arts, World Symposium, Manchester. 1999.

109 Tavendale A & Chesson R. *Karin's Story.* Culture, Health and the Arts, World Symposium, Manchester. 1999.

110 Mathers S A, McKenzie G A, Chesson R A, Graham D T. *Radiographer performed Barium Enemas: UK Practice and the Impact on Radiography Education.* XIth European-African Conference of the International Society of Radiographers and Radiological Technologists, Lisbon, Portugal. 1999.

111 Mathers S A, McKenzie G A & Chesson R A. *Radiographer Performed General Diagnostic Ultrasound: UK Practice and the Impact on Radiography Education.* United Kingdom Association of Sonographers (Scottish Meeting), Stirling. 1999.

112 Jones J, Hart C, Chisholm D, Malley S & Chesson R. *Clinical Evaluation of a language screening tool.* Grampian University Hospitals Trust Research Symposium, Aberdeen. 1999.

113 Cobb G & Chesson R. *Where is the information?* Partnership, participation and power, 2000 Annual Public Health Forum, Harrogate. 2000.

114 Chesson R & Milne A. *Partnership with adolescents in primary care.* Partnership, participation and power, 2000 Annual Public Health Forum, Harrogate. 2000.

115 Hird C & Chesson R. *What do we know about participants in GP referral schemes?* Partnership, participation and power, 2000. Annual Public Health Forum, Harrogate. 2000.

116 Upton C, Chesson R, Davidson R, Hamilton A. *Developing a tool for the early identification of movement, speech and swallowing problems in patients with Parkinson's disease.* Professional Symposium, Parkinson's Disease Society Conference, Liverpool. September 2000.

117 Mathers S, McKenzie G A, Chesson R. *Patient knowledge of ultrasound scanning.* Scottish NHS Research Day, 2000. Stirling. September 2000.

118 Mathers S, McKenzie G A, Chesson R. *Patient knowledge of three scanning techniques.* Royal College of Radiologists Annual Scientific Meeting, London. September 2000.

119 MacLeod M K, Thomson H A, Chesson R, Upton C, Scott R. *Seamless care in physiotherapy Does it exist at the Primary/Secondary care interface?* Chartered Society of Physiotherapists, Annual Congress, Birmingham. October 2000.

Invited Lectures 1999/2000

120 Chesson R. *Carers Research.* Open meeting Respite Care, Aberdeen. February 1999.

121 Chesson R. *Qualitative Research.* Glasgow University Hospital Trust, Glasgow. May 1999.

122 Chesson R. *Health research: manipulating concepts or numerical data?* European Symposium : Research on Conductive Education, Birmingham. June 1999.

123 Chesson R. *Collaborative Practice - what works?* Conference on promoting children and young people's mental health, Aberdeen. September 1999.

124 Chesson R. *Why and how to consult children about health needs.* Symposium on the Rights of the Child Within Medical Care. Royal College of Physicians and Surgeons, Glasgow. December 1999.

125 Chesson R. *Interagency working : Lessons to be learned.* Grampian/Highland Forum (Adolescents and Child Psychiatrists) Dr Gray's Hospital, Elgin. April 2000.

126 Chesson R. *Health research and social care: assumptions and implications.* Department of General Practice and Primary Care, University of Aberdeen. May 2000.

127 Chesson R. *Are your patients satisfied?* XIVth Edinburgh Anaesthesia Festival. Royal College of Surgeons. August 2000.

128 R Chesson. *Challenges to carers.* Professional Symposium, The Parkinson's Disease Society, Liverpool. September 2000.

129 R. Chesson. *Engaging adolescents in primary care.* Community Practitioners and Health Visitors Association Annual Professional Conference. Harrogate. October 2000.

130 R. Chesson. *Psychosocial aspects of caring.* Multiple Sclerosis Society Annual Conference. Birmingham. November 2000.

131 Chesson R & Gillibrand M. *Moray Leisure Centre's GP Referral Scheme.* UK National Seminar on GP exercise referral. Tamworth, Birmingham. November 2000.

