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**An evaluation of the 'Living with Cancer' Project**

**Using neuro-linguistic programming techniques to maximise the  
coping strategies of carers and patients living with cancer in  
Ellesmere Port**

**Penny Sargent  
Miranda Thurston  
Karen Kirby**



**New Opportunities Fund**  
*funded*

**March 2004**



**UNIVERSITY**  
COLLEGE CHESTER

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<sup>1</sup> As of the 31/3/02 Chester and Halton NHS Trust no longer existed. After this date Halton PCT became responsible for the project together with Ellesmere Port and Neston PCT, although the project was delivered in Ellesmere Port only.

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## Glossary

Anchoring	An NLP term that is used to refer to a technique that involves the creation of stimulus-response patterns to enable people to have access to resourceful states in the times and places that they would like them. 'Stacking' multiple resource states on one trigger can make the anchor more powerful, whilst the process of 'collapsing' anchors can neutralise naturally occurring negative associations in order to make certain situations more comfortable and manageable.
Brain Gym	An NLP technique/exercise that allows people to better coordinate their brain and body. It is a set of 26 simple exercises drawn from yoga, applied kinesiology and remedial education that integrate the left and right fore and hind and upper and lower brain functions. The technique can have a positive effect on learning, problem solving, relaxation, positive states and attitudes.
CHI	Commission for Health Improvement.
Hook-ups	A Brain Gym exercise that helps to promote a feeling of calm and relaxation.
NLP	<p>Neuro-Linguistic Programming. NLP is an understanding of the structure of subjective experience and how this can be worked with systematically to produce positive results. Neuro is used to refer to the interconnectedness of the mind-body system. Linguistic refers to the way we use language to describe our experience consciously and unconsciously. It also refers to the way in which language is used. Programming refers to the learning ability of the brain and the tendency of humans to form habitual patterns of thinking and behaviour. When we understand this process of habit formation it is possible to make helpful changes in our habits.</p> <p>NLP is also considered an attitude, methodology and set of techniques. The attitude is of openness and curiosity, the methodology is 'modelling', the systematic understanding of how someone does a particular thing. Techniques follow from a practical understanding of how something is done.</p>
PCT	Primary Care Trust.
Phobia cure	A term used in NLP to refer to a technique that teaches a person to replace a phobic response with a more appropriate alternate response.
Rapport	The ability to appreciate another person's perspective. Mutual understanding or trust between people that creates a feeling of commonality.
Soft language	A term used in NLP to refer to specific language patterns of 'soft frames', positive language and positive presuppositions. This purposeful use of vague language can help remove conscious resistance and open the mind.

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State	This term is used in NLP to refer to the balance of a person's system at a certain point in time. It includes a person's physiological make-up, neurology, body chemistry, experience of emotions, thoughts and state of mind.
Trauma cure	An NLP technique that can be used to help people become free of phobias caused by a specific incident. It helps people to reframe specific traumatic experiences or troubled periods of time in their lives. It is a tool for alleviating the symptoms of post-traumatic stress.
Well-formed outcome	A term used in NLP to refer to the process of a person refining, in detail, a desired outcome. The outcome is described in positive terms and includes details of the purpose and results of the outcome, the terms, timing, conditions and environmental context in which the person wants the outcome. The criteria vary from one specific technique to another although the term is used in this report to refer to a process where a person is encouraged to think about the outcome positively, to imagine it richly, to check that it is under their control, to dovetail it with what others may want, to consider the context, to find ways of building in anything they could potentially lose through achieving the outcome, to consider resources needed, to consider the consequences of the outcome for themselves and others and to decide what the first steps will be and when they will take them.

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## Summary

### Background

Since the Calman-Hine Report (Department of Health, 1995) an increasing volume of research has been published on the issue of improving the quality of cancer care. Numerous publications have highlighted the persistence of poor communication, inadequate information provision and involvement in decision-making and a lack of psycho-social support for patients and their families (Department of Health, 2000a; Department of Health, 2000b; CHI, 2001; Maguire and Pitceathly, 2002; Fallowfield, 2002). Research has also identified the need for improved relationship and inter-personal skills among some health professionals. Several studies have highlighted health professional insensitivity as a key concern among cancer patients. *The NHS Cancer Plan* (Department of Health, 2000a), noted that ‘...many complaints by patients and their relatives relate to a perceived failure of the doctors and health care professionals to communicate adequately or to show they care...’ (p.63).

In response to this research the ‘Living with Cancer’ project was developed with the aim of improving communication, relationship and coping skills of health professionals, cancer patients and their carers in Ellesmere Port. The ‘Living with Cancer’ project was implemented from April 2001 to March 2004. The project delivered NLP Diploma training to 55 health professionals over this period. Additionally, a cancer patient and carer peer support group was established at Ellesmere Port Library with regular NLP education and interventions from two NLP trainers, accredited by the International NLP Trainers Association.

This study set out to describe the ‘Living with Cancer’ project and evaluate the impact of project activities. Specifically, the study had five main aims. Firstly, the research sought to conduct a needs analysis among cancer patients, carers and health professionals to inform the development of the ‘Living with Cancer’ project. Secondly, the study aimed to evaluate the delivery of the peer support group with NLP training to cancer patients and carers. Thirdly, the study aimed to evaluate the delivery of the four-day NLP training courses to health professionals. Fourth, the research sought to explore participants’ perspectives on the value of NLP training for improving experiences within cancer care. Finally, the study aimed to assess the impact of the ‘Living with Cancer’ project on the intra and inter-personal experiences of cancer care among health professionals, patients, and carers who participated in project activities.

### Study design and method

A qualitative methodology was used to evaluate the ‘Living with Cancer’ project. This methodology is suitable for conducting exploratory research into innovative projects such as the delivery of NLP training to health professionals, cancer patients and carers. The findings of this research illuminate the thoughts, beliefs and perspectives of participants about the value of NLP training for improving experiences within cancer care. The evaluation did not set out to conduct a statistical analysis of the impact of the ‘Living with Cancer’ project on health professionals, cancer patients or carers experiences within cancer care. Furthermore, the evaluation did not set out to examine value for money issues.

Three needs analysis focus groups, with health professionals, cancer patients and carers, were conducted to inform the development of the project. During the project two focus groups were held with the cancer patients and carers peer support group to evaluate the delivery of NLP education and interventions to the group. To evaluate the delivery of the four-day NLP training for health professionals, 23 interviews were conducted with health professionals who completed the course.

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The evaluation of the 'Living with Cancer' project was conducted independently by the Centre for Public Health Research, University College Chester. The three researchers who worked on the study do not have any relationships, or financial interests with any NLP organisations or practitioners.

### **Overall findings**

- The 'Living with Cancer' project was responsive to research into cancer care and the findings of the needs analysis focus groups.
- The 'Living with Cancer' project succeeded in delivering NLP communication training to 55 health professionals.
- The project established a peer support group at Ellesmere Port Library.
- From May 2002 until July 2003 two NLP-accredited trainers attended the peer support group to provide NLP education interventions.

### **Findings of the needs analysis focus groups**

The findings of the needs analysis focus groups revealed a number of common concerns across all three groups.

- Health professionals, cancer patients and carers all considered good communication and the development of effective patient-health professional relationships to be fundamental to the delivery of quality cancer care.
- Participants noted the difficulties of communicating in cancer care and gave many examples of poor or inappropriate communication.
- Each group noted that health professionals should be sensitive, empathetic, open, and caring when communicating with patients. They also noted that health professionals should be willing to give their time and listen actively to patients.
- Good communication between health professionals and patients was considered vital for effective information exchange, and to prevent delays in diagnosis and treatment.
- Each focus group recognised the need for improved cancer patient and carer psycho-social support in Ellesmere Port. Peer support groups were seen as an ideal way to improve the level of psycho-social support available to cancer patients and their families.

### **Findings of the evaluation focus groups**

Two evaluation focus groups were conducted with members of the peer support group. The first focus group was conducted in November 2002 and the second in April 2003. The purpose of these focus groups was to evaluate the delivery of the 'Living with Cancer' peer support group and assess the value of the NLP education interventions delivered to group members. The main findings of the evaluation focus groups are listed below.

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- The peer support group met the need, identified in the needs analysis focus groups, to provide a source of psycho-social support for cancer patients and carers in Ellesmere Port.
  - Participants appreciated the peer support group as an environment in which they could share their experiences and knowledge with others. This reduced feelings of isolation and loneliness and promoted feelings of reassurance and comfort.
  - The NLP relaxation techniques taught by the trainers during the peer support group were considered relevant, effective and valuable.
  - Participants stated that the NLP relaxation training helped them to cope with the stress of their disease and provide relief from anxiety and insomnia.
  - Participants valued the communication skills training provided by the NLP trainers. This training gave participants practical and essential skills to improve their communication and relationships with consultants.
  - Despite the overwhelmingly positive response to the peer support group NLP interventions some participants remained sceptical about NLP.
  - There was a feeling that the NLP interventions to the peer support group could have sometimes been better introduced.
  - The integration of NLP education into the peer support groups would seem to warrant further attention in future projects. A solution to this issue may be to adjust the content to the NLP training to increase its relevance to group discussions.
  - In total, 62 cancer patients and carers attended the peer support group, however regular membership hovered at six persons throughout the project. This raised questions about the impact of the project on the larger population of cancer patients and carers in Ellesmere Port and the sustainability of the peer support group.
  - Participants noted the need for formal consultant-led recognition and support, including the direct referral of patients to the group, to help overcome low attendance rates.

### **Findings of the interviews with health professionals**

A number of findings emerged from the interviews with health professionals who participated in the NLP training course.

- The overwhelming response to the NLP training course was positive.
- Most participants believed that the course built upon their existing communication, relationship and inter-personal skills.
- The NLP training was largely thought to complement previous knowledge and training in psychological and behavioural theories.
- Participants described how they had implemented NLP techniques such as ‘soft language’, ‘anchoring’ and ‘well-formed outcomes’ to improve their interactions with patients.

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- However, not all participants considered the training valuable in their work and did not believe that the course added to their previous knowledge.
  - Extensive biomedical training may account for the reluctance among some participants to consider new approaches to communication and relationships.

## **Conclusion**

This study found that the ‘Living with Cancer’ project achieved its aims of establishing a cancer patients and carers peer support group with NLP education interventions. The project also met its primary aim of delivering NLP training courses for health professionals in Ellesmere Port. Through these interventions the project succeeded in increasing the communication, relationship and coping skills of most participants. However, the project attracted a relatively small number of health professionals whose primary role was delivering cancer care. It is therefore likely that the project had a limited impact upon the quality of cancer care experienced by the larger population of cancer patients and carers in Ellesmere Port. Furthermore, the ‘Living with Cancer’ NLP training for health professionals failed to attract any oncology consultants. Given the time constraints faced by frontline clinicians it may be necessary to shorten the training sessions to attract consultants to future projects. It may also be necessary to adapt and re-brand the training, with less emphasis on NLP, to make it more appealing to ‘sceptical’ consultants. Another possible approach to increased clinician participation may be the inclusion of NLP-based communications workshops in undergraduate medical and nursing curricula.

## **Contact details for copies of the report**

Copies of this report are available through the Centre for Public Health Research, University College Chester. Telephone (44) 01244 220 366 or go to <http://www.chester.ac.uk/cphr/>

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# Chapter 1

## Introduction

### 1.1 The 'Living with Cancer' project

The purpose of this research was to evaluate the 'Living with Cancer' project, delivered by Chester and Halton Community NHS Trust through funding provided by the New Opportunities Fund (NOF). The 'Living with Cancer' project had separate aims and objectives to this evaluation research conducted by the Centre for Public Health Research, University College Chester.

The NOF-funded 'Living with Cancer' project targeted residents living within the most deprived wards of Ellesmere Port and was delivered from April 2001 to March 2004. The project was developed in response to increasing evidence of the failure of cancer services to meet the communication, information and psycho-social support needs of patients and carers. Since the Calman-Hine Report (Department of Health, 1995) numerous studies have found the persistence of insensitive, inappropriate and poor quality communication among some health professionals. Research has also reported poor levels of participation in formal communication skills training among health professionals (Department of Health, 2000a). Given this situation it is not surprising that health professionals often fail to match patient expectations of communication, information provision, involvement in treatment decision-making and psycho-social support (CHI, 2001; Arora, 2003; Maguire, 1999; Morton, 2002).

The 'Living with Cancer' project set out to improve this situation by developing the communication, inter-personal and coping skills of health professionals, patients and carers. The project aimed to improve these skills to enhance the experience of cancer patients and carers both within cancer services and throughout the cancer journey. The project sought to improve the communication, inter-personal and coping skills of health professionals, patients and carers through a number of avenues. First, the project aimed to improve the communication, relationship and coping skills of health professionals through a four-day training course in Neuro-Linguistic Programming (NLP). Second, the project sought to improve the communication, relationship and coping skills of patients and carers through NLP training interventions during patient and carers peer support groups. Third, the project set out to improve the ability of health professionals to identify patients' and carers' needs, and the ability of patients and carers to express these needs, through NLP training. Fourth, the establishment of a peer support group for cancer patients and carers aimed to provide psycho-social support and to empower patients to give them a voice within cancer services.

### 1.2 Research aims

This study had five main aims. The first aim was to conduct a needs analysis among cancer patients, carers and health professionals in Ellesmere Port to inform the development of the NLP training input. The needs analysis sought to identify concerns relating to cancer care among patients, carers and health professionals, to ascertain unmet needs within each group and to explore perspectives on how to improve experiences within cancer care through NLP training. The second aim was to evaluate the delivery of a peer support group with NLP training to cancer patients and carers. The third aim of the research was to evaluate the delivery of a four-day NLP training course to health professionals. The fourth aim of the research was to explore participants' perspectives on the value of NLP training for improving experiences within cancer care. The final aim of this study was to assess the impact of the 'Living with Cancer' project on the intra and inter-personal experiences of cancer care among health professionals, patients, and carers who participated in project activities.

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## Chapter 2

### Background and literature review

#### 2.1 Introduction

Cancer represents a considerable burden of disease in the community and is the second most common cause of death in England and Wales (Bendel, 2002). Each year approximately 200,000 people are diagnosed with cancer in the United Kingdom and approximately 120,000 will die as a result of the disease (Department of Health, 2000a). Compared to England and Wales as a whole the North West region of England has higher rates of cancer incidence and mortality. In the period from 1997 to 1999 the North West region had an 'all cancers' standardised mortality rate of 211 per 100,000. The rate for the country as a whole was comparatively lower at 193 per 100,000. Not only does the North West have higher rates of cancer incidence and mortality, it also has poorer five-year survival rates for most cancers compared to the country as a whole (Bendel, 2002).

In 2000 the Department of Health published its strategy for reform and investment in the NHS to increase cancer survival rates through improved cancer services and the reduction of inequalities in cancer care and prognosis. This strategy, *The NHS Cancer Plan* (Department of Health, 2000a) noted wide variation in patients' experiences of cancer care. Patients in some localities reported excellent, sensitively delivered care while patients in other areas were found to have experienced insensitive care, unacceptably long waiting periods and poor information delivery, leading to increased anxiety and uncertainty. Overall, the *NHS Cancer Plan* found cancer services to be 'patchy and not as good as they should be' (Department of Health, 2000a, p.43).

*The NHS Cancer Plan* (Department of Health, 2000a) identified a number of factors that contribute towards poor quality, inconsistent cancer care. Chief among these factors was the recognition that health care professionals often have insufficient training to meet the communication, information and support expectations of patients with cancer. Structural factors such as equipment shortages, inefficient referral systems and poorly coordinated treatment services are also noted by the report as important contributors to poor standards of care.

The 'Living with Cancer' project was initiated in response to the *Calman-Hine Report* (Department of Health, 1995), *The NHS Cancer Plan* (Department of Health, 2000a), and other research that highlighted the need to improve cancer patients' and carers' experiences within cancer services. The following discussion will focus upon the research evidence and policy background that provided the impetus to develop a programme designed to improve health professional-patient communication, information exchange, the involvement of patients in the decision-making process and the provision of psycho-social support to patients and carers. This Chapter will focus on these non-structural factors that underpin quality cancer care. It will not investigate the complex medical, structural, or economic factors that also determine the quality of cancer care.

#### 2.2 Patient-health professional communication

Reports into the provision of cancer care have found that the majority of patients experience open, honest, caring and reassuring communication with health professionals (CHI, 2001). However, a national survey of cancer patients found the most common complaints related to poor communication and inadequate information provision (National Cancer Alliance, 1996). Similarly, *The NHS Cancer Plan* reported that '...many complaints by patients and their



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relatives relate to a perceived failure of the doctors and health care professionals to communicate adequately or to show they care, rather than to problems of clinical competence' (Department of Health, 2000a, p.63). Other research has reported that some health professionals continue to provide patients with their diagnosis through inappropriate avenues, to communicate in an insensitive, cold or distant manner, and provide information in very vague terms.

Effective communication between health professionals and patients is integral to the provision of high quality cancer care. Good communication is essential to elicit information on symptoms and side effects of treatment. It promotes an accurate diagnosis, adherence to treatment and emotional, as well as physical, well-being (Stewart, 1996; NHS Centre for Reviews and Dissemination, 2000; Maguire and Pitceathly, 2002). Open and honest communication is important as it assists the patient in accepting and coming to terms with their cancer diagnosis (Maguire and Pitceathly, 2002). Furthermore, good communication is essential to the patient empowering process and contributes towards increased patient and doctor satisfaction (Stewart, 1996).

Several studies have shown that improved patient-doctor communication leads to improved health outcomes. Studies by Arora (2003) and Ong et al. (2000) reported that good communication between doctors and their cancer patients can have a significant positive impact on patients' quality of life. Schofield et al. (2003) found patients' satisfaction with their doctor's communication style was linked with lower psychological morbidity at four and thirteen month follow-up. Patients who were psychologically prepared by their doctor for a possible diagnosis of cancer, who were provided with as much information about their diagnosis as they wanted to know, had information presented clearly, their questions discussed the same day, and who had a doctor who discussed their feelings and had a reassuring manner, were found to have lower levels of anxiety. Patients who had lower levels of depression had doctors who were open about their diagnosis, who discussed the severity of the situation, gave a life expectancy, discussed how the cancer may affect other aspects of life and who encouraged them to be involved in decision making.

Poor communication between cancer patients and their doctors has been found to have serious effects on patients' psychological and physical well-being (Maguire, 1999; Fallowfield and Jenkins, 1999; Ong et al, 2000). Lack of information about diagnosis, prognosis, and potential therapeutic options has been linked to increased patient distress, anxiety, confusion, uncertainty and dissatisfaction. Additionally, poor health professional communication skills can lead to a loss of patient confidence in health professionals (Fallowfield and Jenkins, 1999).

Good communication in cancer care should exist not only between health professionals and patients but also between health professionals themselves and between health professionals and allied staff. This intra and inter-service communication is fundamental to high quality, continuous care. The Calman-Hine report (Department of Health, 1995, p.19) stressed, 'The importance of communication, appropriate in time and content, between primary care, and the specialist services can not be over-estimated. Any changes in patient management should be made known to all involved in their care'. Yet despite this directive, breakdowns in communication often occur between consultants and referring doctors (Tattersall and Ellis, 1998; Bain and Campbell, 2000; CHI, 2001).

The report *NHS Cancer Care in England and Wales* found that, 'From a patient point of view, there is poor communication and a failure to plan care in a systematic way between the different professionals involved' (CHI, 2001, p.xi). GPs and district nurses are often not informed about a patient's discharge from hospital or their prognosis (CHI, 2001). Such communication breakdowns between health professionals can result in fragmented care,

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referral delays, confusion at the time of discharge from hospital, conflicting advice to patients, increased patient anxiety and tension among health professionals.

Maguire and Pitceathly (2002) offer a number of explanations why health professionals' communication skills fail to meet the needs of patients. The first of these relates to the fact that doctors' training rarely deviates from the medical model. Minimal training and experience in providing patients with psychological and social support often means that doctors do not feel they have the skills to cope professionally with situations where patients raise these matters. Secondly, doctors who have skills in attending to patients' psychological needs, and are willing to do so, may not feel supported by their colleagues. Some health professionals feel that communicating with patients about their psychological and social well-being will increase patient distress or take up too much time.

Additionally, oncology staff sometimes fear that communicating with patients about their emotional health will place their own emotional survival at risk (Maguire and Pitceathly, 2002; Fallowfield and Jenkins, 1999). The cold professional distance sometimes exhibited by oncology professionals can stem from a belief that this is required to preserve their own emotional stability. This professional detachment creates a communication barrier that can be damaging to patients. Professional distancing behaviour is also unsatisfactory for health professionals as it prevents the development of rewarding relationships with patients, leading to lower levels of job satisfaction, and can increase stress and professional 'burnout' (Ramirez et al, 1996; Fallowfield and Jenkins, 1999).

### **2.3 Communications skills training for health professionals**

Despite the widespread acknowledgement that good communication provides the foundation of quality cancer care there is considerable evidence, from both official reports and independent research, to suggest that many health professionals receive inadequate training in communication skills (Department of Health, 2000a; Maguire et al, 1996; Maguire and Pitceathly, 2002; Fallowfield and Jenkins, 1999; Fallowfield et al, 2002). Doctors spend more time engaged in discussions with patients than they do any other task yet less than half feel that they have had adequate training in communication skills and only one in four lead consultants have had formal training in breaking bad news to patients (Department of Health, 2000a). Encouragingly, communication skills training does appear to be more common among nurses. A survey of Clinical Nurse Specialists conducted in 2000 found 80 % had received communication skills training at some stage in their career (CHI, 2001).

To address the acknowledged need for communication skills training the NHS has committed to a plan to provide formal training across the health professions. *The NHS Cancer Plan* (Department of Health, 2000a, p.13-14) states that by 2002, '... it will be a pre-condition of qualification to deliver patient care in the NHS that staff are able to demonstrate competence in communication with patients. And for cancer we shall give staff additional training in communication skills, and in the provision of psychological support'. The plan stipulates that advanced communication skills training should also be incorporated into continuing professional development programmes (CHI, 2001).

A review of the published evidence on communication skills training for health professionals reported generally positive findings (Fallowfield and Jenkins, 2004). Fallowfield et al. (2002) found doctors who participated in a training course significantly improved their communication skills with patients. After completing the training the participants had decreased in their use of closed, leading questions, increased in their use of focussed, open questions, and had increased sensitivity and empathy toward patients. Similarly, Maguire et al. (1996) reported that participation in a communication skills workshop greatly enhanced the communication skills of participating cancer health professionals. Prior to training, 44%

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of participants were able to identify at least 60% of patient problems. After completing the workshop 70% of participants were able to identify at least 60% of patient problems (Maguire et al, 1996). The trained health professionals asked more open directive questions, asked more questions with a psychological focus and clarified psychological aspects. They also had a significantly improved ability to elicit patient problems and a reduction in behaviours that inhibit disclosure. Pilot NHS workshops on 'Mastering Patient Communication', organised by the Clinical Governance Support Team, have also reported encouraging preliminary findings (Greco and Squire, 2003).