Date and location of research included in Application

Paper 1

Chesson R., Stephenson E., & McKay C. (1990) Motor/learning difficulties and the family, *Child; care, health and development* 16**:** 123-138.

Location: Royal Aberdeen Children's Hospital, Aberdeen
Date: 1987-1989

Paper 2

Chesson R. & Sutherland A. (1992) General practice and the provision of information and services for physically disabled people aged 16 to 65 years. *British Journal of General Practice.* 42, 364, 473-476.

Location: Social Work Department, Grampian Regional Council, Aberdeen
Date: 1989/1990

Paper 3

Chesson R. & Sutherland A. (1993) Self reported disability in six electoral districts in Grampian. *Health Bulletin.* 51, (3), 141 - 150.

Location: Social Work Department, Grampian Regional Council, Aberdeen
Date: 1989/1990

Paper 4

Sutherland A. & Chesson R. (1994) The needs of physically disabled people aged 16-65 years and service usage. *British Journal of Occupational Therapy* 75 (5) 171-176.

Location: Social Work Department, Grampian Regional Council, Aberdeen
Date: 1989/1990

Paper 5

Chesson R., Massie, S. and McLeod, M. (1996) Outcome measures used in therapy departments in Scotland. *Physiotherapy* 82, 12, 673-679 .

Location: Woodend Hospital, Grampian Healthcare Trust
Date: 1993

Paper 6

Chesson, R., Harding, L., Hart, C. and O'Loughlin, V. (1997). Do parents and children have common perceptions of admission, treatment and outcome in a child psychiatric unit? *Clinical Child Psychology and Psychiatry* 2, 2, 251-270.

Location: Royal Aberdeen Children's Hospital, Aberdeen
Date: 1994/95

Paper 7

Joy D., Young A., Harvais V. & Chesson R. (1998) The use of photographs as a means of obtaining views of occupational therapy held by children with learning disabilities : a pilot study. *British Journal of Occupational Therapy* 61, 3, 116-120.

Location: Woodlands Hospital, Grampian Healthcare NHS Trust
Date: 1995

Paper 8

Hart C. & Chesson R. (1998) Children as consumers. *British Medical Journal,* 316, 1600-1603.

Location: The Robert Gordon University/Royal Aberdeen Children's Hospital
Date: 1997/1998

Paper 9

Chesson R., Cockhead D. & Romney-Alexander D. (1999) Quality of life with Parkinson's disease: Views of Scottish Consumers and Providers. In Percival R. & Hobson P. *Parkinson's Disease: Studies in Psychological and Social Care,* Leicester: British Psychological Society, 1999 pp 93-131.

Location: School of Health Sciences, The Robert Gordon University
Date: 1993-1997

Paper 10

Chesson R., Moir E. & Tavendale T. (1999) More than a sympathetic ear ? A report on the first year of a writer in residence in a unit for young, physically disabled people. *Clinical Rehabilitation* 13, 310-321.

Location: Maidencraig, Woodend Hospital, Grampian Healthcare NHS Trust
Date: 1995

Paper 11

Bisset A. F., Chesson R. (2000). Is this satisfaction survey satisfactory? - Some points to consider in planning and assessment. *Health Bulletin*, 1, 45-52.

Location: Grampian Health Board/The Robert Gordon University
Date: 1998

Statements by co-authors

Paper Title: Motor/learning difficulties and the family

Authors: Rosemary Chesson, Christina McKay and Elizabeth Stephenson

Journal: Child: care, health and development, 1990, **16**, 123-138

Contribution

	RC	CM	ES
Initiation	10	20	70
Data Collection	—	20	80
Writing Up	80	10	10
Overall Supervision of Project	80	10	10

I confirm that the contribution of authors as shown above accurately reflects the actual production of the above paper.

Name (please print) ELIZABETH A STEPHENSON .

Signature

Date 12/10/00.