Much of the research conducted into communication between health professionals and patients has focussed on the skills of health professionals. Very little attention has been given to the importance of improving patient communication skills to enhance the quality of the cancer care they receive. Leydon et al. (2003) observe that the lack of a 'voice in medicine' among patients contributes towards difficulties in communicating symptoms and being taken seriously by doctors. To overcome this situation Cegala (2003) argues that cancer patients should be provided with training in communication skills. Cegala (2003) notes that patient training in communication skills leads to increased confidence and question-asking during consultations with doctors. This in turn has been found to increase compliance and improve the management of their disease.

Current NHS policy documents outline the introduction of compulsory participation in communication skills training as a registration requirement for doctors. It is also stipulated that formal communication skills training should be implemented for all health professionals and that oncology staff should participate in additional psycho-social skills training (Department of Health, 2000a). These directives are unambiguous yet it remains unclear how many NHS trusts have implemented communication skills training programmes within the timeframe outlined by *The NHS Cancer Plan* (Department of Health, 2000a). *The NHS Cancer Plan: three year progress report* (Department of Health, 2003) states that experts from Cancer Research UK and Marie Curie Cancer Care have been commissioned to develop cancer communication skills training courses for health professionals. However, this training will be delivered through a top-down 'cascade model' rather than a blanket approach.

Despite NHS policy directives and research, communication skills training continues to be perceived as an add-on course for many health professionals, rather than an integral component of the undergraduate curriculum. Undergraduate pre-registration training in communication skills is important as it provides an opportunity to shape the communication style of future health professionals. It also allows young health professionals to participate in communication skills training without interrupting their clinical duties or placing an additional burden on post-registration time schedules.

## **2.4 Characteristics of personally effective health care providers**

There is evidence to suggest that the development of good relationships between health care professionals and patients has physiological, as well as psychological, benefits for patients. Research conducted with breast cancer patients has found that an effective doctor-patient relationship promotes women's sense of control over their disease and increases their ability to cope with cancer (McWilliam et al, 2000). Several studies have found physician compassion, defined as touching the patient's hand, reassuring and expressing support, to have psychological and physiological benefit for patients. Arora (2003) argues that a compassionate approach in doctors reduces anxiety in cancer patients, improves quality of life scores and leads to better health outcomes.

Bakker et al. (2001) suggest that 'connectedness', defined as a conscious effort on the part of both the patient and health professional to work as partners, leads to improved psychological

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and physical outcomes in cancer patients undergoing treatment. Connectedness was found to stem from a willingness on the part of the health professional to treat the patient as an individual, to be an active listener, to make time for the patient and to be optimistic and compassionate. Connected doctor-patient relationships were characterised by trust, partnership and the validation of the patients' emotions and beliefs.

Research has found that cancer patients give high priority to being treated with humanity and receiving psychological support from health professionals (Department of Health, 2000b). Patients' experiences of receiving psycho-social support often rest upon the personal characteristics of individual doctors and nurses. Several studies have investigated the qualities that make health professionals effective in their interactions with cancer patients. One such study, conducted by Farrell (2001a) identified a list of qualities found in personally effective consultants. These included patience, a willingness to listen and answer questions, honesty and straight-forwardness, encouragement of feelings of confidence, approachability, a sense of humour, considerateness, kindness, treating patients as individuals, and having respect for patients. O'Hair (2003) noted that patients value personable doctors who have an open style of communicating and exhibit a high level of involvement in the consultation. While Thom (2001) found that effective doctor-patient relationships develop when physicians are comforting and caring, demonstrate clinical competency, encourage patients to ask questions, and take their time to answer and explain things.

The personal characteristics of nurses are equally important as those of consultants in the provision of quality care to cancer patients. A key finding of the CHI report was the importance of specialist nurses in providing care and support, listening to patients and providing information (CHI, 2001). Similarly, a study of the characteristics of effective cancer nurses found personal demeanour and statements of understanding to be important in helping patients cope with their disease (Bjorklund and Fridlund, 1999). Another study reported that nurses' sympathetic approach and enthusiasm to spend time talking to patients and providing information is particularly valued (Farrell, 2001a). Patients identified the characteristics of good nurses as someone who listens and gives time to listen, who shows sympathy, is approachable, understanding, patient, kind, friendly and makes patients feel human. The professional characteristics of clinical competence and efficiency were also highly valued by patients.

## **2.5 Psycho-social support and cancer care**

A diagnosis of cancer causes considerable emotional distress for the majority of patients. Approximately one third to half of all cancer patients suffer psychological morbidity following their diagnosis, with the most common forms being anxiety and depression (Whelan et al, 1997; Blake-Mortimer et al, 1999). A review of the literature conducted by Blake-Mortimer et al. (1999) reported that psychological distress is associated with poorer health, more rapid disease progression and reduced survival time.

Psycho-social support is an essential element of quality cancer care as it helps patients to come to terms with and adjust to their disease. Cancer patients are not only concerned about treatment, 'They also have a deep need for good emotional support and social and spiritual care' (CHI, 2001, p. 47). The importance of providing support to cancer patients is noted by *The NHS Cancer Plan*, which states that cancer services should, '...ensure patients and their families have better support and information throughout their cancer care' (Department of Health, 2000a). The failure to provide adequate psycho-social support to patients can lead to unnecessary increases in psychological and symptom distress (Slevin et al, 1996; Morasso et al, 1999).

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Studies of cancer patients' expectations of psycho-social support have found that most patients view health professionals as important sources of emotional support. In one study, 73% of cancer patients viewed senior registrars as important sources of emotional support and 63% considered consultants important sources of support (Slevin et al, 1996). This study demonstrated that cancer patients have expectations of consultant-provided care and support that extend beyond the biomedical model.

While most patients view doctors as important sources of psycho-social support there is often a gap between patient expectations and the level of support doctors actually provide. Maguire (1999) suggests that few doctors initiate discussions on matters pertaining to their patients' psychological well-being. Time constraints on the length of consultations often mean that insufficient time is dedicated to discussions about a patient's emotional health. Furthermore, some patients perceive health professionals as reluctant to discuss these problems and may fear being thought of as neurotic if they raise the topic of emotional issues.

Another barrier preventing cancer patients receiving adequate psycho-social support is the lack of professional counselling services linked to cancer treatment services. The Commission for Health Improvement (2001) report *NHS Cancer Care in England and Wales* found that approximately half of all consultants were unaware of any counselling referral service available to newly diagnosed patients. Where counselling services are available long waiting lists are common.

The psycho-social support needs of cancer patients' carers are often totally overlooked, even though their needs can be as acute as those of the patient (Rees et al. 1998). Studies have shown that health care professionals rarely provide carers with enough emotional support. Soothill et al. (2001) found that 42% of cancer patient carers had significant unmet psycho-social needs. These unmet psycho-social needs included daily life management, emotional support and social identity needs. Just over a third (38%) of the carers interviewed had ever been offered the opportunity to access counselling services. Another study reported that only 8% of carers surveyed felt they had adequate support from health care professionals and 48% reported that they had no support at all (Eriksson and Lauri, 2000).

## **2.6 Psycho-social support interventions**

There is a growing body of evidence to suggest that interventions such as cognitive-behaviour therapy, hypnotherapy, relaxation techniques, and guided visualisation have a positive effect on patients' psychological, social, and physical well-being. A randomised trial among breast cancer patients reported that patients who received training in relaxation techniques and guided imagery were more relaxed, had higher Quality of Life scores and experienced reduced emotional suppression (Walker et al, 1999). Taylor and Ingleton (2003) reported that hypnotherapy and cognitive-behaviour therapy improved cancer patients coping skills in relation to medical procedures and psychological traumas. Patients reported that visualisation and relaxation techniques helped them to reduce their anxiety and stress while simultaneously increasing their feelings of control over their disease. Taylor and Ingleton (2003) argue that hypnotherapy, guided imagery and relaxation training helps patients to cope with the side-effects of chemotherapy and adjust to a cancer diagnosis. The authors also argue that these techniques can increase patient confidence, promote restful sleep, and improve the mechanisms of immunity.

A meta-analysis of controlled quantitative studies found psycho-social interventions to have a positive effect on Quality of Life scores among cancer patients (Rehse and Pukrop, 2003). Other research into psycho-social and support group interventions among cancer patients has reported positive effects on patients' psychological adjustment, adherence to treatment and survival time (CHI, 2001; Farrell, 2001a; Samarel et al, 1998; Boer, et al, 1999). Patient

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support groups have been found to assist patients to cope with the symptoms of their disease and the side effects of treatment. Where support groups incorporate training sessions on relaxation and control pain techniques, they have been found to assist patients to deal with stress and pain (Pettersson et al, 2000). It has also been argued that patient support groups improve communication by mutually encouraging members to communicate openly with family members and health professionals (Blake-Mortimer et al, 1999; Fawzy, 1999).

The beneficial health effect of patient support groups was demonstrated in a randomised trial of group support and training in self-hypnosis techniques (for pain control) among breast cancer patients. Those patients who received group therapy and training in self-hypnosis techniques had an average increase of 18 months in survival time compared to controls. Similarly, a randomised trial of melanoma patients' attendance of support groups found significant improvements in mood, an increase in natural killer cell cytotoxicity and reductions in mortality in those who attended (Fawzy et al, 1990 in Blake-Mortimer et al, 1999). Other studies have also reported physiological benefits from patient support interventions. These include improvements in side effects such as weight loss, nausea and vomiting.

Samarel et al. (1998) found breast cancer support groups to have positive effects on the psychological well-being of group members. The majority (73%) of women participating in the support groups reported an improvement in their attitude towards cancer, and in their outlook on life, after participating in the group. The support groups also encouraged participants to adapt to their disease through a shared experience, verbalisation of their emotions and the exchange of information. Group discussions helped women to feel that they were not alone in their experiences. Most participants noted that group sessions on stress management techniques were particularly helpful. The opportunity to provide emotional support to other group members was also found to benefit participants. Samarel et al. (1998) also argue that the support groups helped breast cancer patients adjust to their condition and find an appropriate role within their home, work and social life.

Although most studies of group support have reported positive benefits for participants, a number of studies have reported mixed findings. Some studies have found no significant difference in moods, coping, anxiety or morbidity between case and control groups. Fawzy (1999) argues that the effectiveness of support group interventions can be increased through the inclusion of sessions on behavioural training, stress management, and cognitive therapy. Psycho-social interventions such as support groups should aim for a duration of at least 12 weeks in order for quality relationships to be developed (Rehse and Pukrop, 2003).

## **2.7 Information preferences**

Considerable research has been conducted into the information needs and preferences of cancer patients. Much of this research indicates that the majority of cancer patients want to be fully informed about their illness. Patients are increasingly requesting detailed information about their diagnosis, prognosis, treatment and care. It is acknowledged that this information is essential to reduce anxiety, promote patient empowerment and facilitate greater involvement in treatment and care decision-making. The importance of effective communication is emphasised by the fact that the majority of malpractice lawsuits stem from a breakdown in communication between doctors and patients (Vincent et al, 1994 in Schofield and Butow, 2003).

The information preferences of cancer patients have been found to be mediated by a number of factors. Research suggests that psycho-social factors exert a strong influence on patient information preferences (De Boer et al, 1999). Fear in particular often prevents people from requesting information about their diagnosis and prognosis. Leydon et al. (2000) identified

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patient coping strategies of 'faith', 'hope' and 'charity' as important determinants of the level of information desired by cancer patients. Other research has suggested that gender plays a powerful role in influencing the information preferences of patients. Several studies have found women significantly more likely to prefer detailed information about their disease and treatment than men (Meredith et al, 1996). Other factors that have been found to shape patient information preferences include age, (Jenkins et al, 2001), ethnicity, socio-economic status, education level and literacy (Farrell, 2001b). Additionally, the behaviour of health professionals and the patient's own beliefs and experiences have also been found to influence information preferences (Mossman et al, 1999; Guadagnoli and Ward, 1998).

An overwhelming majority of cancer patients have been found to desire full information relating to their diagnosis (Whelan et al, 1997; Mossman et al, 1999; Guadagnoli and Ward, 1998). A study by Jenkins et al. (2001) reported that 87% of cancer patients interviewed wanted all possible information, including the good and bad news and almost all patients (98%) preferred to know whether their condition was actually cancer. Similarly, Leydon et al. (2000) found all participants in their study wanted basic information about their cancer diagnosis and treatment, however the timing and preferred level of detail varied.

While most studies have confirmed that cancer patients desire high levels of information provision, there continues to be a gap between patient preferences for information and the amount, and quality, of information actually delivered. Perhaps the most disconcerting result to emerge from the research is the finding by Jones et al. (1999) that one in five patients about to begin radiotherapy were not satisfied with the amount of information provided about this treatment. This is a cause for concern as patients who are poorly informed about treatment are more likely to be anxious and distressed, and less likely to comply with treatments (Farrell, 2001b).

Arora (2003, p.3) argues that physicians 'have been shown to underestimate patients' desire for information and over-estimate their own informativeness'. The tendency of patients to forget information further exacerbates this situation. Studies have shown that patients have difficulty retaining and processing information, particularly around the time of diagnosis (van der Molen, 2000). One study has estimated that patients may forget up to 50 % of the information they are told by health professionals during consultations (Ley 1976, in Mossman et al, 1999).

Although most patients want to be well informed about their disease not all patients want extensive information about their condition and treatment at all stages of their illness. There is a need for appropriate, timely information provided in response to the patient's needs and readiness. As information needs often change over time, and at different stages of the patient's experience of cancer, health professionals need to know how best to elicit and respond to patient preferences for information (McWilliam et al, 2000; van der Molen, 2000; Leydon et al, 2000). Patients should be given the opportunity to ask for information or be asked what information they want at every stage of their care (Butow et al, 1997; Farrell, 2001a). Health professionals should avoid jargon and should also verify what the patient has understood (Arora, 2003). Health professionals should also constantly monitor the information seeking behaviours of patients and assess whether their preference for information is related to a dynamic coping strategy or other barriers such as language, clinic organisation or staff attitudes (Leydon et al. 2000).

Recent reports, such as *NHS Cancer Care in England and Wales*, (CHI, 2001) continue to highlight the need for improved information for cancer patients, particularly in relation to testing and treatments. Research suggests there is a need for individually tailored information to meet patients' informational preferences, educational background, cultural orientation and general level of comprehension (McPherson et al, 2001; Bain et al, 2002). In response to the observed need to provide cancer patients with improved information the Department of

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Health made a commitment in 2000 to, 'ensure that high quality written or other forms of information are available' (Department of Health, 2000a p.13-14). However, research has found that patients prefer verbally communicated information directly from their doctors and nurses. Written information is regarded as useful, although only to reinforce, and supplement, information provided verbally.

## **2.8 Patient involvement in treatment and care decision-making**

An important domain of patient-centredness is a partnership approach to health problems and treatments. Little et al. (2001) argue that many patients rank a patient-centred approach higher than the traditional biomedical aspects of their consultations with health professionals. In a review of the literature on patient participation in decision-making Guadagnoli and Ward (1998) argue that, on the whole, patients want to be informed of treatment options and that they want to be actively involved in treatment decision-making. However, various studies have found that cancer patients often do not achieve the level of involvement that they desire in terms of treatment and care decision-making.

Studies investigating patient involvement in decision-making, and their level of satisfaction with this process, have reported widely varying results. An NHS survey of cancer patients found a majority (89%) were satisfied with their level of involvement in treatment and care decision-making (Department of Health, 2000b). However, other studies have reported conflicting results. A significantly lower proportion of patients participating in a CancerBaCUP survey were satisfied with their level of involvement in decision-making (Morton, 2002). The CancerBaCUP study reported that less than half of patients surveyed felt that they were sufficiently involved in decision-making about their pain management.

A study of colorectal cancer patients found a majority (78%) of patients preferred to play a passive role in decision-making (Beaver et al. 1999). Similar results were reported by Sanders and Skevington (2003) who found that most bowel cancer patients in their study preferred a very limited role in decision-making. The authors suggest that a majority of patients were happy to delegate responsibility for treatment decision-making to their oncologist. An explanation for the unwillingness of these groups of cancer patients to be actively involved in decision-making may rest upon the fact that colorectal/bowel cancer most commonly affects older men.

In contrast to research conducted by Sanders and Skevington (2003), numerous other studies have reported that a majority of patients expect a more equal patient-provider relationship. Several studies have suggested that women with breast cancer prefer an active or shared role in decision-making (Bakker et al, 2001; Beaver et al, 1999; Charles et al, 1998; Degner et al, 1997). Charles et al. (1998) suggest that for many women with breast cancer having a partnership approach with their doctor allowed them to share the burden of treatment decision-making as well as broadening the responsibility for potentially 'bad' outcomes. Other cancer patient groups have also been found to prefer an active role in decision-making. Research with male cancer patients has found that a majority prefer shared decision-making with their doctors. Wong et al. (2000) reported that 60 % of men with prostate cancer in their study wanted shared decision-making with their doctors.

While the evidence suggests that health professionals should be involving patients in decision-making, government reports indicate that this is yet to be fully implemented in cancer care. A recent Commission for Health Improvement report (CHI, 2001) found that most cancer patients are not offered any choice of treatment, despite their willingness to participate in treatment decision-making. In particular, the report noted that some patients want to be more active in making decisions about receiving no treatment for their disease.



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Other research also suggests that cancer patients' expectations of participation in decision-making are not being fulfilled. Degner et al.'s (1997) study noted that only 21% of women with breast cancer who stated that they wanted to participate actively in decision-making felt that they achieved their desired role. Conversely, 15% of participants stated that they felt pressured to play a more active role than they desired.

Several theories have been proposed to explain the divergence between patients' expectations of participation in decision-making and their actual role. One explanation for the failure to meet patients' expectations of shared decision-making may rest upon the fact that physicians often fail to perceive accurately patients' preferences for participation in decision-making (Maguire, 1999). Bruera et al. (2001) found doctors' perceptions of patient preferences for participation in decision-making matched patients' actual preferences in just over a third (38%) of cases. Other explanations include the unwillingness of a minority of doctors to share power with patients, and the limited availability of resources for developing and implementing initiatives to support patient participation (Bruera et al, 2001).

A number of patient characteristics have been found to be associated with preferences for participation in treatment and care decision-making. As with information seeking preferences, age, gender and personal beliefs have been shown to influence patient preferences for participation in decision-making. Socio-economic background also influences patient preference for participation in decision-making. Patients from low socio-economic backgrounds have been found to be less likely to prefer a patient-centred approach (Little et al. 2001). Among breast cancer patients young age, English as a first language and higher levels of education are associated with a preference for a collaborative role (Degner et al, 1997). Practical considerations also determine preferences for involvement in decision-making. Patients whose condition had recently worsened, or who are very unwell, are less likely to want to be involved in decision-making (Butow et al, 1997).

Research suggests that the reluctance of some cancer patients to be involved actively in treatment decision-making may stem from a desire to be a 'good' patient, or wanting to avoid feeling guilty or regretful for any unwanted consequences of their decisions (De Haes and Koedoot, 2003). Some cancer patients prefer to trust the clinical knowledge and expertise of their oncologist to make the best decision about their treatment. Other patients may perceive that participation in decision-making could expose them to new, potentially distressing, information. Sanders and Skevington (2003) also suggest that the concept of false-choice influences patients' willingness to participate in treatment decision-making. In this situation patients do not view the option of having chemotherapy as choice, as the risk of not having chemotherapy is simply too great.

As with improved communication and information sharing, patient involvement in decision-making has a number of psychological and physical benefits. Mutual decision-making and power sharing has been found to improve psychological well-being, increase compliance with treatment, and reduce anxiety (Guadagnoli and Ward, 1998). However, it has also been found that patient anxiety may be increased at the time of decision-making if the decision is left entirely to patients to make. Patients who feel they are given too much information at the time of diagnosis have also been shown to be at higher risk of anxiety over time (Guadagnoli and Ward, 1998; Maguire, 1999).

In order to overcome inaccurate perceptions of patient willingness to be involved in decision-making, health care providers should establish a dialogue with patients on the level of control they wish to have in the decision-making process (Maguire, 1999). It is essential for the health care provider to be open to sharing control and to make the patient feel that their contributions are 'valued and respected' (Arora, 2003, p.4). Physicians should reflectively assess patients' willingness to be involved in decision-making and tailor the process accordingly. Furthermore, every effort should be made by physicians to continue their

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decision-making dialogue with patients throughout the cancer journey, as preferences often fluctuate according to physical and psychological health.

## **2.9 Neuro-linguistic programming and cancer care**

One of the generic terms used in this document is ‘communication skills training’. There are numerous models of communication skills training available, with each model focussing on different aspects of the communication process. However, the purpose of this research was to specifically assess the value of NLP training for improving the communication, relationship and coping skills of cancer patients, carers and health professionals. This study did not set out to conduct a comparative analysis of the value of NLP compared to existing communication or psycho-social theories. Therefore, the following discussion will focus on a description of NLP, rather than embarking upon a critique of NLP compared to traditional theories.

The acronym ‘NLP’ refers to neuro-linguistic programming. NLP is described as a theory, methodology and way of thinking (see glossary). It has been described as a pragmatic, practical and results-oriented approach to improving communication and relationships. NLP was originally devised by Richard Bandler and John Grinder in the 1970s. Bandler and Grinder studied several communicators/therapists who achieved consistently good results with clients previously considered ‘resistant’, ‘difficult’ or ‘hopeless’. These experts were then ‘modelled’ and specific patterns of thinking, language and behaviour, were identified as making a profound difference in the context of communication and change. These patterns of thinking, language and behaviour are easily taught, and believed to enhance effectiveness across a variety of contexts.

NLP draws upon many different disciplines and ways of thinking in addition to the original contributions from the early research. It has been described as advanced common sense and people have been reported as recognising elements of NLP that are familiar to them already. Today NLP is used in many different contexts including management and leadership, communication, relationships, negotiation, education, managing change, conflict resolution and psychotherapy. Yet little research has been conducted into the specific outcomes of using NLP. Additionally, the generic nature of NLP skills has meant that little is published in a way that is made directly relevant to health care professionals, with the exception of a brief series of papers and debate in the British Medical Journal (e.g. Walter and Bayat, 2003). There is a need for peer-reviewed research in this area to assess whether NLP may be of any benefit within the context of cancer care generally and specifically, in terms of addressing the issues identified above.

NLP represents just one of a multitude of approaches to communication. It provides a model for understanding the processes of communication and aims to provide options for flexible communication. The characteristics of NLP include the encouragement of a flexible, reflexive and outcome-focussed approach to communicating. NLP avoids an interpretive approach to ‘body language’ and aims to focus on the senses to promote continuous and sensitive feedback when communicating with others (Lidiard, 2004). NLP includes specific tools and techniques that aim to build rapport. These techniques seek to promote the fast creation of empathetic connections, to establish trust and understanding, while simultaneously promoting the management of internal emotional states. NLP also aims to provide strategies for releasing negative emotions, overcoming trauma and phobic responses and increasing control over emotional states (Rushworth, 1994). Furthermore, NLP is characterised by a focus on language and aims to promote the use of specific and purposeful language patterns in particular contexts. In contrast to traditional counselling approaches, that assume weeks and months to produce gradual improvements, NLP tries to quickly produce change. The rapid approach of NLP may prove useful for assisting patients and health professionals alike in the increasingly time-pressured environment of the health consultation.

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NLP in theory provides a possible vehicle for addressing problems within health professional-patient communication and thus improve the quality of cancer care. The flexibility of NLP, combined with the importance given to rapport, language, and the management of internal emotional states, was seen as pertinent to the problems of communication between health professionals, cancer patients and carers. Furthermore, the NLP focus on rapid change was considered highly appropriate within the context of the oncology consultation. NLP interventions may also improve the quality of cancer care by focussing on empowering patients and carers through the delivery of a number of 'coping strategies' such as 'anchoring', visualisation and relaxation techniques, thinking in terms of 'well-formed outcomes' and techniques to help patients overcome trauma.

## **2.10 Conclusion**

There is increasing recognition in the literature that non-medical aspects of cancer care have a considerable impact on patient perceptions of quality care. Some researchers (Little et al, 2001) go so far as to argue that the traditional biomedical aspects of cancer treatment no longer dominate patient perceptions of quality care. These researchers assert that a patient-centred approach is more important in determining patient satisfaction than traditional technical medical skills such as physical examination. Other researchers may debate this argument, yet there is growing consensus that the communication, inter-personal, and psycho-social support skills of health professionals play a crucial role in the delivery of quality, patient-centred, care.

Despite the publication of official policy documents emphasising the importance of effective communication and interpersonal skills in the medical encounter, evidence suggests that patient expectations are still not being met. Mcilfattrick and Keeney (2003) argue that, despite much rhetoric, very little has actually been done over the last 20 years to improve the communication skills of health professionals. Other studies report that patients continue to be given bad news in an insensitive or inappropriate way, that preferences for information provision and involvement in the decision-making process are not being realised, and that psycho-social support is either inadequate or absent altogether. Furthermore, it is apparent that oncology health professionals are not yet receiving adequate communication and interpersonal skills training.

NLP appears to be one of a number of potentially helpful methodologies for improving the communication and inter-personal skills of health professionals working in cancer care. Yet, the suitability of NLP training for this group has not yet been explored in any mainstream research. The study discussed in this report evaluates the usefulness, relevance, and acceptability of NLP training among cancer care health professionals working in the Ellesmere Port area, as well as its value to patients and carers more generally.

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## Chapter 3

### Study design and methods

#### 3.1 The 'Living with Cancer' Project

The 'Living with Cancer' NLP training project was tailored to the needs of health professionals working in cancer services. The NLP trainers used the findings of each needs analysis focus group, with cancer patients, carers, and health professionals, to guide the development of the training programme and the content of the course and peer support group interventions. The four-day NLP training for health professionals focussed on:

- improving the clarity of communication;
- improving relationships;
- increasing awareness of the impact of language;
- increasing personal resourcefulness and coping skills to improve the management of emotions and stress levels.

The NLP training for health professionals was advertised through fliers distributed to primary care services, specialist cancer services, palliative care facilities and local hospices. These fliers were sent out by the Project Manager approximately two months prior to the commencement of each course. The fliers gave a brief description of the course and provided the Project Manager's contact details for further information and enrolment.

Four NLP training courses were delivered to health professionals during the three-year 'Living with Cancer' project. One course was held in February-March 2002, August-September 2002, January-February 2003 and a final course was held in October-November 2003. In addition to each of these four-day diploma courses, three two-day 'Top Up' training courses were held throughout the programme. Two NLP-accredited trainers<sup>2</sup> delivered the NLP training courses for health professionals.

In addition to the NLP training for health professionals the 'Living with Cancer' project established a peer support group for cancer patients and carers. The peer support group was run parallel to a separate Macmillan-funded and coordinated project to deliver a cancer drop-in information and referral service. The first peer support group met in May 2002 and continued to meet on a weekly basis throughout the project. In total, 62 cancer patients and carers attended the peer support group during the project, although the number of regular participants fluctuated on a weekly basis. The same two NLP trainers who delivered the NLP training courses for health professionals, also attended the peer support groups to provide NLP education interventions. The trainers offered the group NLP training interventions around communication skills and techniques, relationship skills, relaxation techniques and coping strategies.

The 'Living with Cancer' funding agreement included a clause to ensure the sustainability of programme activities. To this end, the NLP trainers provided two key members of the peer support groups with training in the skills needed to facilitate weekly meetings. The NLP trainers also provided training and support to the group as a whole to encourage them to continue meeting. In August 2003 the NLP trainers handed responsibility for the organisation and facilitation of the peer support group to its members.

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<sup>2</sup> Accredited by the International NLP Trainers Association.

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### **3.2 Evaluation of the ‘Living with Cancer Project’**

The ‘Living with Cancer’ project steering group commissioned the Centre for Public Health Research, University College Chester, to conduct an independent evaluation. The three researchers who worked on the study do not have any relationships with, ties to, or financial interests in any NLP organisation or practitioners.

### **3.3 Study design**

The evaluation of the ‘Living with Cancer’ project required research methods that move beyond calculations of prevalence and incidence, to examine personal, yet equally important, phenomena such as perceptions, beliefs, feelings, practices, experiences and behaviours. Qualitative methods are appropriate for conducting exploratory research into people’s knowledge, beliefs and understandings of their world. They provide rich data on the ways in which meaning is constructed and maintained by social actors. They also allow insight into the ways in which people interpret and contextualise knowledge, behaviour and meanings (Rice and Ezzy, 1999). The ability of qualitative research methodologies to generate analyses on the ways in which people interpret and attribute meaning to knowledge, behaviour, experiences and action makes them suitable for studying the outcomes of a programme designed to improve people’s diverse experiences of cancer care.

Qualitative methods also allow for an exploration of the social, cultural, structural, and physical contexts of individual experiences of the ‘Living with Cancer’ project. This promotes a deeper understanding of how the project was perceived and experienced, by patients, carers, and health professionals. Furthermore, only qualitative methods have the flexibility to allow participants the opportunity to reflect on the design and delivery of the NLP training, and to suggest ways in which the project may be improved.

Qualitative methods are particularly useful in conducting exploratory research. This feature makes them highly relevant to the evaluation of the ‘Living with Cancer’ project. The ‘Living with Cancer’ project is an innovative health improvement project. The complexities of its outcomes cannot be evaluated through standardised quantitative measures. Rather, the rich, detailed data provided by qualitative methods allows for an evaluation of the various outcomes of the programme without forcing rigid measurements onto the data.

Qualitative methods are also preferable in the study of phenomena where ‘the social context of people’s lives is of critical significance’ (McDonald and Daly, in Rice and Ezzy, 1999, p. 5). Cancer does not occur in a vacuum. Rather, it is embedded in complex, interrelated ways within the psychological, social, spiritual, economic and health spheres of people’s lives. Therefore, a qualitative methodology was used to evaluate a programme designed to improve the multifaceted experiences of people in relation to the cancer journey and cancer services.

### **3.4 Research ethics committee approval**

Ethical approval for the initial needs analysis focus groups with patients and carers was granted by the South Cheshire Local Research Ethics Committee in August 2001. A second application, for ethical approval to conduct post-intervention interviews and focus groups was sought in July 2002. In August 2002 the South Cheshire Local Research Ethics Committee granted approval for the additional research.

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### 3.5 Focus groups

Focus groups were selected as the most suitable research method for collecting data to inform the development of the 'Living with Cancer' NLP training project, and to evaluate the delivery of patient and carer peer support groups. The needs analysis focus groups were designed to explore patient, carer and health professional perspectives on cancer care, to ascertain unmet needs among each group and to explore ways of improving experiences within cancer care through NLP training. The evaluation focus groups with patients and carers sought to gather information on the effectiveness of the project in achieving its aims, objectives and the needs of participants. Focus groups were identified as the most appropriate, accurate, cost effective, timely, and efficient data collection method for these components of the study.

Although focus groups are useful methods at any stage of the research process, they are among the most suitable methods for conducting exploratory studies (Stewart and Shamdasani, 1990). The open-ended nature of focus group interviews allows participants to discuss issues that they feel are relevant to the research topic. This assists researchers in describing new and emerging issues, trends and phenomenon. This feature of focus group methods made them particularly appropriate for exploring cancer patients', carers' and health professionals' experiences of cancer services and the 'Living with Cancer' project.

Focus groups are a highly appropriate methodology for research among socially and economically disadvantaged groups. The verbal basis of focus groups promotes the participation of marginalised individuals who may have poor literacy skills (Calderon et al, 2000; Gettleman and Winkleby, 2000). In this way, Kitzinger (1995, p. 299) argues that focus groups do not 'discriminate against people who cannot read or write'. Furthermore, the social interaction and internal power relations inherent in focus groups can serve to promote the participation of individuals from socially marginalised groups. Unlike individual interviews, where the interviewer maintains control throughout the interview, focus groups involve an equalisation of the balance of power between the interviewer and the participants (Kidd and Parshall, 2000). In this way, individuals can guide the discussion toward issues or concerns that interest them. This situation effectively grants individuals a voice, temporarily empowering groups that may be relatively disenfranchised within the wider society. Given the location of the 'Living with Cancer' project within a socio-economically deprived area, these characteristics were pertinent in the selection of focus groups as a research methodology among patients and carers.

Birchall et al. (2000) argue that focus group methods are useful for conducting research among cancer patients as they provide an effective and efficient method of collecting data, while simultaneously promoting the involvement of patients in the research process. However, Birchall et al. (2000) did not consider the effects of decreased mobility and/or poor health on focus group participation among cancer patients. Poor health and decreased mobility appear to be two factors that may prevent the participation of cancer patients in focus groups, particularly for those in the later phase of the disease, and those receiving chemotherapy. This potential source of bias was taken into account in the analysis of focus group data.

While focus groups are a highly appropriate method for research among cancer patients and carers a practical concern related to their implementation was the need for facilitators to be sensitive to the needs and concerns of participants. Morton (2002) argues that focus groups with cancer patients should be facilitated by a sympathetic, professionally aware person who conducts the group in a balanced manner. Facilitators should avoid being too demanding of participants, both in a physical and emotional sense, yet at the same time they should be careful not to downgrade the process. Morton (2002) also highlights the importance for focus

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groups to be held in a comfortable atmosphere. Each 'Living with Cancer' focus group strictly adhered to these principles to ensure the comfort of all participants.

### **3.6 Recruitment of participants for the needs analysis focus groups**

Three focus groups were conducted to inform the development of the 'Living with Cancer' project. The first focus group was conducted with health professionals in September 2001. The findings of this focus group were utilised by the NLP trainers to tailor the training programme to meet the needs of health professionals working in cancer care. In late January 2002 two other needs analysis focus groups were conducted, one with cancer patients and the other with carers. The findings of these focus groups informed the design and implementation of the 'Living with Cancer' patients and carers support group.

Focus group participants were recruited through purposive (non-probability) sampling methods. The Project Coordinator identified a group of health professionals working within Chester and Halton Community NHS Trust cancer services as 'key informants' (Denscombe, 1998). These health professionals were identified as key informants on the basis of their professional role, and extensive experience, working with patients and carers within cancer services. Each health professional identified as a key informant for the needs analysis exercise was sent a letter of invitation to attend the focus group, a Health Professionals Information Sheet (Appendix 2) and a Consent Form (Appendix 2). Health professionals interested in attending were asked to contact the Project Coordinator, through the telephone number listed on the letter of invitation, to confirm their attendance. Participants were asked to read and complete the consent form prior to the commencement of the focus group.

Participants in the cancer patient focus group were recruited through convenience sampling methods (Bowling, 1997). Leaflets advertising the project and the patient needs analysis focus group were distributed to: the Cancer Care Drop-in Centre; GP surgeries; Day Treatment Centres and local support groups. Patients who expressed an interest in attending the focus group were given a Patient Information Sheet (Appendix 2) which provided information about the project and invited them to take part, and a Consent Form (Appendix 2). Patients were asked to provide a contact number in order for the focus group organiser to contact them with details about the focus group. Before the patient focus group began all participants were asked to read and sign a consent form.

Participants in the carers focus group were recruited through a combination of purposive (non-probability) sampling and snowball sampling techniques (Biernacki, 1981). Cancer carers living in the area, known to the Project Coordinator, were contacted by telephone and invited to attend the focus group. Additionally, participants in the cancer patient focus group were asked to refer carers interested in participating in the research to the Project Coordinator. A Carers Information Sheet (Appendix 2) and Consent Form (Appendix 2) was sent only to those carers who expressed an interest in participating. After one week the Project Coordinator telephoned those who expressed an interest in attending to confirm if they were still willing to attend the focus group. Those willing to participate were provided with the time and location details of the focus group and asked to complete the consent form before the focus group commenced.

### **3.7 Recruitment of participants for the evaluation focus groups with cancer patients and carers**

Two evaluation focus groups were conducted with the cancer patients and carers peer support group established by the 'Living with Cancer' project. The first evaluation focus group was

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conducted in November 2002, approximately four months after the group was established. The second focus group was conducted in March 2003.

Participants in the patients and carers evaluation focus groups were recruited through purposive (non-probability) sampling. As the Ellesmere Port cancer patients and carers peer support group had a relatively small membership (approximately six regular members) the recruitment process sought to include all peer support group members in each evaluation focus group.

A researcher from the Centre for Public Health Research attended two patient and carer peer support meetings, gave a verbal explanation of the research and distributed Patient and Carer Information Sheets (Appendix 3). Group members were then invited to attend a focus group, held at the same venue, immediately after a support group meeting two weeks later. Written consent (Appendix 3) was obtained from all participants prior to each focus group.

### **3.8 Interviews with health professionals**

Semi-structured interviews were identified as the most appropriate methodology for the evaluation of the health professional NLP training component of the 'Living with Cancer' project. This methodology has a number of advantages over pre-coded questionnaires for the collection of data to evaluate training courses. Firstly, semi-structured interviews provide interview respondents with the opportunity to discuss topics relevant to their own experiences and values. Secondly, interviews reduce ambiguity by allowing interviewers the opportunity to clarify the responses made by interview subjects (Bowling, 1997). Thirdly, this methodology gives researchers the flexibility to probe for information on topics they recognise as important to the research purpose (Britten, 1995). Fourth, semi-structured interviews are able to provide rich, detailed and highly relevant 'quotable' data (Bowling, 1997, p.231). Finally, this methodology is useful for exploring new subjects, such as the delivery of NLP training to health professionals. The use of semi-structured interviews in the evaluation of the NLP training course allowed for a thorough exploration of participants' perspectives, feelings, and beliefs about the course.

### **3.9 Recruitment of interview participants**

Between May and November 2003 semi-structured interviews were conducted with 23 of the 55 health professionals (42%) who completed the four-day NLP training workshop. Table 3.9.1 describes the professional role of the 23 health professionals who participated in an interview. Participants were recruited through convenience sampling methods (Bowling, 1997). A researcher from the Centre for Public Health Research attended the closing session of two training courses and explained the purpose of the research. Subject Information Sheets (Appendix 4), with a tear-off section for participants to consent for follow-up interview, and provide their contact details, were distributed. Those health professionals willing to participate in an interview were asked to return the consent and contact details slip to the Centre for Public Health Research in the pre-paid envelope provided. A researcher from the Centre for Public Health Research then contacted those interested in participating by telephone to arrange an interview time and location convenient for the participant.

Some health professional interview participants were recruited through snowball sampling techniques (Biernacki et al, 1981). These participants were asked by work colleagues (who had already participated in an interview) if they would be willing to participate in the research. If they consented their colleague passed on their contact details to a researcher at the Centre for Public Health Research who then contacted them by telephone. The purpose of the study was explained and the health professional was invited to participate. If the health



professional stated that they were willing to participate in a semi-structured interview the researcher then arranged a convenient interview time. All participants completed written Consent Forms (Appendix 4) before the tape-recorded interview commenced.

**Table 3.9.1      Profession of interview participants**

<b>Profession</b>	<b>Number</b>
Administrator	1
Complementary therapies practitioner	2
Counsellor	2
GP	1
Health Service Coordinator	4
Health Visitor	1
Nurse	7
Clinical Nurse Specialist	2
Primary care worker	1
Psychiatrist	1
Social Worker	1
<b>Total</b>	<b>23</b>

### **3.10      Data analysis**

There are numerous different theoretical approaches underlying qualitative research methods. Perhaps the most established and influential of these theories is Grounded Theory (Glaser and Strauss, 1967). Grounded Theory is essentially the development of theories and understandings through data. Grounded Theory involves the systematic analysis of data to generate new hypotheses, explanations and interpretations (Glaser and Strauss, 1967). Unlike some other approaches, which involve logical deductions from existing theories, Grounded Theory is based entirely in the data. Grounded Theory is an iterative process where themes and concepts emerge from the data. This differs from other models where the data is forced into rigid pre-established explanatory models that can ‘contaminate’ emerging categories and concepts (Glaser and Strauss 1967, p. 37). Furthermore, the use of data to form new hypotheses allows for the continual development and reformulation of theory. In this way Grounded Theory is a process rather than a static model. By drawing hypotheses and explanations from the actual data, Grounded Theories have a greater potential to ‘offer insight, enhance understanding and provide a meaningful guide to action’ (Strauss and Corbin, 1998, p.12).

Grounded theory was used as a model for the analysis of data collected in the evaluation of the ‘Living with Cancer’ project. Grounded Theory was separately utilised in each of the three components of the research. Firstly, Grounded Theory was applied in the analysis of data from the initial needs analysis focus groups with patients, carers and health professionals. Secondly, it was utilised to analyse data from the evaluation focus groups with patients and carers who attended the ‘Living with Cancer’ peer support group. Thirdly, Grounded Theory was applied in the analysis of data collected from interviews with health professionals who attended the NLP training course. The use of themes and quotations throughout this report illustrates the utilisation of Grounded Theory for the analysis of study data.

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## Chapter 4

### Findings from the needs analysis focus groups

#### 4.1 Findings from the needs analysis focus group with health professionals

The needs analysis focus group with health professionals was held 18 September 2001. Participants were drawn from cancer services in the Ellesmere Port area. A total of eight participants (all women) attended the focus group.

The focus group discussion centred around health professionals' interactions with cancer patients and carers. Participants considered the characteristics of effective, mutually rewarding, relationships with patients. Professional perspectives on information provision and the involvement of patients in decision-making were also discussed. Furthermore, the group examined the ways in which health professionals could improve patient experiences within cancer treatment and care services.

Establishing good relationships with patients and their families was considered fundamental to the provision of quality cancer care. Participants acknowledged that the failure to establish good relationships with patients may result in patient distress, anxiety, anger and confusion. Not only does the patient suffer, their family and the health professional also may suffer similar negative outcomes.

Participants examined the characteristics of good relationships with patients and carers. A number of qualities fundamental to the development of effective relationships were identified. Foremost among these were notions of 'trust', honesty, and empathy.

*You've got to be open and honest with people.*

The group felt strongly that time has to be taken from the outset to build actively good relationships with patients and their families. This involves early introductions to the patient and their family and maintaining this relationship throughout the cancer journey.

*Early introductions to the patients and the family. Not going in at the end or crisis intervention, it's about building up relationships.*

Taking the time to listen and talk to patients was considered essential for the creation of good relationships. Participants acknowledged the need for health professionals to have good listening skills and to be willing to give patients quality time to sit and talk with them.

*... give them that quality time so they know that you're there for them, which I think is important.*

The avoidance of interruptions when interacting with patients was identified as a primary consideration. Participants also emphasised the need to make patients and carers aware that they have got the time to give them their undivided attention.

*I'm sometimes aware that carers think that they are taking you away from the other patients, when you are on the ward. They can hear little bells ringing, phones ringing. You are quite happy because you know someone is out there. But they say 'have you got time?' it can be difficult for them to understand that we have got the time to sit with them to talk.*

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Sensitivity and empathy were recognised as essential health professional characteristics. These qualities were noted by the group as indispensable not only for building relationships but also for effective information provision and for gauging patient preferences for participation in decision-making.

*You can ask them certain questions and depending on what answer they give, and what they ask you can tell whether to push it any further.*

Body language was also identified as an important element in the creation of good relationships with patients and carers. Participants noted that health professionals should be aware of their body language when interacting with patients and should maintain an 'open' style of body language.

The group observed that emotional stress is often unavoidable in good, empathetic relationships with terminally ill cancer patients. While an emotional connection between the patient and health professional has benefits for both parties, sometimes these emotions can become overwhelming. One participant noted:

*You have bad days ... someone comes in who you have known for a long time and they start crying and you think that's it, I'm going to sit down and cry with them.*

Situations where patients ask if they are dying were noted as particularly emotionally challenging. As one participant observed, this is the most difficult question to answer:

*I find it very hard but one does because one has to when people are saying 'am I dying?' and that sort of situation. It's far easier to be telling them what services are available than you know, to be answering those questions ...*

Difficulties in communicating information to patients and their families was a source of great concern for the health professionals. Patient and family emotional distress were noted as problematic barriers to overcome in the delivery of information about patient treatments. A lack of knowledge about medical treatments was also recognised as a serious barrier to effective information provision.

*We had a problem not so long ago when a patient needed pain control, needed morphine for pain control. We spoke to them, the doctor spoke to them a hundred and one times. Then on the day that we were going to give her this morphine the family said, 'Right you are going to kill her now aren't you?' I mean we had just spent hours, days, trying to explain it and we said no, this is for the pain control, she is in pain, we can't leave her in pain. I don't know whether that family ever realised what we were trying to tell them. They found it quite difficult to understand ...*

Participants raised the topic of patients' spiritual needs in relation to the delivery of quality care. This topic was thought to be often neglected within mainstream cancer services. It was agreed that addressing patients spiritual needs was sometimes very difficult. However, participants noted that this was a very important part of many patients' lives and that they thought it essential for services to consider these needs, especially in the later stages of terminal cancer.

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*Well it was something [spiritual needs] that hadn't been, as far as I knew, addressed so I spoke to the husband and said to him, 'did your wife go to church?'. She went to the hospice day care and she was thrilled to bits at the services that they had in the chapel so I suggested to him that perhaps she might like to see the Priest ... I think the husband felt more comfortable that that was sort of, had been mentioned.*

Participants articulated the need for increased cancer patient support and information services in the area. The group agreed that a drop-in information and referral centre would be a valuable service<sup>3</sup>.