Paper Title: Motor/learning difficulties and the family

Authors: Rosemary Chesson, Christina McKay and Elizabeth Stephenson

Journal: Child: care, health and development, 1990, 16, 123-138

Contribution

	RC	CM	ES
Initiation	10	20	70
Data Collection	—	20	80
Writing Up	80	10	10
Overall Supervision of Project	80	10	10

I confirm that the contribution of authors as shown above accurately reflects the actual production of the above paper.

Name (please print) CHRISTINA E. McKAY

Signature

Date 7 October 2008

Paper Title: General practice and the provision of information and services for physically disabled people aged 16 to 65 years

Authors: Rosemary Chesson and Anne Sutherland

Journal: British Journal of General Practice, November 1992

Contribution

	RC	AS	
Initiation	40	60	
Data Collection	40	60	
Writing Up	70	30	
Overall Supervision of Project	100	—	

I confirm that the contribution of authors as shown above accurately reflects the actual production of the above paper.

Name (please print) ANNE SUTHERLAND

Signature

Date 9-10-00

Paper Title: Self Reported Disability in Six Electoral Districts in Grampian

Authors: Rosemary Chesson and Anne Sutherland

Journal: Health Bulletin 51(3) May 1993

Contribution

	RC	AS	
Initiation	30	70	
Data Collection	40	60	
Writing Up	60	40	
Overall Supervision of Project	100	—	

I confirm that the contribution of authors as shown above accurately reflects the actual production of the above paper.

Name (please print) ANNE SUTHERLAND

Signature

Date 9-10-00

Paper Title: The Needs of Physically Disabled People Aged 16-65 Years and Service Usage in Grampian

Authors: Anne Sutherland and Rosemary Chesson

Journal: British Journal of Occupational Therapy, May 1994, 57(5)

Contribution

	RC	AS	
Initiation	30	70	
Data Collection	40	60	
Writing Up	60	40	
Overall Supervision of Project	—	—	

I confirm that the contribution of authors as shown above accurately reflects the actual production of the above paper.

Name (please print) ANNE SUTHERLAND

Signature

Date 9-10-00

Paper Title: Outcome Measures Used in Therapy Departments in Scotland

Authors: Rosemary Chesson, Margaret Macleod and Susan Massie

Journal: Physiotherapy, December 1996, vol 82, no 12

Contribution

	RC	MM	SM
Initiation	10	20	70
Data Collection	10	80	10
Writing Up	80	20	—
Overall Supervision of Project	100	—	—

I confirm that the contribution of authors as shown above accurately reflects the actual production of the above paper.

Name (please print) SUSAN MASSIE

Signature

Date 12/10/00

Paper Title: Outcome Measures Used in Therapy Departments in Scotland

Authors: Rosemary Chesson, Margaret Macleod and Susan Massie

Journal: Physiotherapy, December 1996, vol 82, no 12

Contribution

	RC	MM	SM
Initiation	10	20	70
Data Collection	10	80	10
Writing Up	80	20	—
Overall Supervision of Project	100	—	—

I confirm that the contribution of authors as shown above accurately reflects the actual production of the above paper.

Name (please print) M. MACLEOD.

Signature

Date 16/10/00

Paper Title: Do Parents and Children Have Common Perceptions of Admission, Treatment and Outcome in a Child Psychiatric Unit?

Authors: Rosemary Chesson, Leonora Harding, Cleone Hart and Victor O'Loughlin

Journal: Clinical Child Psychology and Psychiatry ISSN: 1359-1049, 1997

Contribution

(100%) (100%) (100%)

	RC	LH	CH
Initiation	80	10	10
Data Collection	50	5	45
Writing Up	80	10	10
Overall Supervision of Project	100	–	–

I confirm that the contribution of authors as shown above accurately reflects the actual production of the above paper.

Name (please print) LEONORA HARDING.

Signature

Date 12th Oct 2000.

Paper Title: Do Parents and Children Have Common Perceptions of Admission, Treatment and Outcome in a Child Psychiatric Unit?