*I think the drop in is a good idea, we need something like that where they [patients] can access information, written information, or even videos.*

Participants considered continuity of care a primary concern in the provision of cancer services. Continuity of care was noted to assist in the development of good relationships, to reduce communication problems between health professionals and to enhance patient satisfaction. The group agreed that continuity of care is fundamental to quality patient care and job satisfaction among health professionals.

The problem of a lack of awareness about cancer services in the community was discussed at length during the focus group. Participants felt that some doctors are unwilling to refer patients to supportive services and that patients are generally unaware of the existence of these services. Participants expressed the view that delays in patients receiving this care often results in confusion and anger, which increases stress for the patient, their family and the health professionals involved in their care.

*They [patients] can be very angry as well, can't they? They haven't had the services because they haven't known about them.*

The group also expressed the view that communication difficulties often occur between health professionals. Breakdowns in written and verbal communications were thought to lead to a loss of confidence in the service, missed doses of pain control medication and increased stress. Participants noted the need for better communication between health professionals, especially between day and evening staff.

*... really perhaps there should be more liaison between the day staff and the evening service.*

## **4.2 Findings from the needs analysis focus group with patients**

The needs analysis focus group with patients was held on 29 January. Eight participants attended the group, five women and three men. The group discussed a range of topics relating to their personal experience of the cancer journey and their interactions with cancer services and health professionals.

A dominant topic throughout the focus group discussion was the perception that some health professionals lacked sensitivity, empathy, and the ability to communicate effectively about

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<sup>3</sup> The 'Living with Cancer' needs analysis focus groups were conducted prior to the establishment of a Macmillan cancer drop-in information and referral service.

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diagnosis and treatment options. Consultants in particular were often considered technically competent but unable to establish effective relationships with patients.

*I saw em a doctor [name] who's got the bedside manner of an ape because he said yes, do you know why you're here? I said yes I do ... 'Well yes, you have got cancer, that's right' and then he carried on, looked at me like this, as if to say right, what are you going to do now .... I almost got the impression he couldn't wait to get out of the room. I asked him a question. I can't even remember what the question was now, he said I'll find that out and he didn't even pick up the telephone and he went and just kind of left. My mum was actually with me and we both actually looked at each other and I said do you think there's something wrong with him but I was absolutely astounded, really astounded. I think he's quite a competent doctor you know I've got quite a good confidence in his abilities to treat me because I have seen him one other time. I just couldn't get on with how he, you know, how he dealt with it. Bedside manner does count for a lot.*

*Some of them are demi-gods, they **tell** you, you're not supposed to ask questions.*

Participants perceived many consultants as having poor interpersonal skills. The group discussed various negative experiences of consultants delivering bad news in an unsympathetic manner. This was a source of continuing anger and bitterness for some participants. However, not all clinicians were thought to be lacking in personal skills. Participants appreciated those doctors who they felt comfortable talking to, who took the time to explain things for them, who responded to their informational preferences and emotional state, and who had a good 'bedside manner'.

*... I mean doctor [name] was wonderful. He said look I can even draw what we've took out, what we're gonna do and what's going to happen to you and it was absolutely wonderful, it really was, that doctor [name] for me was fantastic. He's got a lovely bedside manner.*

Participants on the whole had high regard for nurses. However, even among this group of health professionals it was noted that they could sometimes fail to meet patient expectations for psycho-social support.

*Technically, and what was actually gonna happen to me yes, it was brilliant but actually on a patient like bed manner type, all I was saying to the nurses was 'what's it gonna be like? What's gonna happen to me?' And it was more the actual how I was gonna feel that I wanted to know more than the technical side of what they were going to do ... I just wanted to know how I was gonna feel, again its the personal bit, its the how, its me, its my life you're playing with here.*

Generally, participants felt that their interactions with nurses were overwhelmingly positive. Nurses were considered excellent sources of information, care, and emotional support. Some participants polarised the personal care provided by nurses with the distanced professionalism of doctors.

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*The specialist talks to me and explains to me but it seems that you're just on a production line. He might as well be working down at Vauxhalls like, put a few screws in and pass him, pass him to the next person. Yes that's the way it seems to me ...*

*All of the nurses make sure, even if it's five minutes, they'll have a sit down, right are you ok, is there any medication you need? And it's just that bit of personal time between you. And its just that bit ... of timeout for you instead of oh right you're the next patient ... you know like you're on a system... if you're upset they'll have a bit of a chat with you and they'll make that time. That's instead of just like you're on a system and you're just going along, you're in for your treatment then you're out from your treatment, a conveyor belt kind of thing. Yeah, instead of feeling like that it just makes you feel like they are caring for you ... just that five minutes, it just makes such a difference.*

Macmillan nurses were viewed as accessible sources of valuable, 'specialist' information about cancer care. In contrast to busy doctors, participants felt that Macmillan and other nurses were generally more approachable and willing to give their time to patients.

*You don't feel like you're taking up her [Macmillan nurse] time, she says 'If you need anything... ring me'.*

Macmillan nurses were also seen as providing peace of mind in relation to symptom control and, often more importantly, emotional distress. Participants felt that they could rely on Macmillan nurses to provide support when they were feeling stressed or depressed. The knowledge, experience and caring characteristics of Macmillan nurses were thought to provide reassurance, comfort, 'peace of mind' and confidence during periods when often patients felt they had no-one else to turn to.

*... she [Macmillan nurse] gave you that confidence. You felt great in front of the woman ... I mean I can't give any more accolades for that woman she's absolutely fantastic. I mean she comes to your house, she makes you feel so welcome and she's brilliant, absolutely brilliant.*

Despite the important role of Macmillan nurses, concerns were raised that consultants and GPs are reluctant to refer patients to the service until they are in the very final stage of the cancer journey. Participants noted that late referrals to the Macmillan nursing service caused many cancer patients to miss out on essential support, not only from Macmillan nurses, but also from a range of other services.

The importance of efficient and effective communication between health professionals was emphasised by participants. Delays in test results and correspondence between doctors was a source of considerable stress. Participants questioned why this was occurring in the age of electronic communication and technology such as email. They also queried the ability of cancer treatment services to provide quality care when communication between health professionals was so poor.

*I don't think that the lot of them get together like I keep saying, they don't get together, they're not talking to each other ... Now I know they're very busy ... but you don't get the feeling that there's close follow up and you do sometimes think well does this colleague know?*

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*... And I find that the, er the information from your specialist is not getting back to your doctor. It's weeks and weeks after.*

Participants also discussed the potential of doctors' receptionists to act as impediments to effective communication. The group discussed the gatekeeper role of medical receptionists with vehemence. They described how their illness heightened their emotional sensitivity and made them feel particularly vulnerable to intrusive questions asked by administrative staff. Participants gave examples of situations where they had experienced aggressive questioning from medical administrative staff, often leading to emotional distress and sometimes resulting in an argument.

*I rang up and I must have been on to the secretary for about 10 minutes saying no I need the doctor out, 'well why can't you come down', 'well I'm not allowed to come down', 'well why aren't you'. It was really intrusive, and after going through something like that I was still quite emotional about things. I was trying to get back on my feet and it was well why, well why, well why and I was just saying and I had to literally say 'look I've been in I've had this', I've had this'.*

Participants acknowledged the difficult position of doctors' receptionists as mediators between patients and doctors. It was felt that one way to overcome tension between medical receptionists and very ill patients would be to somehow flag cancer patients as persons requiring urgent access to their doctor.

*If there was some way they could red flag people who've got cancer or who have had a serious operation so when the receptionist gets a phone call they know that it could be a potential emergency.*

A considerable amount of the focus group discussion centred around information needs, preferences and experiences. Group members discussed their shock and emotional upheaval at the time they were provided with their diagnosis. It was agreed that providing patients with information at this time was ineffective. The emotional distress experienced by patients was often so overwhelming that they had great difficulty processing and retaining information.

*When they first tell you they could talk for another five minutes and you will hardly hear a word they say because you, you feel like somebody's whipped the carpet right from out underneath your feet.*

Some patients felt that their information needs had not been met by their doctors while others felt that their doctors accurately matched their preferred level of information provision and involvement in decision-making. One participant stated that at the time of her diagnosis she preferred to leave the decision-making role to her doctor, although this changed after she came to terms with her cancer.

*... they tell you yeah it is cancer and you know what do you want us to do now? You think hang on, shouldn't this be a little more in your court not mine?*

Overall, the group highlighted the need for health professionals to be more aware of patients' information preferences and willingness to be involved in treatment decision-making. It was felt that the best way for health professionals to meet patients' information and decision-making preferences was simply to take the time to listen to patients and answer questions. Group members whose doctors had done this reported greater patient satisfaction.

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*I had [Doctor's name] and she said anything you need, you might think it's the daftest thing, but anything, you ring me. And I did and there was a couple of questions like you said, three days later. I was like well what about that, what about this, what about that and I rang and she gave me that information over the phone, em and I did make that choice ...*

The group made several suggestions on how cancer treatment services could improve information provision to patients. Foremost among these suggestions was the observation that health professionals should not rush patients into making decisions about treatment. Patients should be given sufficient time to absorb information and to discuss treatment options with their family before making their decision.

*And they were saying you know, do you want the breast removed or, I thought I can't make that sort of decision, not here, not now ... Let me think about it in my own home and talk to my husband about it. Just get my head around it first. I can't just say yay or nay like that without more information and you did need more information for that sort of decision. I did get put in touch with the breast care nurse and we did have quite a good chat at the hospital that afternoon but it did take me overnight to try and, try and take the information in, try and make a decision.*

The group also felt that patients should be provided with the opportunity to speak to other patients who have already undergone treatment. Participants felt that only other patients could accurately describe how they could expect to feel while receiving treatment.

*They gave me a lot of information and I used the internet ... I would have loved to have spoken to somebody who'd had the stem cell transplant, not so much as what it involved and what was gonna happen because medically you leave that to the doctors and the nurses ... but more about how you felt because I was very scared of the unknown ... I would have loved to have just spoken to somebody and said well how does it feel, not the technicalities.*

It was also noted that health professionals should use lay terms when providing patients with information. It should never be assumed that patients will understand relatively simple biological or medical terms. Health professionals should assess patient's level of understanding and should adjust their information accordingly.

*... they said about having this stem cell transplant. And when they said to me stem cell transplant ... hadn't got a clue... I'm sitting there and thinking what, what are stem cells to begin with never mind any, what are they you know, what are they? ... So its not only timeliness, its putting things in a way that you understand ... I went and Dr [name of consultant] said your bloods made up of this that and the other and this is what we want to do and everything. Again, it didn't all go in, what he was telling me because you're trying to take in so much information, but there's so much that your brain just goes, hold on a minute, slow down here.*

The group felt that there is a need for all newly diagnosed patients to be provided with a patient information pack or 'starter pack' with leaflets, details of relevant services and contact telephone numbers. It was highlighted that patient information packs should be tailored to



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each phase of treatment. The information should be broken down into relevant, manageable pieces and should contain practical advice on a range of topics, including exercise and diet.

#### **4.3 Findings from the needs analysis focus group with carers**

The carers' needs analysis focus group was held 30 January 2002. Despite concerted efforts to recruit a group of 10-12 participants, attendance was quite poor with only two men and one woman participating. All of the participants were bereaved carers of cancer patients.

The group discussed their experiences of being carers within mainstream cancer services as well as their own personal experiences of being a carer on the cancer journey. The diagnosis experience, from a carers' point of view, was discussed at length. Each participant felt that there had been unnecessary delays in the diagnosis of their loved-ones. The group also expressed their anger in relation to the insensitive manner in which some health professionals delivered diagnosis information.

*Tests were being done etc and a person in a very high profile, very high profile position came into the ward where my wife was lying still the stomach swollen and she came in with a student nurse and her words to us were 'cancer, malignant' and walked out, that was it, that was all that was said.*

The group identified communicating about cancer with family members and friends as a particularly challenging aspect of their role as carers. Participants reported often feeling uncomfortable and upset when discussing their partner's illness with family members and friends.

*Your family and friends would come in and say we know how you feel, but they don't really know what to say ... Family and friends to this day still don't know what to say. So certainly when it was all happening, family and friends would come we'd be in tears.*

Participants spent a considerable amount of time discussing their information needs. As carers of cancer patients the group felt that they were often poorly informed about their partners' diagnosis, treatment, and prognosis. This lack of information contributed to the carers' stress levels and made them generally feel less able to cope.

*It was the not knowing when she went back into hospital. ... She was having major problems and I'm asking questions. How poorly is she? Is there any hope for her, etc and no-one, nobody would come and sit me down and talk. And this was going on over three years, the only person that sat me down was a Macmillan nurse ... this nurse sat me down and explained how poorly she was and that's the first time anybody spoke to me in over three years ... the pressures, stress building up on me personally was absolutely horrendous, not getting any response, not getting any information back at all ... No response, so you're surmising, she might die tomorrow, she might die in ten years time. You know, and to have that pressure on me as a carer, I could hardly cope with it.*

Participants felt that information about their partner's prognosis was essential in order to come to terms with cancer and to prepare for the future. One participant emphasised the need to have accurate information to prepare psychologically his children for the death of their mother.

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*For me that information [months to live] was, right start here, do this. It was like setting your stall out, you know we have got one bite at this. It starts now, with the kids we had to strengthen them, prepare them in that time that we had, and that was a joint thing.*

The group not only noted a lack of information in relation to their partners' disease but also in terms of general carers information. Participants agreed that basic information on cancer nursing, support services, social security benefits, and patient car parking arrangements, should be provided at the point of diagnosis. The group noted that this information is essential to ease the stress on both the patient and carer.

*You know the sort of information I would have liked within the first 24 hours? Something simple like contacts if you had a problem in the early hours of the morning for example, who do I contact? Would it be the GP, district nurse or whatever? Who do I contact? That service should be available right away, contact numbers and names if you have a major problem.*

While all participants agreed that patients and carers need accurate information about diagnosis, prognosis and support services, one participant felt that being given an estimate of months to live could be damaging. This participant recalled that her husband was 'distraught' upon being informed by his doctor that he had a certain amount of time to live. This highlights the need for health professionals to be sensitive to the information preferences of patients and carers. Information preferences should be explored prior to the delivery of any potentially distressing information. Participants stressed the importance of health professionals 'listening' to patients and carers.

*This comes down to the professional people ... listening to the carer and patient and listening to what they are telling them and saying this person he or she doesn't seem that they could cope with this. So its about them being very, very good at their job and understanding during a chat that this person is giving every indication that they want to know how long this person is going to live or the other way, they don't want to be told, you know.*

Health professionals who offered emotional support in addition to medical care were highly praised by the carers group. Participants greatly appreciated open, honest and caring health professionals who unreservedly gave their time and attention to patients and carers.

*There was a good lung specialist nurse up at [hospital], she gave us her card, and she was there for any problems we had. I actually felt that we got a lot of support from her ... I telephoned this lady and she was 100 % there, she explained everything, she was very, very good.*

Macmillan nurses were highlighted as very important sources of practical and emotional support for patients and carers. Their knowledge, experience and 'understanding' was greatly appreciated by the participants. The psycho-social support provided by Macmillan nurses was also greatly valued by participants.

*... the day before she [Macmillan nurse] was due, [wife] would be on such a high, look forward to it. She may have been there for an hour, an hour and a half, and she might not have said hardly anything but [wife] would say 'oh, I feel so strong now', and that would last for a few days ... she did us the power of good.*

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While most members of the focus group gave examples of good sources of support from health professionals, one participant noted an occasion he experienced great distress from a lack of support. This participant felt that more support services should be offered to patients and carers while patients are receiving chemotherapy.

*The time she was in the hospital there was no support at all. The oncologist came to see us and did say they would start chemotherapy as soon as possible as a precaution ... so yes ok we go along with that and she started to have her monthly chemotherapy and still no support as such, nobody, I don't know who to talk, or turn, to.*

The group emphasised that carers often have complex psycho-social support needs. Participants agreed that carers of cancer patients are usually physically exhausted and emotionally distressed. One participant felt strongly that carers needs are sometimes forgotten by mainstream cancer services.

*I don't want to take anything away from the patients in anyway but, so much emphasis is put on the patient and the treatment. And I don't think there is enough emphasis, having been there, been a carer, that I haven't had that respect or, help, if you like, as a carer ... But we all know ... that the carer goes through more stress than the patient, and that's a fact, and I found it. Well I was nursing this person 24 hours a day, tension, stress, I was losing my hair, you know. Because there wasn't an outlet for me, there wasn't anyone thinking about my needs.*

One participant suggested that the lack of psycho-social support for carers stems from the emphasis, within mainstream services, on treating the disease rather than the whole person. This participant felt strongly that the failure to provide families of cancer patients with enough support leads to ongoing bitterness.

*I feel like, well there is more going in to dealing with the actual disease than dealing with the devastation that the disease causes ... the people that are left behind are as malignant as the cancer that the person died of in the first place ... they are going away feeling bitter and twisted about it, that they haven't had the opportunity to either know or understand how things can be.*

Reflecting on their own experiences of being a carer, participants described the support needs of cancer carers in general. One of the most important needs identified by the group was having a person they could talk to.

*It's someone who I can talk to ... someone who could come and sit and listen.*

It was felt that talking to someone experienced in cancer care, or who had previously been a carer, would help to prepare psychologically new carers for the cancer journey ahead. Experienced carers were also viewed as important sources of practical knowledge and guidance.

*Yes, somebody saying to me what I should be saying to the patient, or knowing what I should be saying, if you like. Personally I think sometimes, should I have said that. I know that you learn from experience but, its nice to have a little bit of pre warning, if you like, about how to be a carer if you like. As I say what to do, because you*

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*are dropped in to that situation, and you don't know, yes, you do it and you get through it but sometimes you are hoping for that job to be made easier.*

Participants felt that their experience as cancer carers had, in some ways, had a positive effect on their lives. Participants acknowledged that many positive things could come out of caring for a loved one throughout the cancer journey. Positive outcomes included a greater understanding and tolerance towards other people, feelings of personal growth and a sense of increased emotional strength.

*You get stronger, and deal with things. And you've felt that. And its not a case of its all in your head, you do feel stronger about things.*

Participants stated that they would somehow like to 'give back' to others what they had gained through their own journey as cancer carers. However, they did not know how they could best 'give' or share their time, knowledge, and experiences to benefit others.

*You've been there as well. I often think when I am sat in the house with all this time on my hands that I could help, and maybe do something, and I think what we have been through has made us a better person and it would be nice to pass that on to someone else.*

Support groups were recognised as one potential avenue where bereaved carers could 'give back' to others. Participants noted that their personal experience of being a carer could help other people adjust to their situation. Participants felt that they could offer other cancer carers some help, even if only in a small way. Support groups were also seen as important for bereaved carers, to help them come to terms with their loss.

*You are in a room of like-minded people and you know that we have been there before. And we do understand, and its not just a case of patronising, we do know what it's all about. And if you being here can make things better for yourself or other people or somebody else later on, then it doesn't matter how small it is ...*

#### **4.4 Conclusion**

Several themes were common across all three needs analysis focus groups, suggesting that, at baseline, health professionals, cancer patients, and cancer carers shared common concerns in relation to the provision of quality cancer care. All three groups considered good communication between patients, carers, and health professionals fundamental to the delivery of quality care. Health professional empathy and a caring approach to patients was also highlighted as a major issue of concern. Each focus group emphasised the need for skilled, sensitive, accurate and appropriate information provision to cancer patients and carers. All three groups also expressed the need for increased psycho-social support to patients and their families.

The importance of good communication, not only between patients, carers and health professionals, but also within and between cancer services, was a major theme in each focus group. The three groups discussed their personal experiences of communicating within cancer care and the inherent difficulties of communicating with others about cancer.

The health professional group noted the difficulty of communicating 'bad news' and technical medical information to patients and carers. They suggested that the communication of negative information about a patient's prognosis is often distressing for both the patient and

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health professional. A major issue of concern for the health professional group was the management of their own internal emotional states so that could communicate bad news more effectively.

The patients and carers focus groups provided extensive examples of the poor communication skills of health professionals with whom they had come into contact. Both of these groups emphasised the need for improved communication between health professionals, patients and carers and between health professionals themselves. All three groups noted that poor communication increases anxiety, stress and emotional trauma for patients, carers and health professionals. It was also noted that poor communication can lead to unnecessary and dangerous delays in diagnosis and treatment. The patients and carers focus groups argued that health professionals should take more time to listen actively and talk to patients. They argued that health professionals need to improve their communication skills in order to provide better quality cancer care. However, the patients and carers groups also recognised a need to improve their own communication skills to better cope with the realities of communication within cancer services.

Closely related to the topic of communication within cancer services was the theme of developing good working relationships between cancer patients and health professionals. All three focus groups considered good relationships between health professionals and patients integral to quality cancer care. Each group discussed the characteristics they saw as integral to the development of effective relationships. These included honesty, trust, openness, a willingness to give time and listen to others, sensitivity, empathy, a caring approach to others, and a readiness to acknowledge and respond to the emotions of others.

The provision of timely, accurate, and appropriate information, in a sensitive and caring manner, was a major theme throughout each focus group. The focus groups with health professionals, patients, and carers provided many examples of difficult or inappropriate information provision. This was recognised as having serious negative consequences for patients, carers and health professionals. Each group highlighted the need for further health professional training on information provision. The patients and carers groups also expressed a need for cancer patients and carers to become empowered in relation to their information needs.

All three needs analysis focus groups also highlighted the need for improved patient and carer access to information and psycho-social support in the Ellesmere Port area. The focus group with health professionals recognised the need for community-based patient support services and a 'drop-in' information and referral service. Similarly, the focus groups with patients and carers emphasised the need for access to local cancer support and information services. Participants in the patient and carer focus groups stressed the need to talk to other patients and carers, to share information and experiences, and to access psychological support throughout the cancer journey. The focus groups supported the suggestion of establishing a cancer patient and carer peer support group. Psycho-social support at the time of diagnosis, during palliative care, and during bereavement emerged a chief concern for all three groups. The carers focus group in particular were very encouraging of peer support groups as a way of providing psycho-social support. They also recognised support groups as an opportunity to share their knowledge and experience to '*give back*' to the cancer community.

Each of these key themes informed the development of the NLP training programme for health professionals and the NLP education interventions to the patients and carers peer support group. The NLP-accredited trainers were given a summary of the central themes and issues that emerged from each of the three needs analysis focus groups. The trainers utilised this information to tailor the standard NLP training to meet specifically the needs of cancer patients and carers, and oncology health professionals in Ellesmere Port.

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## Chapter 5

### Findings from the evaluation focus groups with cancer patients and carers

#### 5.1 Introduction

Two evaluation focus groups were conducted with members of the patients and carers peer support group. Each focus group was held immediately after a peer support group meeting, in the meeting room used by the peer support group. The first focus group was held in November 2002 and had five male and three female participants. The second focus group was held in April 2003 and had one female and two male participants. One carer attended each focus group, the remaining participants were all patients.

The 'Living with Cancer' project established regular cancer patients and carers peer support groups at Ellesmere Port library in June 2002. Two NLP-accredited trainers attended the peer support groups over a twelve-month period. The trainers provided NLP education, primarily consisting of relaxation techniques and communication skills, to the support group members. The purpose of the evaluation focus groups with the peer support group was to assess the implementation of the support groups and evaluate the delivery of NLP education interventions to the group (further details of the NLP interventions are in the appendix). Each focus group was audio-taped and transcribed. The transcripts were then coded and analysed using Grounded Theory, leading to the identification of a number of themes.

#### 5.2 Findings from the evaluation focus groups with cancer patients and carers

The dominant theme that emerged from the focus groups was the concept of shared experiences. Focus group members discussed the value of the peer support group as providing a space to discuss their experiences of cancer, their problems, fears, and hopes for the future. Group members said that they were reassured by their discussions with people who were experiencing similar problems to their own. This sense of shared experience helped to alleviate feelings of loneliness and isolation. Participants viewed the peer support group as an emotionally positive experience, using terms such as '*comforting*' and '*consoling*' to describe the interactive group discussions.

*It was particularly good too, people together in a kind of, with the same experiences and sometimes something happens to you, you're the loneliest person in the world, but maybe at the end of the day, it can be comforting to know people who have had similar experiences.*  
(Group member from focus group one)

One group member felt '*dumped*' by cancer services after he had completed his cancer treatment. This participant believed that life could never return to '*normal*', despite the expectations of his doctors. For this participant, the peer support group provided a unique source of support, where he could talk with others who had actually '*gone through the same thing as you*'.

*When you have cancer and then you finish your treatment, you're sort of just like dumped, that's what it felt like to me, you're just sort of dumped back into so called normal life again, but you don't feel normal and you'll never feel normal again ... to actually come to a group where there's people that have actually gone through the same thing as you, it's been a help to talk too. Because out there*

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*when you're sort of on your own, I mean you know, there's people that have been with you, like your carers and family and so on, but they still don't know what it's actually like to experience it for themselves. So it is nice to come to a group and speak to people that actually know what you're talking about. (Group member from focus group one)*

An important aspect of the shared experience was the reassurance that peer support group members gained through their detailed medical discussions with others about cancer. Group members said they felt relieved to be able to discuss their disease and treatment with others who had similar levels of technical knowledge.

*It is actually a comfort to know that people have actually gone through the same thing, that when you talk to them about your blood levels and this and that, they actually know what you're on about, it doesn't go over their head, they actually know what you mean. And when you go for the Chemo, they've actually been there. (Group member from focus group one)*

Related to the concept of shared experience was the theme of sharing knowledge. The group strongly expressed the view that sharing their knowledge in the peer support group could improve other people's experience of the cancer journey. The knowledge of individual group members and the group as a whole was regarded as an important resource that other patients and carers could tap into to help solve or reduce common problems.

*There are people that can now benefit from what you actually had and I don't know how you felt about it, but if you can turn round to somebody else and just impart a small bit of knowledge, a small benefit to them, that they don't necessarily have to have what had happened to you ... a lot of people that I have met through these groups, whatever, I think they're all of a similar mind. If they could ... help through their experiences, so other people's experiences, though they're the same, are probably lightened or lessened in some way because of the understanding they've really achieved from other people with those experiences. (Group member from focus group one)*

A major theme to emerge from the focus groups was the relevance of the relaxation techniques taught by the NLP trainers. It was acknowledged that a cancer diagnosis induces considerable stress for the patient, carer, and the family as a whole. This stress continues throughout the cancer journey. Many of those fortunate enough to experience successful treatment and recovery do not automatically experience relief from stress. One group member observed:

*I found my stress has taken the shape of dizziness and panic attacks, like that and I feel like I'm going to pass out, so the stress was affecting my life when I was better, the treatment had finished and things were looking positive, but then the stress kicked in. (Group member from focus group one)*

There was a lengthy discussion among the focus group participants about the relaxation component of the peer support group. The relaxation techniques taught by the NLP trainers were considered valuable tools to control, and provide relief from, stress, anxiety and insomnia. Participants also positively appraised the skills of the NLP trainers in promoting a relaxing atmosphere in the group.

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*The weekly build up is one thing that I think is most important. When we do tai chi, sit down and put the tape on, the relaxation tape and they [the NLP trainers] just sit and talk and we are sitting with eyes closed and relaxing and they take us through the relaxation. Some of us fall asleep. So it's like you're going away from there totally relaxed. And as I've said we come in with some problems and the relaxation helps with that. (Group member from focus group two)*

One group member commented that the trainers had provided her with effective strategies to help her relax and cope with stress in her own time. This participant had incorporated the trainer's relaxation techniques and audio-tape into her daily routine to manage panic attacks and insomnia.

*... at night, getting stressed about how I was going to feel in the evening or frightened of the evening ... and that's what I'm fighting at the moment. I've found that [the NLP trainer] has really helped. I mean I go to bed with [NLP trainer's] tape every night now. I want to take [NLP trainer] home with me. (Group member from focus group one)*

Much of the focus group discussion was devoted to the topic of the perceived value of NLP techniques. One participant stated that she initially felt 'sceptical' about the techniques. However, after practicing them and feeling a benefit she now uses visualisation and 'anchoring' techniques on a regular basis to reduce her stress.

*It's like when you're feeling anxious or when you're feeling stressed you tend to do it and it sort of makes you feel more relaxed, but you have to keep doing it ... You breathe shallower and then you put your hands, cross them over and then you go like that and you sit with your hands on your chest, like that ... And it sort of calms you down, I mean it didn't have a great deal of effect at first because ... I was a bit sceptical really, but then when I started using it and listening to [NLP trainer's] tapes and visualising things more, sort of re-training my brain how to think about the situation better, more positive. I think that's really helped me ... [the NLP trainer] and I do a thing called Anchors, where she sits me down and she relaxes me and she makes me visualize, good sort of relaxation and nice places and so on, and she gives me an anchor... to visualize calm and peace and tranquillity. My anchor is to put my thumb on my knuckle, and that triggers off, in my mind and in my memory, what I was doing and the way I felt when I was, [NLP trainer] was, actually practising the technique on me. And it does work, because when I'm feeling stressed, I then start to you know, to do my anchor, it does trigger those memories, so it's very useful for me. (Group member from focus group one)*

Participants felt that the peer support group sessions not only taught them valuable relaxation skills, they also taught other practical skills to help them cope with their disease. One of the most important topics addressed by the trainers, and the group as a whole, was communication with health professionals. The group discovered, in a discussion on this topic, that more than one group member was having problems communicating with their oncology consultant. The NLP trainers suggested helpful techniques and strategies for coping with difficult communication situations. The mirroring technique, taught by the NLP trainers, was considered practical and helpful when communicating with 'patronising' consultants.



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*Yes well we're picking skills up. In actual fact we're picking up something on a weekly basis really, you know. There's different skills that come into it. One of the things which stands out in particular is we've had a lot of talk about communications ... For instance we've learnt a few skills of how to talk to the consultants you know rather than let them talk down to you. For instance we've learnt particularly one thing that is like mirror images like. (Group member from focus group two)*

Overall, the group had a very positive view of the professional input into the cancer patients and carers peer support groups. The NLP education, medical information, and service information was greatly appreciated by the group. This was illustrated in the comment of one participant who praised the efforts of the NLP trainers in the peer support group.

*One important thing to take out from here that I think can help a lot is ... when you come you're getting professional advice, both medical with the Macmillan Nurses and [the NLP trainers]. It's certainly absolutely brilliant, they're doing a really great job. (Group member from focus group two)*

Some participants found the NLP education interventions conducive to their participation in the peer support group discussions. The techniques helped them to relax and hone their concentration.

*You do a physical exercise like that, when we were half way through the meeting and you are deep down and you get up and just the act of walking round, doing things at this stage, the physical thing helps with everything, to leave behind all the problems you have, clear the mind. And then when it gets so I can have a good laugh, you get back down and your attitude to it is now so much lighter. (Group member from focus one)*

However, there was also a fair amount of confusion among participants about the purpose of the NLP education component in the peer support groups. Some participants questioned the relevance of the NLP techniques and activities in the peer support group. It was thought by some participants that the techniques 'were an afterthought' or 'just sort of, plonked in the group, just for something to do'. One participant thought that the trainers should have 'been a bit more forceful' in emphasising the benefits of the NLP techniques.

One participant had a sceptical view of the NLP education component in the peer support group. This participant felt that he could not personally relate to the NLP techniques, yet he did not dismiss the relevance of the education for other people.

*I thought it was a load of rubbish myself personally like, but everyone to his own. But I just thought the talking part was the best ... Sharing with other people ... Talking is very good, I must admit. (Group member from focus group one)*

Another participant described how his initial scepticism about NLP was overcome by actively deciding to have an open mind.

*I just thought when we come to that meeting, I thought, silly buggers playing silly games, you know. I thought well if I don't have a go. I did I had a go, and it was fun, it was relaxing, it was different from*

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*your everyday thing that you would do. And it took you off out of it, you know. (Group member from focus group one)*

Despite some reservations about the NLP techniques taught during the peer support groups, participants had an overwhelmingly positive view of the trainers themselves. The group praised the skills of the trainers and expressed great disappointment at the prospect of the trainers discontinuing their involvement with the peer support group.

*When she's [NLP trainer] talking, different things, just her voice was really calm, you know, talking to us about different things and I mean, my eyes were watering. I don't know why, but she was saying all these nice things and that, we just, we felt as though we were put to sleep. (Group member from focus group one)*

*I would miss, if and when they [NLP trainers] think their input ends. I will miss them very much. (Group member from focus group two)*

The theme of reciprocity recurred throughout each focus group discussion with patients and carers. Participants felt that their relationship with the peer support group was characterised by reciprocity. It was thought that in order to benefit from participation in the peer support group individual members would have to be willing to 'give something to the group as well'. This theme was raised repeatedly by participants during the focus group discussions.

*The thing is you've got to want to go, you've got to want to give something to the group as well, there's no point going and sitting there thinking, god this is boring I'm going home, you know what I mean, and I'm not going back again. It's there for you. (Group member from focus group one)*

The topic of how to improve the peer support group was discussed at length by participants. There was considerable concern that the group was poorly attended throughout the 'Living with Cancer' project. Participants thought that the group would need to double in membership in order to be sustainable in the long-term. One participant commented, 'We're going between four and six here at the moment, so we're 50 % there in a way'. There was a strong feeling of regret among participants that the membership potential of the group was not yet realised.

*Well what upsets me ... we leave here and we go home, like you're shaking your heads and thinking of the population of Ellesmere Port and there's only five, six people coming to a group like this. And it's so professionally run and so helpful, what you get out of it. You know it's the people being diagnosed or half way through cancer treatments now that I feel sorry for that are actually missing this opportunity. (Group member from focus group two)*

Participants proposed that official recognition of the support group as one potential solution to the problem of limited group membership. It was felt that consultant recognition and referrals to the group was important if attendance numbers were to be boosted.

*One of the things that we want to get in the group that we've spoken about is if we could get ourselves going is getting the group to be recognised by the professions is the sense that when you're diagnosed with cancer then the consultant says look here's a leaflet here, this is a wonderful support group, try that. People are wandering around with no purpose. (Group member from focus group one)*

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Participants also believed that the support group could be improved through regular information and advice visits from a range of professional organisations. One participant recognised the value of having an Advisor from the Citizens Advice Bureau visit the group.

*I came up with a suggestion two weeks ago, perhaps we can have professional visitors now and again on benefits. Because it's a problem when you're ill and you don't want to be filling forms in when you're not well. (Group member from focus group one)*

There was agreement among participants that the peer support group meeting facilities could be improved. The group currently meets in a room at the Ellesmere Port library. However, participants felt that the room was uninspiring and drab. Some participants contrasted the facilities and resources available to their own support group with those available to a cancer support group based at Liverpool hospital. The meeting facilities of the group were noted as something that must be addressed if the group was to continue in the future.

*The group is good, people get relaxation out of it. But change the environment. (Group member from focus group one)*

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## Chapter 6

### Findings from the interviews with health professionals

#### 6.1 Introduction

In total, 55 health professionals working in the Ellesmere Port area participated in the NLP training programme. These health professionals came from a broad spectrum of disciplines, from complementary therapy to psychiatry. Table 6.1.1 describes the professional role of each participant. Of the 55 health professionals who completed the training, 31 (56%) worked in a cancer service or primarily worked with cancer patients and/or carers in their professional position. A total of 19 (35%) training participants worked in a health service where they provide incidental care to cancer patients or carers as part of the professional role. Five (9%) training participants did not have any contact with cancer patients or carers in their professional role.

**Table 6.1.1 Professional role of NLP training participants**

Profession	Number
Administrator	1
Complementary therapies practitioner	2
Counsellor	3
GP	1
Health Service Coordinator	7
Health Visitor	2
Nurse	27
Clinical Nurse Specialist	2
Primary care worker	1
Psychiatrist	1
Social Worker	2
Unknown	6
<b>Total</b>	<b>55</b>

Between May and December 2003 a total of 23 interviews were conducted with health professionals who attended the 'Living with Cancer' NLP training course. This group included nurses working in cancer care and general medical services, Clinical Nurse Specialists, a GP, a psychiatrist, psychotherapists, health visitors, complementary therapies practitioners, primary care workers, mental health workers, social workers and service coordinators/facilitators. Most interviews were conducted at the participant's place of work, although a small number of interviews were conducted at the Centre for Public Health Research. Interviews were audio-taped and took approximately twenty minutes to complete. Each interview was transcribed then coded and analysed using Grounded Theory (refer to Appendix 4 for interview schedule).

A number of themes emerged from analysis of the interviews with health professionals. These themes included the decision to participate, thoughts and perspectives on NLP theories, practical implementation of NLP in the workplace, the relationship between NLP and existing knowledge and practices, and participant views on the delivery of the NLP training course.

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## 6.2 The decision to enrol

The first theme to emerge from analysis of the interview transcripts was the decision to enrol in the NLP training course. Participants cited a number of factors that contributed to their decision to participate in the training course. Curiosity about NLP was frequently discussed as a significant factor leading to the decision to enrol in the course.

*I'd heard sometime ago something about NLP from some people in the trust who had done the course. And I was curious about what it stood for. I think because of the name ... I wanted to know what it was about. I'd read just a little bit about it but I didn't know what it was about but I sort of had an idea of what it was. (Service Coordinator/Facilitator 5)*

Some participants had been aware of NLP for many years but had not previously participated in formal training due to cost and time considerations. These health professionals welcomed the opportunity to complete the four-day diploma course at no personal expense.

*I have been interested in NLP since I was a student nurse. But because the training is quite expensive when it's done privately I've never got round to doing it ... (Clinical Nurse Specialist 1)*

While many participants were unfamiliar with NLP prior to the training course, some had an understanding of NLP as a way of improving communication and inter-personal skills. These participants discussed their decision to enrol in the course as largely stemming from a desire to enhance their existing communication and relationships skills. Participants also stated that their decision was prompted by an eagerness to learn fresh new strategies to communicate more effectively and manage their own emotional states.

*I had done some reading around NLP so I knew that a lot of it would be around sort of rapport building, communication skills, so I was hoping to improve on my ability to engage with the clients that I work with because some of the young people that I work with can be quite difficult to engage, quite reluctant to speak to someone about their difficulties. So it's about being able to enhance rapport, also learn some specific techniques for helping people to deal with their difficulties, their emotional states. So its kind of things like that that I hoped to get from it. (Clinical Nurse Specialist 1)*

The value of learning was discussed as an influential factor leading to the decision to enrol in the NLP training course. Participants positively appraised learning as both a process and an outcome in itself. As one participant explained, 'knowledge is always interesting ... it's never totally wasted' (Nurse 4). The process of learning for the sake of learning was considered parallel in value to newly acquired knowledge and skills.

*I think any learning is valuable. And if it's anything that can help relieve anxiety and stress and worry in the patient, that's good. We have to use everything which is available to us. (Complementary therapist 1)*

## 6.3 Thoughts and perspectives on NLP

The 23 health professionals who participated in interviews about the NLP training programme expressed a range of views about the value of NLP and its relevance to their professional

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lives. Overall, the response to the course was very positive, however some participants remained sceptical about NLP. Participants with extensive training in the biomedical field tended to be more sceptical about NLP than others. However, this was not always the case. One participant explained that her scientific background actually gave her a greater appreciation of the logic of NLP.

*I think one of the things about the NLP training I found really quite attractive, it was based on something that I could appreciate, which was communication. Everyone can relate to it, it was really based on something. Yes, I can understand that. Because I come from a science background, I'm fairly logical and I like to know where things come from. And if you know what your base is then it's far easier to understand and to use something. (GP)*

Sceptics explained their reservations about NLP as stemming from the absence of reliable scientific data to support the claims made about NLP. These participants viewed NLP as 'pseudo-scientific' rather than being based on hard evidence.

*... one of the things I thought about the course was how would I actually justify this as a therapeutic technique to colleagues? ... for them there isn't the sort of data and the sort of justification for the findings. And some of the experiential experiments we did I found very frustrating because there was an implication that people's behaviour was changing for reasons that were to do with the interventions of NLP. There were 100 other possibilities as to why that person's behaviour changed ... (Psychiatrist)*

Participants felt that NLP can be effective, efficient, and highly appropriate in the increasingly time-restricted medical encounter. However, some participants expressed doubts that NLP techniques were 'too simplistic' to be effective in the clinical context. This group regarded claims about the effectiveness of NLP as 'suspicious', arguing that NLP techniques could not possibly be as helpful as complex traditional counselling techniques that take several months to produce positive results. Others argued that NLP perhaps initially appears simplistic, yet it is actually a very powerful way of interacting with patients, carers and colleagues.

*I've just found it [NLP] to be incredibly powerful. In fact I can't believe how powerful it is. And that's why when I speak to patients and I tell patients about it you know I use my examples and say you know this works for me. I would have thought what a load of rubbish, if somebody had explained it because it seemed so simplistic. But it does work. So you know, I use it all the time. I've taught members of staff, I've got quite a few members of staff that have used it for a difficult time that they've had to encounter. I said you know try this It's just another tool to your list. But it's a really good coping strategy. (Nurse 5)*

It was felt, in some cases, that NLP made unsubstantiated claims of ownership over certain techniques that are common in both everyday human interaction and traditional communication and counselling theories. Concerns were raised that NLP misleadingly labelled common communication behaviours as NLP-specific techniques.

*I would argue it is not NLP and that is one of the things I raised. Obviously somebody is a very good communicator and put a lot of good practice under the NLP umbrella. Some of those practices are*

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*being taught in lots of other different guises ... a lot of NLP is basic communication which I feel doesn't necessarily belong to NLP.*  
(Service Coordinator/Facilitator 3)

The initial scepticism of some participants eased during the NLP training course. These participants discussed how they entered the training very dubious about NLP, however, their perspective changed by the end of the course. Others held onto their doubts throughout and after the course. Participants who continued to have reservations about NLP preferred to rely on tested and trusted knowledge and traditional techniques.

*It was, because of by its nature the fact that it is the use of the neural system to, you know, interact with the psychological, it was quite different. I didn't feel it was for me. I was very comfortable with the way that I communicated and interacted already. ... It wasn't, I wasn't comfortable with it, but why change what works, you know ... I was much happier using the method that I was already using.*  
(Nurse 4)

Those who remained cynical about NLP nonetheless did not totally dismiss the value of the training for others. Even the most sceptical of participants reasoned that the course had the potential to provide some benefit to everyone. If nothing else, the training was seen as an opportunity to take time out from hectic work schedules and learn about something new in a relaxing environment.

Overall though, the general view was that training in NLP could yield practical benefits for most health workers. One participant stated that the training would be useful for nurses at all stages of their career, including nurses new to the profession.

*If one was starting from the beginning, for example I think this training would be very useful for nurses, I think it would make an excellent foundation from which to start.* (Nurse 3)

Another participant suggested that not only health workers but auxiliary health staff as well should be offered NLP training.

*I think it's a good course ... and I think yes everyone in the building almost could do with it, because everybody here gets to know the patients: the cleaning staff, the domestics, the kitchen staff, all get to know the patients ... Everybody's involved ... So I think it's a good course and I think the more people that can go on it the better.*  
(Complementary therapist 1)

Only two participants expressed concerns regarding the implementation of NLP in the patient-health professional relationship. These participants suggested that health professionals with limited experience in NLP may find themselves 'out of their depth' and potentially cause more harm than good to vulnerable patients. It was also suggested that NLP could be inappropriate or 'patronising' to cancer patients. One participant was also anxious about the lack of ongoing supervision for those who had completed the training.

*... I think it is quite worrying that there are people who are not really skilled enough will suddenly be using techniques that they probably don't understand ... Because you walk away with a diploma it could be very, very misleading to people. Counselling courses go on and on and on and you have supervision and you are looking actually at how you interact and what has worked and what*

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*hasn't worked so well and obviously as I said on going supervision. That is a very dangerous thing to me with NLP. It is a four day course ... Nobody is there seeing how they work ... that is a bit of an issue for me really. (Service Coordinator/Facilitator 3)*

In contrast to these comments, other participants felt that the course was relevant and helpful within cancer care. This was reflected in the statement made by one participant, '*I certainly see the relevance of it when we are working with cancer patients*' (Psychotherapist 1). NLP was considered a potentially helpful, yet essentially harmless, way of working with patients.

*I think with NLP if you do it wrong it doesn't really matter because you can't really do any damage. You could if you did it very wrong. But the benefits are very quick. (Primary care worker 1)*

#### **6.4 Implementing NLP**

Participants felt that the NLP training course had taught them valuable new communication techniques, as well as improving their existing interpersonal skills. It was acknowledged that the ability to communicate effectively, to build positive working relationships, and to manage inner emotional states, are essential skills for all health professionals. There was a feeling among participants that they were proficient in these skills prior to the training, however the course allowed them to hone their existing skills.

*I would really hope that anyone working in this field would have a decent ability to do things like build rapport and to communicate and to make steps to make sure they have understood what the other person is trying to express to them. But it has definitely, definitely helped with fine-tuning. (Primary Care Mental Health Worker 1)*

However, not all participants felt that the course provided them with new knowledge to improve their existing skills. This was reflected in the comment of one participant, who stated, '*...for me it didn't deliver massive amounts*' (Psychiatrist). This group thought of the course as interesting but did not regard it as having a significant impact upon their existing knowledge, skills or ways of working.

Nevertheless, an important sub-theme to emerge from the analysis of interviews with health professionals was the perception that the training course had a positive impact on existing skills. One of the key areas in which health professionals felt they had improved was in terms of their own self-awareness and reflexivity. Participants felt that their increased self-awareness and reflexivity allowed them to improve the quality of their communication with others, to manage more appropriately stressful situations and to improve relationships with patients, carers and colleagues.