Authors: Rosemary Chesson, Leonora Harding, Cleone Hart and Victor O'Loughlin

Journal: Clinical Child Psychology and Psychiatry ISSN: 1359-1049, 1997

Contribution

	RC	LH	CH
Initiation	80	10	10
Data Collection	50	5	45
Writing Up	80	10	10
Overall Supervision of Project	100	—	—

I confirm that the contribution of authors as shown above accurately reflects the actual production of the above paper.

Name (please print) Dr C. HART

Signature

Date 9/10/10

Paper Title: Children as consumers

Authors: Cleone Hart, Rosemary Chesson

Journal: BMJ Volume 316 23 May 1998

Contribution

	RC	CH	
Initiation	80	20	
Data Collection	50	50	
Writing Up	50	50	
Overall Supervision of Project	100	—	

I confirm that the contribution of authors as shown above accurately reflects the actual production of the above paper.

Name (please print) Dr C. HART

Signature

Date 9/10/00

Paper Title: The Use of Photographs as a Means of obtaining Views of Occupational Therapy held by Children with learning Disabilities: a Pilot Study

Authors: Debbie Joy, Anita Young, Val Harvais and Rosemary Chesson

Journal: British Journal of Occupational Therapy, March 1998, 61(3)

Contribution

	RC (100%)	DJ (100%)	AJ (100%)
Initiation	33	33	33
Data Collection	10	80	10
Writing Up	40	50	10
Overall Supervision of Project	100	—	—

I confirm that the contribution of authors as shown above accurately reflects the actual production of the above paper.

Name (please print) DEBBIE JOY

Signature

Date 6.8.01

Paper Title: The Use of Photographs as a Means of obtaining Views of Occupational Therapy held by Children with learning Disabilities: a Pilot Study

Authors: Debbie Joy, Anita Young, Val Harvais and Rosemary Chesson

Journal: British Journal of Occupational Therapy, March 1998, 61(3)

Contribution

	RC (100%)	DJ (100%)	AY (100%)
Initiation	33	33	33
Data Collection	10	80	10
Writing Up	40	50	10
Overall Supervision of Project	100	—	—

I confirm that the contribution of authors as shown above accurately reflects the actual production of the above paper.

Name (please print) ANITA YOUNG

Signature

Date 30 July 2001.

Paper Title: Quality of life with Parkinson's disease: views of Scottish consumers and providers

Authors: Rosemary Chesson, Diana Cockhead and Debbie Romney-Alexander

Book chapter
~~Journal~~:

Contribution

	RC	DC	DA
Initiation	100	—	—
Data Collection	—	50	50
Writing Up	90	5	5
Overall Supervision of Project	100	100	100.

I confirm that the contribution of authors as shown above accurately reflects the actual production of the above paper.

Name (please print) DIANA COCKHEAD

Signature

Date 12. October 2000

Paper Title: More than a sympathetic ear? A report on the first year of a writer in residence in a unit for young, physically disabled people

Authors: Rosemary Chesson, Eileen Moir and Alison Tavendale

Journal: Clinical Rehabilitation 1999; 13: 310-321

Contribution

	RC	EM	AT
Initiation	40	–	60
Data Collection	–	50	50
Writing Up	50	10	40
Overall Supervision of Project	100	–	–

I confirm that the contribution of authors as shown above accurately reflects the actual production of the above paper.

Name (please print) ALISON TAVENDALE

Signature

Date 5.10.00.

Paper Title: More than a sympathetic ear? A report on the first year of a writer in residence in a unit for young, physically disabled people

Authors: Rosemary Chesson, Eileen Moir and Alison Tavendale

Journal: Clinical Rehabilitation 1999; **13**: 310-321

Contribution

	RC	EM	AT
Initiation	40	—	60
Data Collection	—	50	50
Writing Up	50	10	40
Overall Supervision of Project	100	—	—

I confirm that the contribution of authors as shown above accurately reflects the actual production of the above paper.

Name (please print) Eileen M. Moir

Signature

Date 10. 10. 00