*There are several techniques that we have used and several new ways of thinking that NLP's brought to me, I'm more self-reflective than I was before ... I certainly almost observe my interaction from a distance with patients and with relatives and with clients and with staff. Almost like a silent witness I stand back and observe what's going on which is another thing that the course taught us to do. Not to judge myself specifically but to look at ways that I perhaps could have done things better. So it's certainly become, I've become more reflective. (Nurse 5)*



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Participants felt that the NLP course had improved their ability to communicate effectively by increasing their understanding of body language and spoken language. The ability to listen more effectively and to read more accurately the subtle nuances of body language was acknowledged as a valuable skill.

*You are able to listen a lot better. Not only listen to what they're saying, you listen to what they're not saying. Which is an art in itself, you have to learn it. (Nurse 2)*

*I think I'm much more attuned to reading a lot more [body language]. It's like reading the fine print as well as the bold print ... with using the NLP, if you look closely enough, there's a lot more there. (Family Support Worker 1)*

The NLP concept of 'soft language' appeared to have a considerable impression upon participants. This method of communication was seen as highly relevant within cancer care. Participants positively appraised the concept of 'soft language' and discussed how they had integrated it into their work practices since completing the training course.

*I think the use of soft language is the most important ... I think that was the most positive thing that came out of the NLP ... the soft language ... that's used here all the time. (Complementary therapist 1)*

Participants stated that the rapport skills taught in the training course had a positive impact on their relationships with patients and carers. The training course provided many participants with their first opportunity to learn about techniques to build and close rapport. Participants felt that they had struggled for many years to cope with situations that required the 'closing' of rapport, such as the end of an appointment. Learning about techniques to 'close' rapport equipped them with a vital skill to improve relationships with patients.

*The 'closing' was useful, how to sort of back off a bit. ... stopping the rapport if you want to, say if your appointment time has gone. It's sort of backing off a bit as you get closer and closer to the end of the appointment ... you've got to back off because you've got someone else coming in, in a short space of time. That I did find difficult and NLP was useful for it. (Complementary therapist 2)*

Participants discussed at length the NLP technique of 'anchoring'. Participants viewed this technique as useful in helping patients to cope with stressful, upsetting or frightening situations. Many participants also implemented this technique to manage their own personal states.

*... there are particular skills that I have been taught on the course that do help, definitely help patients and their families through specific times when they have got very fearful thoughts, when they're very anxious, when they've sort of lost hope and are very discouraged. I find that some of the techniques that I have employed from the course are really useful to patients because they are able to sort of incorporate them as their own coping strategies ... anchoring ... has been very useful ... if you've got a patient who is finding it difficult to think in a positive way, or has fearful thoughts anchoring is a way in which you can try and get the patient to think differently by erm, encouraging them to access states that they have experienced in the past where they have perhaps enjoyed things or*

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*been positive ... I've used that with terminally ill patients quite a few times, for various things. Just for generally feeling fearful, as well as specific things like going for treatments ... And most people have found it very successful. It's just something that you can give them when it's a time where it's otherwise quite difficult to be able to offer somebody some support. (Nurse 5)*

The technique of thinking in terms of 'well-formed outcomes' was viewed as beneficial not only for patients, but also for health professionals themselves. This technique was appreciated as a strategy to promote and maintain motivation to achieve long-term goals gradually.

*... one of the things we did was looking from where we were now and where we want to be and then doing like stepping stones in between and I do that with this job all the time... To break it down into, to do with like stepping stones. Instead of looking far away to look half way. So what you would like to see half way. What you think would be your half way achievements but then there might be 20 little steps between that and the middle or there might be 12 or there might be 10. But you recognise your goals a step at a time rather than being overwhelmed by the whole thing. That has been really useful... (Service Coordinator/Facilitator 1)*

Other techniques that participants found helpful in their professional role since completing the training included the 'brain gym', the 'trauma cure', 'affirmation statements' and 'positive thinking'. Participants gave many examples of the ways in which they had implemented these new skills to improve patient care.

*Well I've used the trauma one twice. And one person's come back and said that's brilliant. He said, I just keep doing it to myself, you know because it hasn't totally exposed it, you know, there's still a little bit of whatever that trauma was, he says, but I just keeping doing it, saying it back to myself and it's much better. (GP)*

The ability of NLP skills and techniques to empower patients was also raised by participants during the interviews. It was felt that teaching patients NLP skills allowed them to increase their sense of control over their body, their disease symptoms and their emotional state. Respondents who taught patients NLP skills felt that they were imparting a valuable and effective tool and also some control over their life.

*So therapies that we learned, it's giving them something they can take home with them to help them cope with the pain. To get them thinking about other things. Although the pain is still there it makes them feel less stressed about it. (Complementary therapist 1)*

Participants discussed the value of NLP for managing internal states and provided many examples of the various ways in which they utilised NLP techniques to manage their stress and emotions. Some participants used their new skills to manage their emotions in regard to workplace conflict. This imbued participants with a sense of composure, confidence and empowerment.

*One technique that I learned that I didn't know about before was if you look up then you're not so in touch with your feelings and I found that useful for myself when I've been in difficult situations. If there was something I felt a bit sensitive about I sort of detach myself from my feelings and dealing with it in a more composed and*

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*confident way. So that's been really helpful.* (Service Coordinator/Facilitator 5)

Workplace stress emerged as a recurring theme during analysis of the interviews. Structural factors such as poor service management, under-staffing, and excessive workloads were a source of considerable stress for participants. The NLP skills learned during the course provided many participants with effective stress management strategies. For some participants, the training altered their approach to their work, allowing them to reduce dramatically their stress levels. This led to a perceived improvement in the quality their work.

*I think I'm a lot calmer about my time management. I'm more objective. That's back to this business about your own state and I certainly feel, you know, I've previously done stress management courses but I can't say it made a huge impact on me but I do think this course helped my state. And I do think that internal difference reflects on the quality of my work. I feel better and calmer. Maybe I'm more realistic, maybe I'm calmer, I don't know. How you feel reflects on the way things go. So I probably am more effective because if I'm calm and in a good state then hopefully that will have an effect on the people I'm working on.* (Family Support Worker 1)

Participants noted that many of the skills and techniques taught during the training course have been part of their daily interactions throughout much of their work and personal life. However, they felt that the formalised NLP training programme enhanced these existing skills.

*I realised after I went on the course that I was already doing some of it. The observation part, observing the patient's body language and using listening skills ... I was already doing visualisation and have been for some time ... And then this just took it a step further. I found this very useful.* (Complementary therapist 1)

While participants recognised the benefits of using NLP skills and techniques in the work environment, some noted the existence of potential barriers to implementing NLP with patients, carers and colleagues. An inability to establish rapport was recognised as a chief factor preventing the use of NLP techniques. Time constraints, a lack of privacy, and negative attitudes among some colleagues and patients were also noted as barriers to using NLP. Participants discussed situations where they were unable to establish rapport with patients or carers. These situations not only prevented the use of potentially beneficial NLP techniques, they also prevented the delivery of quality care.

*When you start talking about coping skills some of them [patients] just blank off. And maybe they've got some perceived views of, you know, this is a bit ridiculous. But you have to work with them. And I think once they get to know you, you can do a bit at a time.* (Primary care worker 1)

Participants who were keen to use NLP in the workplace recognised that the dominant bio-medical model of service delivery could impinge on their implementation of NLP with patients and carers. The scientific bias of colleagues was emphasised as a significant barrier to utilising NLP techniques in joint working situations.

*There are one or two individuals who are very scientific and ... I don't think it [NLP] would sit easily with them. And when I am joint working I think I would struggle to use some of the techniques*

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*especially if it is somebody who is senior to me in position and status ... So yes I can see there are certain individuals if I am joint working with them. I would probably choose it [NLP] less often. (Clinical Nurse Specialist 2)*

The general feeling among participants was that they would continue using their new NLP skills and techniques well into the future, although the techniques identified as sustainable varied from one participant to the next. For some respondents the relaxation and visualisation components of the course were highly relevant to their daily work with patients and carers. For other respondents, skills such as ‘reading body language’ and the ‘phobia cure techniques’ were more often employed in their professional role. Participants felt that the course provided them with a range of tools and techniques that they could ‘dip into’ when the need arose. It was felt that the practical relevance and effectiveness of NLP would guarantee its continued implementation within professional and personal contexts.

*I’m really enthusiastic about it, it’s one thing that’s really changed. I have gone on using it, which is quite good for a course. Normally you say yes that’s interesting and then you sort of reflect on these things and use them but usually nothing much happens but it [NLP] is one of the things that I really have used. (GP)*

However, there was some concern among participants that they would lose those NLP skills that they did not implement frequently enough to remain conversant and confident with. This was a source of concern for participants who observed that their new skills were very effective in helping patients cope with illness.

*I think the only fear I’ve got in a way is that if I don’t use these skills I’m going to lose them ... A lot of them will keep because I’m using them, but some of the really profound stuff, like the phobia and the trauma cure, it’s not something that I will be required to use very often ... some of these skills are going to be used so infrequently just the one or two very specific treatments that I must admit I feel I’m going to have to practice them or I could lose my confidence in using them. I would soon forget that these were so profound. So you know that’s why I make a positive effort to keep the more basic stuff in the practice on a daily basis. I don’t want to lose it. I mean it’s a case of use it or lose it. I mean you never remember everything from every course but because they were so powerful, I know they were so good, I don’t want to lose them. (Nurse 5)*

To help combat a loss of skills some participants suggested that they would like to attend NLP refresher courses every one to two years. The course materials and book *Making a Difference in Cancer Care* were noted as important resources to keep the training fresh in mind.

*It’s remembering to actually do it and it’s remembering to put all these things in place, all the tools. I mean I like to read through the book and pick up bits that I’ve forgotten to use or I don’t use as much, because they are beneficial. (Complementary therapist 2)*

## **6.5 Relationship of NLP to existing knowledge and practices**

The relationship of NLP to traditional psycho-social theories was a central theme throughout the interviews with health professionals. Participants grappled to merge NLP theories into their existing paradigms of working with patients and carers. It was felt that many

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components of NLP complemented existing knowledge and ways of working, while other components contrasted with traditional theories.

*It was interesting in that there were some aspects that, certainly one of the things that it challenged was some of my previously held notions, um which I personally, I supposed grapple with. I think I can subscribe to some of it and some of it I still, I'm still trying to assimilate. Yes, I mean it was interesting and it was probably complementary [to previous counselling knowledge] but it was, there were certain aspects that were obviously quite different. (Family Support Worker 1)*

Participants held dichotomous views about the ways in which NLP tied into traditional psycho-social theories. Participants believed that NLP either diverged from, or complemented, their existing knowledge. Those who felt that NLP complemented traditional theories felt reassured by their perception of the similarities between well-researched cognitive behavioural techniques and NLP.

*To me it seems to fit very nicely into cognitive behaviour therapy type therapies, the basic model of the understanding of the world. So it kind of enhanced my knowledge of those types of therapies. (Clinical Nurse Specialist 1)*

Those who felt that NLP contrasted with traditional psycho-social models perceived very few similarities between the two. These participants felt that NLP was fundamentally different from traditional theories, and in many ways ‘*unconventional*’. However, willingness to integrate NLP into existing knowledge paradigms was not always dependant upon perceived compatibility. Some participants who observed that NLP was a very different way of working with patients also noted that NLP may, in some situations, be more helpful.

*I've done a lot of training in listening skills so it's asking the right questions, and opening things up and letting people go over things, and over things as long as they need to. And in bereavement work often, that's how you work. You allow people to go over things but the NLP approach is really quite different in that what we were being encouraged to do is sort of acknowledge that but move on ... I can actually see where there are situations where applying the NLP technique might be better, because it's helping people to move on. You know, there's a limit to how many times you can go over things. If you're really wanting to move people on then I think, you know, moving to the NLP approach is the way to do it. Some I can see there's some situations where the NLP would be preferable but I'm not comfortable with it in every situation. (Family Support Worker 1)*

## **6.6 Views on the delivery of the training course**

Participants discussed in detail their thoughts and opinions on the delivery of the NLP training course. Overall, the response to the training was positive. Most participants stated that they thoroughly enjoyed the course and found it valuable for improving their communication and inter-personal skills. The course was also appreciated as an opportunity to satisfy long-standing curiosity about NLP at no personal expense.

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*I must admit the course was I think probably one of the best courses I've been on, and the one of the most enjoyable courses and congratulations to the people who ran it. (Health Visitor 1)*

However, not all participants held entirely positive views of the NLP training course. Some participants felt that the training was 'interesting' but considered their own personal resistance to the theories of NLP prevented them gaining a great deal from the course. One participant suggested that he felt like he was in an 'evangelical' meeting during the course. Not being able to join in with the experiences of others he felt isolated and 'cold'.

*I felt like I was at an evangelical meeting and everyone else had been touched by the hand of god and I was just being left very cold by it all. And you know I felt a bit like erm slightly left out of the experience because it just wasn't happening for me. And I didn't know whether that was because I was somehow resisting some part of the process. But in general I think I'm pretty open-minded ... (Psychiatrist)*

A lack of personal affinity with NLP theories clearly influenced perceptions of the value of the training. Those who continued to hold onto their doubts about NLP suggested that the four-day commitment of the course was not justifiable in a time-scarce work environment.

*I didn't feel a great deal of sympathy with it and yet ... It was enjoyable but whether I learnt enough to justify taking four days out of a busy work schedule is a different kettle of fish because I don't think I actually came out with any improvement to what I was doing already it is justifying the four days out. Apart from that it was very relaxing, and it was good and you learn to appreciate yourself as well. (Social Worker 1)*

This participant indicates that the course did not yield sufficient benefits for her to justify a large time commitment. However, it is important to note that the participant does not totally dismiss the NLP training course as a pointless exercise. Instead, the course is described as 'relaxing', 'good', and promotes a sense of self-appreciation.

Participants discussed the pace of the training as either 'languid' or 'slow', with the first session in particular being noted as taking a long time to 'get going'. For some participants this led to a feeling of frustration. Others found the pace variable but not always comfortable, as it was often 'too slow' or 'too fast'.

*I struggled with the pace. I am going to be critical. I struggled with the pace. I felt at times it was far too slow. More often it was too slow but sometimes it just rushed along too fast. That was me personally. Especially the mornings, it just seemed to take forever to get started and then in the afternoons there would be a bit of a rush. (Clinical Nurse Specialist 2)*

However, some participants commented that the pace of the course was well suited to their learning needs. Furthermore, the changeable pace of activities was thought to make the learning process more interesting and enjoyable.

*I stayed alert and interested throughout. There was a good sort of changes of pace and methods. That worked really well. The trainers were really interesting. (Nurse 2)*

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The pace of the training was thought to fit nicely with NLP theories relating to relaxation and the management of internal states. Some participants suggested that the pace of the training was actually faster than it initially appeared. It was thought that the gentle introduction of techniques often concealed the pace and complexity of the learning.

*It was slightly bemusing at first. I think that is the word I would use because it was delivered in a very gentle way. I thought we would be up and learning techniques from day one and somehow I felt that the techniques were almost slipped in. Really, really powerful stuff. Very, very important stuff but almost under played and very, very low key. Now I don't know whether that was about perhaps acknowledging that we might have reservations or be wary so that it would kind of just increase that wariness if these were presented as, just look at this weird and wonderful technique. They had very soft language themselves and sometimes I felt as if we were almost just chatting and then I would get home and I would revise what I had done and I would think, my God we have learnt a lot today and this is impressive stuff and what is going on here. So lots and lots of food for thought. I think the way they delivered it was perhaps unusual but maybe that is all part of the NLP. (Primary Care Mental Health Worker 1)*

Some participants acknowledged that their perception of the course as 'slow' was perhaps related to their existing knowledge on psycho-social theories. These participants suggested that their previous participation in psycho-social training placed them at an advanced level compared to the rest of the group. It was noted that all group-based training courses are faced with the dilemma of how to pace information delivery to accommodate each individual's existing level of knowledge and inherent ability to synthesise new information. This was not seen as a problem unique to the NLP four-day Diploma course.

It was suggested that the NLP training course could be improved if it was 'condensed' into two days or into morning sessions only. The current four-day 9am to 5pm schedule of the course was considered by some participants to be too demanding in terms of time commitment and concentration levels.

*I think, in practice it would be more effective if it was just a morning session. I think, well personally, I find it a long day to be sitting and taking something in. I think the period after lunch is well known as being the time when you don't really take in as much. You feel a bit drowsy after you've eaten your lunch. It's not such an effective time for training. (Service Coordinator/Facilitator 5)*

Participants on the course enjoyed the varied, interactive learning style of the course. The interactive format of the course was noted as an improvement on traditional lecture-based learning methods. For some participants the NLP training course was their first experience of an interactive learning environment. The practical exercises were described as having multiple benefits for the learning experience. These included improved recall of techniques, increased 'confidence' in performing techniques, and a sense of 'fun' while learning.

*We did things and we kept reviewing and building up and that worked very well because it helped affirm and embed what we were doing ... It slowly built up and it helped me to remember what was going on ... So that was really good. It was, the day was well structured so obviously we were applying the principles of NLP while they were doing it. (Nurse 3)*

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Participants unanimously praised the teaching skills and personal qualities of the NLP trainers. The trainers were noted as ‘excellent’ and ‘absolutely brilliant’ at explaining and modelling NLP. Participants noticed the excellent rapport between the two trainers and recognised their skill in promoting a feeling of rapport throughout the group.

*I think both [the NLP trainers] were absolutely superb. They modelled what they were teaching beautifully. Absolutely beautifully. I mean they really did practice what they preached and it was quite obvious. So I thought they were smashing. And I felt that for the most part everything that they explained was very, very clear ... (Clinical Nurse Specialist 2)*

One participant believed that the cost of hiring the venue was extravagant when the scarcity of local cancer resources and funding for cancer services is considered. This participant felt that the training should have been held in a meeting room within a local NHS service.

*... I probably have some issues about the cost of the whole project, you know and we are scraping about for pennies. So I think the Boat Museum was perhaps an extravagant place to have it ... (Service Coordinator/Facilitator 2)*

While the NLP training course was largely considered valuable and relevant to the professional lives of participants, one participant felt that the course was not attracting enough health professionals working within oncology services.

*... a lot of the people on the course don't have much to do with cancer patients which I think is really, really important to be acknowledged within the research. Not many of those people on that course that I did had come across cancer patients ... I would say a good five or six people in my impression. I am not saying they will never come across a cancer patient but it is not that many. (Service Coordinator/Facilitator 3)*

This participant observed that the training should be restricted to health professionals who work directly with cancer patients, carers and their families. It was argued that the participation of persons who work in unrelated areas diminished any claims about the training directly improving the experiences of cancer patients and carers. However, the participant felt that no NLP training course was likely to attract great numbers of health professionals working within oncological services. The four-day commitment of the course was considered impractical given the limited number of study days available to clinicians. Furthermore, it was suggested that the common perception of NLP among clinicians was that it is an ‘airy fairy’ practice. This prevents serious consideration of the course as a communications skills training programme. This participant argued that the training course should perhaps be re-packaged and re-branded if it is to be taken seriously by clinicians.

*I know I probably sound as though I am talking for lots of health professionals but I have heard health professionals, it is probably very unfair for health professionals to comment unless they have been on the NLP but they laugh about it. I am not saying that is right. I know perhaps the very people who this do need more communication, well we all could. But taught in a bit less airy fairy kind of way. (Service Coordinator/Facilitator 3)*



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## Chapter 7

### Discussion

#### 7.1 Introduction

The purpose of this study was to describe the delivery, and evaluate the impact, of the Ellesmere Port 'Living with Cancer' project. The project established peer support groups for cancer patients and carers at Ellesmere Port Library, provided NLP training interventions to peer support group members, and delivered four NLP Diploma courses for health professionals working in the Ellesmere Port area. The peer support groups were established in May 2002, with approximately six peers attending the weekly meetings. Two trainers delivered NLP education interventions to the peer support group between May 2002 and July 2003. In total, 55 health professionals completed the four-day NLP Diploma course, 31 went on to participate in an additional two-day 'Top Up' training course and seven completed the 'Practitioner' course.

The first aim of this study was to conduct a needs analysis among cancer patients, carers and health professionals in Ellesmere Port. The findings of the needs analysis focus groups, presented in Chapter 4, informed the development of the health professional NLP training course and NLP education interventions during the patient and carer peer support groups. The results presented in Chapter 5 and Chapter 6 will be discussed with reference to the aims of the project, current research into cancer care and the findings of the needs analysis focus groups in order to evaluate the 'Living with Cancer' project.

#### 7.2 'Living with Cancer' peer support groups

The needs analysis focus groups identified the importance of psycho-social support for patients and carers throughout the cancer journey. Participants in the patients and carers groups discussed the lack of formal psycho-social support available through mainstream cancer services in the Ellesmere Port area, particularly in the early days of diagnosis and treatment. This parallels recent research that has found that cancer patients and carers often have intense unmet needs for emotional, social and spiritual support (CHI, 2001; Rees et al, 1998; Maguire, 1999; Eriksson and Lauri, 2000). One such study, conducted by Soothill et al. (2001) found that almost two-thirds of cancer carers have never been offered access to counselling services. To address this situation *The NHS Cancer Plan* states that all cancer services should work towards ensuring the delivery of psycho-social support to patients and their families (Department of Health, 2000a).

The evaluation focus groups discussed in Chapter 5 explored whether the 'Living with Cancer' project met the identified need of providing a source of psycho-social support for cancer patients and carers in Ellesmere Port. Analysis of the focus group transcripts revealed that the cancer patients and carers peer support group did provide an important source of psycho-social support. Evidence of the psycho-social supportive role of the group emerged from the focus group discussions. A predominant theme of the focus groups was the importance of the peer support group as a forum for sharing experiences. Sharing experiences during peer support group meetings provided comfort and reassurance to group members, as well as promoting the sense of a common, unifying bond. This reduced feelings of isolation and anxiety among participants, and allowed the development of mutually supportive relationships.

The peer support group appears to have succeeded in achieving the 'Living with Cancer' aim of providing a source of psycho-social support for cancer patients and carers in Ellesmere

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Port. However, this support arrived too late for several group members who were already well advanced on their cancer journey. Furthermore, the success of the peer support group in providing psycho-social support to cancer patients and carers in Ellesmere Port was limited by small numbers. This highlights the need for continued promotion of the group, and for professional referrals, so that newly diagnosed patients and their carers can access this important source of psycho-social support and information. If the peer support group is unsuccessful in attracting new members the long-term sustainability of the group seems doubtful.

Research has shown that one third to one half of all cancer patients suffer some form of psychological morbidity following diagnosis (Whelan et al, 1997; Blake-Mortimer et al, 1999). This finding was reflected in the needs analysis focus groups with all three groups discussing the stress and emotional trauma associated with cancer.

The 'Living with Cancer' peer support group attempted to alleviate stress among cancer patients and carers by teaching the group NLP relaxation and inner-state management techniques. The evaluation focus groups revealed that the relaxation techniques taught by the NLP trainers were thought to be effective and valuable by the peer support group. Most peer support group members enjoyed the relaxation component of the weekly meetings and considered this part of the meeting very helpful for reducing their stress. Participants gave examples of the ways in which they had implemented specific NLP techniques to manage their stress in other situations. This finding reflects research that has found an association between psycho-social support interventions with relaxation components and reduced anxiety and stress, and an increased ability to cope, among cancer patients (Walker et al, 1999; Taylor and Ingleton, 2003; Petersson et al, 2000).

Each needs analysis focus group noted that communication difficulties were a significant source of potentially avoidable stress within cancer care. Difficulties in communicating were linked to the development of ineffectual relationships between health professionals and patients, poor information provision and a lack of patient involvement in decision-making. The peer support group NLP component was developed to address this situation by improving group members' understanding of communication and teaching them specific techniques to improve their communication with health professionals. During the evaluation focus groups participants gave examples of the practical ways in which the NLP communication interventions had helped them improve their communication with difficult health professionals. This promoted a sense of empowerment and reduced their anxiety and distress. In this way NLP may be viewed as a potential vehicle for patient empowerment within health services. Other research into general communication skills training for patients has reported similar findings. A study conducted by Cegala (2003) found that patients who are trained in communication skills have increased confidence in their consultations with doctors.

Generally, participants valued the NLP educational input into the peer support groups. Participants appreciated being taught new skills to improve their ability to communicate effectively, cope with stress, and deal with difficult relationships. However, some participants remained sceptical of the value of the NLP techniques they were taught. There was also some confusion surrounding the purpose of the educational input. Some group members felt that the NLP education was '*plonked*' into the meeting rather than being an essential component of the support group session. This suggests that future NLP input may need to be formally introduced, with sufficient background information, or perhaps delivered in a more structured format. Another solution to this issue may be to adjust the NLP input to increase its relevance to the peer group discussion.

There was great support among participants for the continued involvement of the NLP trainers in the peer support group. Participants recognised the skill of the trainers and

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considered their presence essential to the success of the group. Participants particularly appreciated the group facilitator role of the trainers during relaxation exercises.

As with the long-term sustainability of the peer support group, the long-term value of NLP education for peer support group members remains unclear. The continued usefulness of NLP relaxation, communication and relationship skills training largely depends on the willingness of individual group members to practice and remain proficient in techniques. As with any learning, the value of the NLP education component will diminish if peer support group members forget to use techniques. Perhaps this largely inevitable loss of skill could be alleviated through free NLP training sessions to the peer support group. The evaluation focus groups emphasised the importance of regular professional input to the peer support group. NLP refresher training could be introduced alongside scheduled visits from oncology staff, advisors from the Citizens Advice Bureau and representatives from relevant community-based welfare organisations to prevent loss of skills. This continued input would help imbed skills into the everyday lives of patients and carers.

An important finding of the evaluation research was that the 'Living with Cancer' peer support group did not attract the number of members originally expected. The initial plan to conduct separate peer support groups for patients and carers had to be abandoned due to small numbers. For practical reasons the two groups were merged into one cancer patients and carers support group. This single group also struggled to attract sufficient members throughout the project, with only six persons attending on a regular basis.

It is difficult to hypothesise why the group was unable to attract a larger membership. Previous attempts by unrelated cancer projects in the Ellesmere Port area faced similar problems in attempting to recruit and sustain a patient support group. One explanation for this result is the very nature of cancer and its treatment. Members will inevitably drop in and out of any cancer peer support group as their physical and psycho-social health changes. It is also inevitable that they will move on from the group once their needs have been met. Given these difficulties there are concerns that the 'Living with Cancer' peer support group will be unsustainable without the continued input of project staff.

Perhaps the patients and carers support group will be easier to sustain given the larger number of local health professionals trained in NLP. In theory, health professionals who completed the four-day NLP training course could help coordinate an ongoing support group for patients and carers. At present there are plans for an NLP Practitioner and two volunteers to coordinate and facilitate a cancer patients and carers peer support group in Ellesmere Port. This assistance may need to continue to ensure the long-term sustainability of the group. The group coordinators should also engage with oncology professionals to work towards consultant recognition and referrals. This will promote expanded membership of the group and important links to cancer services and resources.

Overall, evidence from the focus group suggests that the peer support group component of the 'Living with Cancer' project did improve the intra and inter-personal experiences of cancer care among those patients and carers who attended the group. However, it would be unrealistic to argue that this component of the project had a significant positive impact upon the larger population of cancer patients and carers in Ellesmere Port.

### **7.3 NLP training for health professionals**

The 'Living with Cancer' NLP training for health professionals was developed in response to the literature on cancer care and the findings of the needs analysis focus groups. This research revealed a number of common concerns among cancer care research on a national level and research with local cancer patients, carers and health professionals. A core issue that emerged

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from the focus groups and literature was the need for improved communication between patients and health professionals and improved communication within and between health services. Reports such as *The NHS Cancer Plan* (Department of Health, 2000a) and *NHS Cancer Care in England and Wales* (CHI, 2001) found that an unacceptably large number of health professionals working in cancer care have poor communication skills. These reports highlighted the insensitive, cold and distant manner in which some health professionals continue to interact with patients (Department of Health, 1995; National Cancer Alliance, 1996; Department of Health, 2000a). They also noted the unacceptable level of breakdowns in communication that occur within and between cancer services (CHI, 2001; Department of Health, 1995).

The needs analysis focus groups with patients, carers and health professionals revealed a similar level of concern about communication within cancer care. All three groups noted the crucial importance of health professionals communicating with patients in a sensitive, open and empathic manner. The groups also recognised the imperative for health professionals to be willing to give their time to listen to patients. The patients and carers groups gave several examples of situations where they had been treated in an insensitive or cold manner by a health professional. Each group noted that communication difficulties often resulted in preventable emotional distress, anger, bitterness and delays in diagnosis and treatment.

In response to this research the 'Living with Cancer' project developed a four-day NLP training course for health professionals. The training was designed to improve the communication, relationship and inter-personal skills of health professionals working in cancer care in Ellesmere Port. Interviews with 23 of the 55 health professionals who completed the training provide evidence of the extent to which the 'Living with Cancer' project improved the communication, relationship and inter-personal skills of participants. The findings presented in Chapter 6 relate to the thematic analysis from the dataset of interviews with these 23 health professionals. For reasons of practicality and relevance, this report focuses only on the dominant themes and topics that emerged from thematic analysis. Not every issue raised by participants in their interviews is presented in this report, nor should the findings be taken as representative of the wider group. Rather, these findings are illustrative of the perspectives on NLP from a sub-group of health professionals who attended the training course.

Analysis of the health professional interview data revealed the significance of curiosity as a motivational factor influencing the decision of health professionals to enrol in the NLP training course. Participants tended to fall into two groups regarding their curiosity about NLP. The first group described how they had a long-standing curiosity about NLP. For these participants the opportunity to enrol in a training course at no personal expense was too good an opportunity to miss. The second group were largely unfamiliar with the term NLP. Participants in this group stated that they decided to enrol on the course to satisfy their curiosity about NLP. Many had previously heard the term NLP used but were unsure what the acronym stood for and did not know anything about NLP theories or practice.

Most health professionals who participated in an interview considered the NLP training course to have a positive impact on their communication skills. However, it is important to note that this feeling was not unanimous. A small minority of participants continued to be sceptical about NLP throughout and after the course. These participants did not feel that the course contributed to their existing skills and knowledge or improved their current ways of working with patients and carers. Previous training in psycho-social theory and the dominance of the biomedical tradition within health services may partially explain the scepticism of this group. This group considered the course an '*interesting*' or '*relaxing*' way of spending four days but believed that NLP essentially conflicted with their existing paradigms of knowledge and ways of working with patients and carers.

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Those health professionals who believed the course improved their communication skills described how the course built upon and honed their existing communication and relationship skills. In particular, participants felt that the course improved their body language, rapport and verbal communication skills. Many participants also commented that the course increased their ability to listen actively to patients. Another significant finding of the interviews was the perception among many participants that the NLP training increased their reflectivity when interacting with patients. Several participants explained that this enhanced their understanding of patients', and their own, perspectives and allowed them to be more sensitive in their communication. Research confirms that these skills are fundamental to health professionals' ability to provide quality cancer care, to build effective relationships with patients and to meet patient expectations of information provision and involvement in decision-making (Arora, 2003; Butow et al, 1997; Department of Health 2000b; Farrell, 2001a; Leydon et al, 2000; Maguire, 1999; O'Hair, 2003; Thom, 2001).

An important finding of the interviews with health professionals was the positive reaction of participants to the NLP technique of '*soft language*'. Many participants commented that they had integrated soft language into their work and that this technique had improved their communication with patients and carers. Soft language was used by participants to encourage a feeling of calm and relaxation in their interactions with patients and carers. Participants felt that the use of soft language helped patients to relax and cope with potentially distressing situations such as painful medical procedures or being informed of bad news. Similarly, health professionals noted the value and suitability of the NLP technique of '*positive language*'. Many participants stated that '*positive language*' had become embedded in their ways of working with patients and carers since completing the training course. Participants felt that the use of positive language improved their communication style and allowed them to work more productively on issues with patients and carers. Several health professionals gave examples of the ways in which they had used positive language to encourage compliance in patients and achieve desired outcomes.

These findings provide evidence of the positive impact of the 'Living with Cancer' NLP training on health professionals' communication and relationship skills. This outcome of the 'Living with Cancer' project is important given the considerable research that has called for improvements in the communication skills of health professionals working in cancer care (Department of Health, 1995; CHI, 2001; National Cancer Alliance, 1996; Department of Health, 2000a; Department of Health, 2000b). These findings also provide evidence that the 'Living with Cancer' NLP training component met the requirement, identified in the needs analysis focus groups, for improved health professional communication skills at a local level.

As discussed in Chapter 6, most health professionals reported that they had successfully incorporated a number of NLP techniques into their work with patients and carers. Among the most popular of these techniques was '*anchoring*'. Participants viewed anchoring as a relevant, valuable, effective and easily accessible technique to improve patients, and their own, ability to cope with stressful or upsetting situations and to manage their internal states. Many of those who recognised the value of NLP had begun disseminating their new skills to patients, carers and colleagues, facilitating a cascade effect of the training. Health professionals reported that they had received positive feedback about NLP techniques from patients, carers, colleagues, friends and family members. The anchoring technique was considered especially useful to help patients cope with unpleasant reactions to scans, the collection of blood samples and chemotherapy treatment.

This finding provides evidence of the how the 'Living with Cancer' project met the identified need to increase the coping skills of local health professionals, cancer patients and carers. The needs analysis focus groups emphasised the importance of coping and internal state management skills for health professionals, patients and carers. Health professionals raised the issue of needing to control their emotions when communicating bad news to patients.

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Similarly, the patients and carers groups highlighted the need for improved skills to manage their emotions and increase their ability to cope with bad news, difficult relationships, and stressful or fearful situations. The interviews with health professionals indicate that the NLP training course was successful in improving the coping and internal state management skills of most health professionals. It may also be argued that the project succeeded in improving the coping and internal state management skills of a wider population of cancer patients and carers in Ellesmere Port, through health professionals instructing patients in techniques such as '*anchoring*'.

Only two participants viewed the practice of NLP by inexperienced persons as potentially harmful to cancer patients. These participants believed that the four-day NLP Diploma course is insufficient to equip health professionals with the level of skill needed to interact successfully with cancer patients. They argued that health professionals who completed the training course could find themselves '*out of their depth*' when working with dying patients. They also suggested that NLP may be inappropriate when used in the palliative stage. However, these views contrasted with those of the majority of participants who believed that NLP was an essentially harmless, yet potentially helpful, tool that health professionals could add to their existing practices.

Participants felt that many of the NLP skills and techniques learned during the Diploma course are sustainable in the long-term, although the techniques most relevant to their daily interactions would be more easily maintained than others. The training materials and book, *Making a Difference in Cancer Care*, were regarded as valuable reference materials for the present and future. Participants discussed how they could easily '*dip into*' the course materials to refresh their memory of a certain technique when this was required.

The format and delivery of the NLP Diploma course was generally considered enjoyable and stimulating. Participants appreciated the interactive learning style, noting that this teaching method was '*fun*', that it assisted the learning process and that it also helped in the later recall of new information and techniques. There was consensus among participants that the NLP trainers were highly skilled and professional educators. Participants praised the trainers as '*excellent models*' of NLP theory and considered them knowledgeable, skilled at explaining concepts and techniques, approachable, and helpful.

The relaxing pace of the training assisted participants in the processing and retention of new information and techniques. For most of the group, the relaxed pace had an additional benefit of contributing to their enjoyment of the course. However, a number of participants remarked that the '*languid*' or '*slow*' pace of the course was frustrating. Participants contrasted the slow, relaxed, pace of the course with their usual hectic professional schedules. For some participants the course was a welcoming change, however others stated that they found it very difficult to '*relax into*' the pace of the course. It was suggested that the pace of the course could be improved by condensing the four-day content into two days or four morning sessions. Condensing the course content may have an additional benefit of attracting more oncology professionals to the NLP Diploma course. At present, the four-day commitment of the training may be perceived as too onerous for busy consultants and oncology nurses.

A significant finding of this study was that the NLP training course failed to attract large numbers of health professionals who work directly with cancer patients or carers. Approximately half (44%) of those who completed the course do not have daily direct contact with cancer patients or carers, although many of this group do provide incidental care, on an irregular basis, to cancer patients as part of their professional role. The 'Living with Cancer' project aimed to improve the experiences of cancer patients and carers within mainstream services by providing NLP training to health professionals who work directly with this group. Given the fact that 44% of those who participated in the training did not have daily direct

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contact with cancer patients, it is difficult to argue that the programme entirely fulfilled this aim.

It is notable that the NLP Diploma course failed to attract any oncology consultants despite *The NHS Cancer Plan* (Department of Health, 2000a) directive that all oncology staff should participate in formal communication skills training. While it is not possible to know the exact reasons why no oncology consultants enrolled in the training, some participants suggested that NLP is perceived as too unscientific to appeal to bio-medically trained clinicians. There is perhaps a reluctance among consultants to 'unlearn' or review previously learnt communication skills. Furthermore, it is often difficult to engage with people about something when they have pre-conceived ideas about what it is and how useful it might, especially then they work in a time-pressured environment. It may be hypothesised that time constraints played a role in consultants deciding against participation. Finally, perhaps the availability of the training was not very effectively promoted to consultants.

Perhaps more oncology clinicians could be attracted to similar training programmes in the future if the course is re-packaged with less emphasis on NLP, and re-branded as advanced communication skills training workshop. Many of the generic components of NLP could be incorporated into the revised training programme, yet adapted to oncology service-specific situations. Another possible approach to increase clinician participation in future communication training programmes would be the inclusion of NLP-based communications workshops in undergraduate medical and nursing curricula.

The limited uptake of the NLP training course among oncology health professionals has implications for the interpretation of the findings on the 'Living with Cancer' project. Interviews with health professionals found that the NLP training course improved participants' communication, relationship, inter-personal and coping skills. However, it may be argued that the low number of participants who work in cancer-specific services restricts the extent to which the 'Living with Cancer' project had a positive impact upon the wider population of cancer patients and carers in Ellesmere Port. Nevertheless, given the prevalence of cancer in the community it is likely that health professionals working in general services will encounter cancer patients and carers in their professional and personal lives. The limited number of study days available to health workers, and a reluctance upon the part of service managers to fund expensive training courses, needs to be considered in the development of any future NLP training programmes.

## **7.4 Conclusion**

This study had five main aims. The first aim was to conduct a needs analysis among cancer patients, carers and health professionals to inform the development of the 'Living with Cancer' project. The second aim was to evaluate the delivery of a peer support group with NLP training to cancer patients and carers. The third aim of the research was to evaluate the delivery of a four-day NLP training course to health professionals. The fourth aim of the research was to explore participants' perspectives on the value of NLP training for improving experiences within cancer care. The final aim of this study was to assess the impact of the 'Living with Cancer' project on the intra and inter-personal experiences of cancer care among health professionals, patients, and carers who participated in project activities.

The fourth aim of this study was to explore health professionals', cancer patients' and carers' perspectives on the value of NLP training for improving experiences within cancer care. The findings presented in this report provide some initial evidence of the potential of NLP training to address some of the deeply rooted communication problems, identified in the literature and the needs analysis focus groups, within cancer care. Thus, increasing engagement with NLP techniques among health professionals, patients and carers is worthy of further research.

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The findings of this evaluation study indicate that the project did improve the intra and inter-personal experiences of most participants in the peer support group and NLP health professional training. The project improved the intra and inter-personal experiences of cancer patients and carers through the delivery of psycho-social support in the form of regular peer support group meetings. NLP education interventions to the peer group improved participants' intra and inter-personal experiences of cancer care by increasing group members' knowledge of communication and relationship skills and improving the ability of participants to manage their internal states. The 'Living with Cancer' project improved the intra and inter-personal experiences of health professionals working in cancer care through the delivery of NLP training courses. Most participants in these courses felt that the training improved their communication and relationship skills, and improved their ability to manage their own internal emotional states. This in turn improved their ability to provide quality care to cancer patients and carers and enhanced the intra and inter-personal experiences of all three groups within health services.

However, the limited regular membership of the cancer patients and carers peer support group, and the small number of oncology health professionals attracted to the NLP training, raises concerns in regard to the of benefit of the project to the larger population of local cancer health professionals, patients and carers. It also raises questions about the long-term sustainability of the project. To avoid these problems in future projects it may be advisable to adapt and re-brand the NLP communication skills training to a general 'advanced communication skills' training programme. Future projects should also investigate the possibility of integrating the training into undergraduate medical and nursing curricula. Peer support projects may be more successful in the future if they collaborate with oncology consultants and services to achieve professional recognition and the support of small community-based groups. Furthermore, peer support projects should work with cancer services to advertise and promote patient support groups and develop referral pathways.



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## **Appendix 1**

### **NLP training documents**

NLP and other processes used with the patients and carers peer support group

NLP Diploma syllabus

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### **NLP and other processes used with the patients and carers peer support group**

This environment was somewhat time constrained and had a different purpose than the formal training of health professionals for certification. The emphasis was on giving patients and carers experiences of simple processes that they could then use for themselves in order to feel better, communicate more effectively, have more resourceful choices etc. It is important to note that this approach is different to the ethos of some support groups. Where participants did want to talk about difficulties, the sharing of negative experiences and emotions were not an end in themselves. The emphasis in these groups was on solving problems and moving towards an enhanced quality of experience. We did not spend as much time giving the processes their full titles and explaining the theory/concepts behind the processes as would have been done in a formal training environment. Many of the processes are enjoyable and relaxing in and of themselves in addition to achieving a number of other specific benefits. They included:

- The fight or flight response - explanation and ‘normalising’.
- Brain gym techniques specifically for stress management - including PACE, hook-ups, positive points and exercises for releasing the Tendon-Guard Reflex, plus other brain gym exercises for problem solving.
- Tai chi exercises - for increased arm-mobility and expanding the breath, relaxation and mental clarity.
- Yoga breathing exercises -including mudras for enabling easier deeper breathing.
- Conversational re-framing.
- Trances - for aiding restful sleep, solving problems, feeling more resourceful in specific circumstances.
- How to create rapport - e.g. matching and mirroring with health professionals that they had previously found difficult and intimidating.
- Phobia cure - enabling one patient to start swimming and enabling another to accompany their spouse on holiday on an aeroplane.
- Anchoring techniques - so patients and carers could have resources available to them in different circumstances away from the group.
- The grief resolution process - for a carer who was struggling with bereavement.
- Simple meditation to enhance sensory enjoyment.
- Timelines for planning pleasurable events in the future.
- Eye-movements and emotional first aid.
- Changing the representation of difficult memories to enable comfortable access of the information without the bad feelings associated (particularly with reference to upsetting exchanges with health professionals).
- Simple relaxation and visualisation.



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## **NLP Diploma syllabus (accredited by INLPTA<sup>4</sup>)**

The syllabus may have varied very slightly on Day 4 from one group to the next in line with the particular needs of the group. However, the core syllabus remained the same throughout.

### **Day 1**

Opening frames, participants outcomes

What is NLP?

Where did NLP originate from?

The present state-desired state model

The six 'legs' of NLP Outcome/Sensory Acuity/Flexibility/State/Rapport and Action

Well-formed outcomes (including the concepts of Secondary-gain and Ecology)

### **Day 2**

Directing attention and building sensory acuity

Calibration of individuals to aid communication

Rapport (including matching/mirroring/pacing and leading)

### **Day 3**

The NLP Communication Model (including the processes of deletion/distortion/generalisation and the concept of 'maps of the world')

Stimulus response patterns and how helpful beliefs affect communication

NLP presuppositions

The importance of recognising naturally occurring trance states (especially associated with shock or strong emotion)

Soft language (including positive language, soft frames and positive presuppositions)

Sensory-based language

### **Day 4**

Eye movement patterns

Uses for eye movement patterns in emotional first-aid and lessening the discomfort associated with 'difficult' memories

Other ways of utilising eye movements

Taster sessions of other techniques from NLP and Brain Gym, that give a sense of how we can change our state and solve problems more effectively. These processes included: anchoring, changing an internal representation, the 'Dennison laterality re-patterning' timeline review process, positive points,)

### **'Top up' Day 5**

The 'chain of states' model (bridging the gap between unresourceful and resourceful states)

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<sup>4</sup> The International NLP Trainers Association (INLPTA) is a professional organisation for NLP trainers.

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Basic anchoring and stacking/collapsing anchors (having access to the kinds of emotional resources you want at the times and in the places that you want them)

### **‘Top up’ Day 6**

Introduction to sub-modalities (the structure of our internal representation)

Contrastive analysis and mapping across (processes for making fast and helpful changes in the way we code different experiences)

The Trauma cure (double dissociation technique for phobias of specific origin or reducing the unpleasant after effects of traumatic events)

Clare Rushworth’s fast phobia cure (for phobias of non-specific origin and difficult situations where extra resources are needed)

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## **Appendix 2**

### **Needs analysis focus groups documents**

Health Professional Information Sheet

Health Professional Consent Form

Health Professional Focus Group Interview Schedule

Patient Information Sheet

Patient Consent Form

Patient Focus Group Interview Guide

Carer Information Sheet

Carer Consent Form

Carer Focus Group Interview Schedule

## **Health Professional Information Sheet** **Focus Group Participation**

### **‘Living with Cancer’**

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

### **What is the purpose of the study?**

Chester and Halton Community NHS Trust have received funding for a 3-year ‘Living with Cancer’ project in Ellesmere Port, working with patients, carers and health professionals. The study aims to contribute to improving care locally for those ‘Living with Cancer’ and their carers.

We hope to find out the views of health professionals working in cancer services to inform the development of training programme to improve communication, information delivery, care and support to cancer patients and carers.

### **Why have I been chosen?**

You are being asked to take part because of your knowledge and experience of being a health professional working in cancer services. There will be about ten other health professionals taking part.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

### **What will happen to me if I take part?**

The research team would like to invite you to attend a focus group meeting where, led by a researcher, you and other health professionals may raise and discuss the issues that are important to you. You will also be invited to discuss your perspective on communications training needs and ideas for further training in this area.

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**What are the possible disadvantages and risks of taking part?**

It is not expected that participation in the health professionals focus group will have any disadvantages. However, if you become uncomfortable or upset talking about your experiences as a health professional working in cancer care, you may leave the discussion at anytime.

**What are the possible benefits of taking part?**

It is possible that you may welcome the opportunity to share and discuss your views and experiences with other health professionals, but this cannot be guaranteed. It is hoped that the issues raised in the group will inform the development of a training workshop for other health professionals working in cancer care in the Ellesmere Port area.

**What will happen to the results of the research study?**

The findings will be used in the training of health professionals to improve care and support for patients and carers in the Ellesmere Port area. Individuals who participate will not be identified in any subsequent report or publication.

**Who is organising and funding the research?**

Chester and Halton Community NHS Trust have received funding from the New Opportunities Fund to carry out this research. The Centre for Public Health Research at University College Chester will be involved in organising the study.

**Who may I contact for further information?**

If you would like more information about the research before you decide whether or not you would be willing to take part, please contact:

Jill Littlewood (Project Co-ordinator) on 01244 356817

**Thank you for your interest and co-operation in this research.**

# HEALTH PROFESSIONAL CONSENT FORM

## For Focus Group Participation

**Title of Project:** 'Living with Cancer': Maximising the coping strategies of carers and patients 'Living with Cancer'

**Name of Researcher:** Miranda Thurston

**Please initial box**

1. I confirm that I have read and understand the information sheet dated for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I agree to take part in the above study. ☐

\_\_\_\_\_  
Name of subject

\_\_\_\_\_  
Date

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Signature

\_\_\_\_\_  
Name of Person taking consent  
(if different from researcher)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**'Living with Cancer'**  
**Health Professional Needs Analysis Focus Group**  
**Interview Schedule**

- What works well when building relationships with patients/carers  
Ask for specific examples to provide evidence.
- What works well and why?
- What doesn't work so well and why?
  
- Which personal skills make for good communication?
- Why? Why are certain skills are important?
- Give examples of why specific skills are important or why they feel they need to improve them.
  
- How do health professionals break bad news?
- Could improvements be made in this area? How?
- Ask about specific problems they may have encountered in their own experience of giving bad news.
  
- How do health professionals provide information about diagnosis, treatments, side-effects, pain management etc?
- Could communication in this area be improved?
- What improvements are needed? Why?
- How do you think this could be achieved?
- What are professionals' views on patient/carer involvement? Why?
- Ask for examples from professionals' own experience.
  
- To what extent do you think that patients want to be involved in their treatment/care decisions?
- Why do you think this is?
- Ask for examples, from experience.
- To what extent do professionals want patient/carer involvement? Reasons?
  
- What are your views on health professional/patient and health professional/carer relationships (ask for specific examples)?
  
- What are your views about communicating with patients/carers about coping strategies related to life management issues (rather than just the medical side)?

## **Patient Information Sheet** **Focus Group Participation**

### **‘Living with Cancer’**

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

### **What is the purpose of the study?**

Chester and Halton Community NHS Trust have received funding for a 3-year ‘Living with Cancer’ project in Ellesmere Port, working with patients, carers and health professionals. The study aims to contribute to improving care locally for those ‘Living with Cancer’ and their carers.

We hope to find out the views and expectations of patients and their carers regarding their particular needs or wishes, the type of information they require and the preferred methods of receiving and understanding it. The findings will be incorporated into a training programme for health professionals so that they will be able to provide the most appropriate information, care and support to patients and their carers.

### **Why have I been chosen?**

You are being asked to take part because you may have insight and views about what would most help you to cope with ‘Living with Cancer’. There will be about ten other patients taking part.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.



**What will happen to me if I take part?**

The research team would like to invite you to attend a focus group meeting where, led by a health professional, you and other patients may raise and discuss the issues that are important to you. Lunch will be provided and the Chester and Halton Community NHS Trust will reimburse you for travel costs to and from the venue.

**What are the possible disadvantages and risks of taking part?**

If talking about your experiences of 'Living with Cancer' causes you any distress, there will be individuals trained in offering support present at the meeting.

**What are the possible benefits of taking part?**

As a patient it is possible that you may welcome the opportunity to share and discuss your views and experiences with other patients, but this cannot be guaranteed. It is hoped that the findings may be used to train health professionals and ultimately lead to improved care for patients and carers in the Ellesmere Port area.

**What will happen to the results of the research study?**

The findings will be used in the training of health professionals to improve care and support for patients and carers in the Ellesmere Port area. Individuals who participate will not be identified in any subsequent report or publication.

**Who is organising and funding the research?**

Chester and Halton Community NHS Trust have received funding from the New Opportunities Fund to carry out this research. The Centre for Public Health Research at University College Chester will be involved in organising the study.

**Who may I contact for further information?**

If you would like more information about the research before you decide whether or not you would be willing to take part, please contact:

Jill Littlewood (Project Co-ordinator) on 01244 356817

**Thank you for your interest and co-operation in this research.**

# PATIENT CONSENT FORM

## For Focus Group Participation

**Title of Project:** 'Living with Cancer': Maximising the coping strategies of carers and patients 'Living with Cancer'

**Name of Researcher:** Miranda Thurston

**Please initial box**

1. I confirm that I have read and understand the information sheet dated for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I agree to take part in the above study. ☐

Name of subject	Date	Signature

Name of Person taking consent (if different from researcher)	Date	Signature

Researcher	Date	Signature

## **Carer Information Sheet** **Focus Group Participation**

### **‘Living with Cancer’**

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

### **What is the purpose of the study?**

Chester and Halton Community NHS Trust have received funding for a 3-year ‘Living with Cancer’ project in Ellesmere Port, working with patients, carers and health professionals. The study aims to contribute to improving care locally for those ‘Living with Cancer’ and their carers.

We hope to find out the views and expectations of patients and carers regarding their particular needs or wishes, the type of information they require and the preferred methods of receiving and understanding it. The findings will be used to inform a training programme for health professionals so that they will be able to provide the most appropriate information, care and support to patients and carers.

### **Why have I been chosen?**

You are being asked to take part because you have experience of caring for a person who has completed the ‘cancer journey’ and may therefore have insight and views that will be helpful to health professionals who wish to improve the care of cancer patients and carers in the Ellesmere Port locality. There will be about ten other carers taking part.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

**What will happen to me if I take part?**

The research team would like to invite you to attend a focus group meeting where, led by a health professional, you and other carers may raise and discuss the issues that are important to you. Lunch will be provided and the Chester and Halton Community NHS Trust will reimburse you for travel costs to and from the venue.

**What are the possible disadvantages and risks of taking part?**

If talking about your experiences causes you any distress, there will be individuals trained in offering support present at the meeting.

**What are the possible benefits of taking part?**

It is possible that you may welcome the opportunity to share and discuss your views and experiences with other carers, but this cannot be guaranteed. In the long term it is hoped that the findings may be used in the training of professionals to improve care and support for patients and carers in the Ellesmere Port area.

**What will happen to the results of the research study?**

The findings will be used in the training of health professionals to improve care and support for patients and carers in the Ellesmere Port area. Individuals who participate will not be identified in any subsequent report or publication.

**Who is organising and funding the research?**

Chester and Halton Community NHS Trust have received funding from the New Opportunities Fund to carry out this research. The Centre for Public Health Research at University College Chester will be involved in organising the study.

**Who may I contact for further information?**

If you would like more information about the research before you decide whether or not you would be willing to take part, please contact:

Jill Littlewood (Project Co-ordinator) on 01244 356817

**Thank you for your interest and co-operation in this research.**

# CARER CONSENT FORM

## For Focus Group Participation

**Title of Project:** 'Living with Cancer': Maximising the coping strategies of carers and patients 'Living with Cancer'

**Name of Researcher:** Miranda Thurston

**Please initial box**

1. I confirm that I have read and understand the information sheet dated for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I agree to take part in the above study.

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Name of subject

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Name of Person taking consent  
(if different from researcher)

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Date

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Signature

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Researcher

\_\_\_\_\_  
Date

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Signature

**‘Living with Cancer’**  
**Patient Needs Analysis Focus Group**  
**Interview Schedule**

**In order to inform the training of health professionals who provide care for people who are ‘Living with Cancer’, it is important that the views of patients are incorporated. There are no predetermined ideas about issues that patients may wish to raise at the focus group, but the following themes are designed for use as probes to initiate the exploration of perceptions about the experience of ‘Living with Cancer’:**

- Perceptions of relationships/communication with health professionals
- Communication issues concerning how information imparted about illness/treatment
- Aspects of communicating: which find easiest/most comfortable/most difficult/uncomfortable
- Information needs re impact of illness on everyday life/coping strategies
- Patients’ perceptions around retaining/processing information at different stages of illness
- Perceptions of coping strategies/individual needs for information
- Issues around access to appropriate information/support (practical/psychological)
- Issues around repercussions of illness on practicalities of day-to-day life/relationships
- Issues around involvement in decisions about own treatment/care
- Perceptions of provision of care

**‘Living with Cancer’**  
**Carer Needs Analysis Focus Group**  
**Interview Schedule**

**In order to inform the training of health professionals who provide care for people who are ‘Living with Cancer’, it is important that the views of carers are incorporated. There are no predetermined ideas about issues that carers may wish to raise at the focus group, but the following themes are designed for use as probes to initiate the exploration of perceptions about the experience of caring for someone with cancer:**

- Perceptions of relationships/communication between carers and health professionals
- Communication issues concerning how information imparted about illness/treatment
- Aspects of communicating: which find easiest/most comfortable/most difficult/uncomfortable
- Information needs re impact of illness on everyday life/coping strategies
- Carers’ perceptions around retaining/processing information at different stages of illness
- Perceptions of coping strategies/individual needs for information
- Issues around access to appropriate information/support (practical/psychological)
- Issues around repercussions of illness on practicalities of day-to-day life/relationships
- Issues around involvement in decisions about treatment/care of the patient
- Perceptions of provision of care

## **Appendix 3**

### **Evaluation focus groups documents**

Patient and Carer Information Sheet

Patient and Carer Consent Form

Patient and Carer Evaluation Focus Group Interview Schedule



## **Patient and Carer Information Sheet** **Focus Group Participation**

### **‘Living with Cancer’**

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

### **What is the purpose of the study?**

Chester and Halton Community NHS Trust have received funding for a 3-year ‘Living with Cancer’ project in Ellesmere Port, working with patients, carers and health professionals. The study aims to contribute to improving care locally for those ‘Living with Cancer’ and their carers.

We hope to find out the views and expectations of patients and carers regarding their particular needs or wishes, the type of information they require and the preferred methods of receiving and understanding it. We also would like to explore the perspectives of cancer patients and carers who have attended the Ellesmere Port cancer patients and carers peer support group. The findings will be used to inform a training programme for health professionals and evaluate the ‘Living with Cancer’ project.

### **Why have I been chosen?**

You are being asked to take part because you have experience of either being a cancer patient or caring for a person who has cancer. You may therefore have insight and views that will be helpful to health professionals who wish to improve the care of cancer patients and carers in the Ellesmere Port locality. There will be approximately ten cancer patients and carers taking part.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

**What will happen to me if I take part?**

The research team would like to invite you to attend a focus group meeting where, led by a researcher, you and other cancer patients and carers may raise and discuss the issues that are important to you. This focus group will take place in the same venue as the peer support group, immediately after a meeting. Refreshments will be provided.

**What are the possible disadvantages and risks of taking part?**

If talking about your experiences causes you any distress, there will be individuals trained in offering support present at the meeting.

**What are the possible benefits of taking part?**

It is possible that you may welcome the opportunity to share and discuss your views and experiences with other patients and/or carers, but this cannot be guaranteed. In the long term it is hoped that the findings may be used in the training of professionals to improve care and support for patients and carers in the Ellesmere Port area.

**What will happen to the results of the research study?**

The findings will be used in the training of health professionals to improve care and support for patients and carers in the Ellesmere Port area. Individuals who participate will not be identified in any subsequent report or publication.

**Who is organising and funding the research?**

Chester and Halton Community NHS Trust have received funding from the New Opportunities Fund to carry out this research. The Centre for Public Health Research at University College Chester will be involved in organising the study.

**Who may I contact for further information?**

If you would like more information about the research before you decide whether or not you would be willing to take part, please contact:

Jill Littlewood (Project Co-ordinator) on 01244 356817

**Thank you for your interest and co-operation in this research.**

# PATIENT AND CARER CONSENT FORM

## For Focus Group Participation

**Title of Project:** 'Living with Cancer': Maximising the coping strategies of carers and patients 'Living with Cancer'

**Name of Researcher:** Miranda Thurston

**Please initial box**

1. I confirm that I have read and understand the information sheet dated for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I agree to take part in the above study.

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Name of subject

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Date

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Signature

\_\_\_\_\_  
Name of Person taking consent  
(if different from researcher)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

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Signature

**‘Living with Cancer’**  
**Patient and Carer Evaluation Focus Group**  
**Interview Schedule**

The NLP educational input to the peer support groups was designed based on information received from patients and carers at the first meeting to ascertain what they wanted to gain from attending the subsequent sessions and was therefore delivered with a view to addressing these needs. Therefore, in order to assess to what extent, and in which ways, patients and carers have benefited from attending the peer support groups, it is necessary to explore the extent to which their needs were met.

**Introduction - explore general impressions**

Before focus group commences ascertain who are patients and who are carers.

Introduction – explore general impressions

Invite patients and carers to describe what happened in the peer support groups:

What were their experiences?

Find out their views as to the value of peer support per se.

Find out their views specifically as to the value of the NLP input.

What are their general perceptions of the value/impact of attendance on their everyday life (with examples of situations to illustrate how and why they feel attending has or hasn't made an impact)?

**Explore (with examples of situations) perceptions and experiences as to the value/impact of participation in the peer support groups.**

The following probes are designed to initiate the exploration of these perceptions and experiences:

sharing experiences with others, sharing problems and information;  
receiving practical advice and motivation;  
enabling them to help others;  
coping with stress, relaxing;  
coping with tiredness (eg. after chemotherapy);  
aiding sleep;  
lifting mood/feeling more positive;  
feeling calm/in control;  
dealing with trauma (diagnosis, bereavement etc.);  
communicating with others, expressing feelings;  
dealing with their own emotions;  
changing their emotional state;  
accepting the situation they find themselves in;  
carrying on as normal.

What have patients and carers taken away from the peer support groups – explore (with examples)?

Ask patients and carers for their ideas and suggestions as to ways of recruiting to the peer support groups.

What have people taken away from the peer support groups? – explore with examples

Do they think they will continue to meet as a group?

If yes, why?

If not, why?

### **Peer support per se**

What do they think about the idea of support groups?

In practice, what value do they place on meeting with others in the support groups?

How helpful has attending support groups been?

If helpful, in which ways have they been helpful? (eg. sharing experiences with others, sharing problems, sharing information, receiving practical advice)

If not helpful, what do you think are the reasons for this?

### **NLP input to peer support groups**

Thinking now specifically about the educational input (NLP), how useful have they found the techniques they were taught?

Have they helped you to live with and cope with your situation?

If found techniques useful/helpful, which techniques were helpful?

How were they helpful?

In which situations do you use them?

Why do you think they were useful?

If NOT found techniques useful/helpful, which techniques were not helpful?

How were they not helpful?

Why do you think they were not useful?

NLP techniques designed to help with:

enabling them to help others;

copng with stress, relaxing;

copng with tiredness (eg. after chemotherapy);

aidng sleep;

lifting mood/feeling more positive;

feeling calm/in control;

dealing with trauma (diagnosis, bereavement etc.);  
communicating with others, expressing feelings;  
dealing with their own emotions;  
changing their emotional state;  
accepting the situation they find themselves in;  
carrying on as normal.

## **Appendix 4**

### **Interview documents**

Health Professional Information Sheet

Health Professional Consent Form

Health Professional Interview Schedule

## **Health Professional Information Sheet**

### **‘Living with Cancer’**

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

#### **What is the purpose of the study?**

Chester and Halton Community NHS Trust (now Halton PCT) have received funding for a 3-year ‘Living with Cancer’ project in Ellesmere Port, working with patients, carers and health professionals. The study aims to contribute to improving care locally for those ‘Living with Cancer’ and their carers.

As part of the ‘Living with Cancer’ project, a variety of health professionals have undergone training in advanced communication skills based on neuro-linguistic programming (NLP). We hope to find out the views of health professionals regarding their perceptions and experiences of the impact of the training on their work with patients and carers and also on managing their own emotions. A written report will be produced at the end of the project.

#### **Why have I been chosen?**

You are being asked to take part because, as a health professional that has attended the training in (NLP) advanced communication skills, your views and experiences as to the impact of the training, are valuable in terms of contributing to understanding the value of training health professionals in these skills. All the health professionals who have received the training will be invited to take part in the research.

#### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason.

#### **What will happen to me if I take part?**

If you do decide to take part you should keep this information sheet but return the ‘consent-to-be-contacted’ slip (at the end of this document) in the prepaid envelope



provided. On receipt of this slip, a researcher from the Centre for Public Health Research at University College Chester will contact you by telephone to arrange an interview with you at a mutually convenient time and place. When you attend you will be asked to sign a consent form before the interview commences. With your permission, the interview will be audio taped.

**What are the possible disadvantages and risks of taking part?**

There are no disadvantages or risks foreseen in taking part in the study.

**What are the possible benefits of taking part?**

It is possible that you may welcome the opportunity to discuss your perceptions of the training you have received but this cannot be guaranteed. It is hoped that the findings may ultimately lead to improved care for patients and carers in the Ellesmere Port area.

**What will happen to the results of the research study?**

The findings will be used to improve care and support for patients and carers in the Ellesmere Port area. Individuals who participate will not be identified in any subsequent report or publication.

**Who is organising and funding the research?**

The research is funded by Chester and Halton Community and NHS Trust (now Halton PCT). The Centre for Public Health Research at University College Chester will be involved in carrying out the study.

**Who may I contact for further information?**

If you would like more information about the research before you decide whether or not you would be willing to take part, please contact:

Penny Sargent (Senior Researcher, Centre for Public Health Research) on 01244 375444 (ext. 2058)

**Thank you for your interest and co-operation in this research.**

### **‘Living with Cancer’ research study**

Health professionals who are willing to be interviewed should return this slip to the Centre for Public Health Research in the attached prepaid envelope.

I agree to a researcher contacting me to arrange for me to attend an interview in due course.

Name: \_\_\_\_\_ Daytime Phone Number: \_\_\_\_\_

Address: \_\_\_\_\_

Date: \_\_\_\_\_ Signature: \_\_\_\_\_

## **‘Living with Cancer’ Health Professional Interview Schedule**

### **Section 1 - Participant Background**

- Can you please tell us a little about yourself:
  - What is your role in providing care to cancer patients and/or in your work with carers? (eg. Nurse, GP etc? Do you mainly work with patients or carers or both?)
  - Where do you provide this care/service? (eg. Home visits, hospice etc)
  - Can you describe your typical daily interactions with cancer patients and/or carers? (so we can understand a little about the type of interactions you have with patients and how you feel about these interactions)
  - How long have you been in your current position?
- How did you hear about the training?
- Why did you decide to participate in the training?

### **Section 2 - Expectations of training programme**

Before attending the training programme in (NLP) advanced communication skills, what were your expectations as to what you might gain from receiving this training?

The three areas for development (as identified by health professionals before undergoing training) were:

1. Improving communication
2. Improving relationships (building relationships, creating rapport with patients, carers and colleagues, handling difficult relationships/confrontation/anger)
3. Managing own states, own stress levels

To what extent do you feel that the training programme addressed your training needs?

### **Section 3 - Using NLP**

Since completing the NLP training, how and to what extent, do you think you are putting what you learnt into practice in your work with patients?

Probe:

- Since receiving training, are there any new and different aspects of NLP (eg. changing state, influencing, stress management, building rapport and trust) which you feel you have incorporated into your work with patients (which aspects of NLP skills are you consciously aware of using/having used)?

- To what extent, and in which situations do you/have you perceived yourself to be consciously aware of using NLP skills with patients (describe with examples)?
- Are there any particular barriers within your workplace that may prevent you implementing these communication skills with patients?

Since completing the NLP training, how and to what extent, do you think you are putting what you learnt into practice in your work with carers?

Probe:

- Since receiving training, are there any new and different aspects of NLP (eg. changing state, influencing, stress management, building rapport and trust) which you feel you have incorporated into your work with carers (which aspects of NLP skills are you consciously aware of using/having used)?
- To what extent, and in which situations do you/have you perceived yourself to be consciously aware of using NLP skills with carers (describe with examples)?
- Are there any particular barriers within your workplace that may prevent you implementing these communication skills with carers?

#### **Section 4 - Reflecting on impact/value of NLP on practice**

How valuable do you feel the training programme has been in terms of improving the quality of your communication with patients and carers?

Probe:

- Do you feel that receiving training in NLP skills has made an impact on the quality of your communication with patients/carers?
- Give examples of problems/situations where you perceive NLP skills to have been useful/not useful in communicating with patients/carers;
- How and in which ways do you perceive NLP to have been useful/not useful in these situations?
- How, and in which ways, do you perceive your NLP skills to have made an impact on your relationships with patients/carers?
- Which aspects, if any, of NLP do you recognise that you were practising prior to receiving the training, as part of your daily interactions?
- What affect has the training had on these previous practices?

How valuable do you feel that receiving training in NLP skills has been in terms of improving the quality of the care you provide to patients and carers?

Probe:

- Give examples of how and in which situations you perceive NLP skills to have made an impact on the quality of care you provide.

How valuable do you feel that receiving training in NLP skills has been in terms of managing your own stress levels and emotions in relation to your job?:

- Give examples of problems/situations where you perceive NLP to have helped
- What NLP skills did you use?

- How effective do you perceive NLP to be in terms of managing your own stress levels?

## **Section 6- The future**

- How do you feel about the long-term implementation and sustainability of the skills you learned during the training. (Do you feel that you will be able to continue implementing these new skills? Why or why not? Which skills do you feel you will be able to continue implementing and which skills do you perceive as being a challenge to continue?)